A REVIEW OF HOME BASED CARE MODELS AND SERVICES FOR PEOPLE LIVING WITH HIV/AIDS WITHIN AND OUTSIDE AFRICA

Conducted by the

African Palliative Care Association (APCA)
Kampala
Uganda

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Project leadership and coordination:

- Anne Aslett, Director, International Programmes, EJAF
- Stephen Crawford, Grants Administrator, EJAF
- Dr. Faith Mwangi-Powell, Executive Director, APCA
- Fatia Kiyange, Training and Standards Manager
- Esther Akullo- Owor, Programme Support Officer
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- Susan Mathew, Consultant – HIV/AIDS, Public Health, USA
- Irina Ibraghimova, Expert, Evidence Based Practice in Health
- Dr. Edward Mukooza, Health Consultant, Uganda
- Dr. Sam Biraaro, Health Consultant, Uganda
- Dr. Robai Gakunga, Health Consultant, Kenya

Project Advisory Committee

- Dr. Stephen Connor, NHPCO, WPCA
- Richard Harding, Kings College London (KCL)
- Eunice Garanganga Hospice Palliative Care Association of Zimbabwe (HOSPAZ)
- Dr. Ekiria Kikule, Mildmay Centre Uganda
- Dr. Carla Simmons, Kitovu Mobile Home Care Programme, Uganda
- Anne Anselt, Elton John AIDS Foundation (EJAF)
- Jenny Hunt, Palliative Care Consultant, Zimbabwe
- Dr. Karilyn Collins, Palliative Care Physician, UK
- Mary Callaway, OSI/International Palliative Care Initiative
- Olivia Dix, Palliative Care Consultant, Diana, Princess of Wales Memorial Fund
- Dr. Faith Mwangi-Powell, Executive Director, APCA
- Julia Downing, Deputy Executive Director, APCA
- Fatia Kiyange
- Sue Cameron, HPCA
- Training and Standards Manager, APCA

Country level coordination

- Palliative Care Association of Malawi (PACAM)
- Kenya Hospices and Palliative Care Association (KHPCA)
- Palliative Care Association of Zambia (PCAZ)
- Tanzania Palliative Care Association (TPCA)

Participating sites, their professional and community care providers, patients and their families:

Malawi:

- Lighthouse Trust HBC,
- Dowa Hospital HBC,
- Dedza Catholic Diocese HBC
- Ndirande HBC operating under the Blantyre City Authority
- Ministry of Health of Malawi, Home Based Care Department

Kenya:

- Kibera Community Self Help Programme (KICOSHEP)
- Nyamurerwa Home Based Care, Siaya District Hospital Comprehensive Care Centre, Kisumu.
- Nakuru Holy Cross Parish Home Based Care programme, APHIA II Rift Valley Province project.
- Malindi Gede Health Centre, Mombasa
- Ministry of Health, Home Based Care Department

Zambia:

- Home Based Care Programme of Chishilano Multifunctional Centre, Ndola Copperbelt
- Home Based Care Programme of St. Francis Centre, Livingstone, Southern region
- Bwafwano Integrated Care and Support Program, Lusaka Peri-Urban area
- FOCA Home Based Care Programme
- Ministry of Health, Home based care Department

Tanzania:

- WAMATA - urban, private Non Governmental Organisation (NGO)
- PASADA - rural and urban, private Faith Based Organisation (FBO)
- Kiwakukki (Moshi): rural/urban, private NGO
- Kinondoni - hospital based, urban, public Home Based Care Programme.
- Ministry of Health, Home Based Care Department

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Acronyms

AIC	AIDS Information Centre
APCA	African Palliative Care Association
ART	Antiretroviral Therapy
CAC	Community AIDS Committee
CACC	Constituency AIDS Control Committee
CBO	Community-Based Organisation
CCC	Comprehensive Care Center
CCG	Community Caregiver
CHAM	Christian Hospital Association of Malawi
CHBC	Community Home-Based Care
CHW	Community Health Workers
CINDI	Care and Support of Children In Distress
CMAZ	Churches Medical Association of Zambia
COPHIA	Community-Based HIV/AIDS Prevention, Care, and Support Program
DACC	District AIDS Coordinating Committee
DACC	District AIDS Control Committee
DATF	District AIDS Task Force
DHMT	District Health Management Team
DOTS	Directly Observed Treatment – Short Course
FACT	Family AIDS Care Trust
FBO	Faith-Based Organisation
FGD	Focus Group Discussion
FLEP	Family Life Education Programme
HBC	Home-Based Care
HC	Health Center
HPCA-SA	Hospice and Palliative Care Association – South Africa
HIV/AIDS	Human Immune Deficiency Virus/ Acquired Immune Deficiency Syndrome
HS	Hospital Supported
HV	Home Visiting
GDL	Government District Level
ICHC	Integrated Community Home-Based Care
KEHPCA	Kenya Hospice and Palliative Care Association
KICOSEP	Kibera Community Self Help Project
KMTC	Kenya Medical Training College
KHANA	Khmer HIV/AIDS NGO Alliance
LAPCA	Lesotho AIDS Program Coordinating Authority
LCH	Lilongwe Central Hospital
MOHSW	Ministry of Health and Social Welfare

NAC	National AIDS Council
NACO	National AIDS Control Organization
NASCOP	National AIDS/STD Control Program
NCASC	National Center for AIDS and STD Control
NC	Nurse Counsellor
NGO	Non-Governmental Organization
NNPC	Neighbourhood Network of Palliative Care
OI	Opportunistic Infection
OVC	Orphans and Vulnerable Children
PACC	Provincial AIDS Control Committee
PACAM	Palliative Care Association of Malawi
PASADA	Pastoral Activities and Services for People with AIDS in Dar es Salaam Archdiocese
PCAZ	Palliative Care Association of Zambia
PCP	Primary Care Provider
PHN	Public Health Nurse
PLWHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
PPCS	Pain and Palliative Care Society
PSC	Patient supported Care
SA	Situational Analysis
STEPs	Scaling Up HIV/AIDS Intervention Through Expanded Partnerships
TACAIDS	Tanzania Commission for AIDS
TASO	The AIDS Support Organization
TSC	Technical Subcommittee
TPCA	Tanzania Palliative Care Association
UAC	Uganda AIDS Commission
VAC	Village AIDS Committee
VCT	Voluntary Counselling and Testing
WAMATA	Walioi Katika Mapambano na AIDS Tanzania
WHO	World Health Organization
ZAC	Zanzibar AIDS Commission
ZASF	Zambia AIDS Strategic Framework

1.0 Executive Summary

2 Background

The African Palliative Care Association (APCA) is a pan-African non-governmental organization whose mandate is to promote and support the scale-up of culturally appropriate and affordable palliative care throughout Africa. Home-based care (HBC) is one of the models through which effective and comprehensive palliative care can be delivered to people living with HIV/AIDS (PLWHA) and their families. APCA with support from the Elton John AIDS Foundation undertook a literature review and a situational analysis (SA), both of which will be referred to as a HBC review throughout this document), of HBC services with the aim of making clear and practical recommendations for the integration of all aspects of palliative care within existing HBC services. The purpose of this review was to underpin the development of palliative care standards of all levels of service delivery.. The literature search entailed a comprehensive review of existing information on home based care for people living with HIV/AIDS in resource poor settings while the situational analysis was a cross-sectional study using qualitative and quantitative methods to explore the nature of existing home based care models in was using in four African countries, including;: Tanzania, Zambia, Malawi and Kenya. This report provides the findings for both the literature review and the situation analysis.

Since the beginning of the HIV/AIDS epidemic, HBC has been promoted across Africa and elsewhere in the world as a suitable model for delivering services to PLWHA and their families. However, not much has evaluation has been done to establish what constitutes HBC or how palliative care can be integrated into these services.. This issue was the central purpose for the literature revoiew and the situational anlysis. In addition, there is general assumption that HBC is the most feasible model for integration of palliative care into existing services for PLWHA, although this view is supported by limited evidence base.

3 Problem Statement

Home-based care is assumed to be one of the appropriate models for delivering services for PLWHA and indeed palliative care services. However, different HBC models are in different countries, although the quality and scope of services is unknown. There is a general consensus among supporters and promoters of palliative care globally on the need to integrate palliative care into existing services for PLWHA including home-based care but to date there has been no review or recommendations on how this can be implemented. There is also limited evidence on which models are the best practice models for home based care in Africa. This review therefore sought to answer such knowledge gaps and to use the findings to provide practical recommendations for the integration of palliative care into existing HBC services.

3.1 Justification

This work provides evidence- based recommendations for the integration of all aspects of palliative care into existing home-based care services for PLWHA.. It identifies areas of strength and existing gaps for palliative care provision within HBC services for further development of palliative care within existing HBC services. Both the literature review and the situational analysis identifies best practice models for home-based care for PLWHA for adaptation by other services across Africa as well informing the establishment of practice standards for palliative care across all levels of care, including; primary, secondary and tertiary levels. These standards will not only ensure that services provide quality care it also provides a guide for the integration of palliative care into all services across all levels.

3.2 The aims

The aim of the review was to undertake an assessment of existing home-based care models for PLWHA within project countries to establish the current levels of service delivery and opportunities through which palliative care can be integrated or strengthened, and to inform the development of palliative care standards suitable for all services. In addition the results of the review make clear and practical recommendations for integration of all aspects of palliative care in existing HBC services for PLWHA.

3.3 Questions that were answered by the HBC Review

The review answered the following questions:

i) What models of home-based care delivery for PLWHA exist?
ii) Within the current home-based care delivery models for PLWHA, what are the strength and gaps for palliative care provision?
iii) Are there best practice models for HBC for PLWHA that can be promoted by APCA and adapted by countries across Africa?
iv) What are some of the practical recommendations for the integration/ implementation of all aspects of palliative into existing home-based care services for PLWHA?

3.4 Scope of the HBC review

The literature search was a comprehensive review of information on HBC services in resource constraints setting, which provided a good overview of HBC services both in Africa and outside Africa for comparison purposes, while the situation analysis was , undertaken in four African countries i.e. Tanzania, Zambia, Malawi and Kenya. For this, a cross-section of home-based care services in the project countries were selected for in-depth assessment. These included Non Governmental Organisations (NGOs), Community Based Organisations (CBOs) Faith Based Organisation (FBOs), hospice/ palliative care services, hospital based services, and public services. The services were categorized into both urban- and rural-based.

3.5 Design

The review was undertaken in two phases. Phase 1 was a comprehensive literature search and Phase 2 was a HBC situational analysis in each of the project countries.

3.5.1 Phase One

The literature search entailed a comprehensive review of existing information on home based care for people living with HIV/AIDS in resource poor settings. This involved;

- Systematic review, including grey literature and unpublished work
- Examining how models of home based care are described
- Identification of challenges for home based care delivery
- Review of home based care and its relationship with home based palliative care
- Examining the gaps in literature
- Making comparisons with information from African and from outside Africa.

3.5.2 Phase Two

Phase Two was a cross-sectional study/situational analysis (SA) and using qualitative and quantitative methods to explore the nature of existing home based care models in the project countries.

The aim of the situation analysis was to:

- Establish the existing models of home-based care delivery for PLWHA.
- Determine the strength and gaps for palliative care provision within current home-based care delivery models for PLWHA.
- Identify best practice models for HBC for PLWHA that can be promoted by APCA across Africa.
- Establish some practical recommendations for the integration/ implementation of all aspects of palliative care within existing home-based care services for PLWHA.

Purposive sampling was used to select Home Based programmes to participate in the SA based on pre-set criteria. In each country, APCA worked in collaboration with the national palliative care associations and the home based care stakeholders, such as the Ministry of Health and the home based care programmes to select the service to participate in the review. A total of 4 home based care programmes for PLWHA in each project country participated in the review. In each country one policy level person from the Ministry of Health department of Home Based Care was selected purposively, with the facilitation of APCA and in collaboration with the national palliative care association. In each of the 4 programmes selected in each country, one staff in management and five formal care givers (health workers such as doctors or nurses/allied health workers such as social workers) were purposively selected and included in the sample.

In addition, five community volunteers/ caregivers associated with the programme were included. In consultation with the caring teams of each programme, four people living with HIV (PLWHA) and four family care givers to PLWHA were selected and included in the sample. The overall sample comprised of 308 respondents.

4 Results

4.1 Phase One

From the literature review there were four distinction models that are recognised based on the type of services they provide, these include:

- Community home-based care (CHBC)
- Integrated community-based home care (ICHC)
- Hospice care with HBC services
- Hospital-supported HBC services
- Outreach services which include HBC

Within these models, ICHC was noted to be the best practice model of HBC for PLWHA, according to the South African National Department of Health's HIV/AIDS/TB/STI Directorate (24). An evaluation of the ICHC model indicated that it is feasible to replicate this model in resource-poor settings (92). Though ICHC began as a rural model, the evaluation indicated that it is feasible to replicate the ICHC model in urban and peri-urban settings, too (82). The primary goal of ICHC is to meet the needs of PLWHA and their families in a continuum of care (24). Nursing care, psychosocial support, social support, and clinical management including pain control are all part of the ICHC model (43).

The CHBC model is noted for its comprehensiveness of care (30, 99) that encompasses a comprehensive spectrum of patient needs: physical, spiritual, palliative, social, and material. Within the context of HIV/AIDS, CHBC aims to mitigate the impacts of HIV/AIDS on patients, families, and communities. CHBC has been adopted by many communities in Sub-Saharan Africa and has become an essential component in the response to HIV/AIDS for two reasons in particular: 1) facility-based community resources are overburdened by the demand for HIV/AIDS care and support services, and 2) CHBC better parallels cultural values in many settings for care of the ill and dying at home.

Other models focus on *who* the main providers and/or supporters of HBC services for PLWHA are, such as the following:

- CBOs, NGOs, FBOs, and hospices (community-based)
- Hospitals (government and non-government)

In addition, all except two Southern African countries in the literature review (Lesotho and South Africa) have hospital-supported HBC services for PLWHA. All East African countries in the literature review have hospital-supported HBC services.

With regard to staffing, the literature search showed that in all countries care is largely provided by volunteers and families. Nurses are also often utilized by HBC programs. Compared to nurses and volunteers, the literature did not elaborate as much about allied health professionals, such as social workers and counsellors. Still relative to nurses and volunteers, few physicians are full time staff members of HBC programs.

Review of national level HBC guidelines in several countries also indicates that they mention palliative care. Furthermore, three of the four countries targeted by Phase Two have at least one example of HBC service provision which includes morphine access for patients. .

The literature search also identified some challenges with HBC services these include :

- Lack of TB care for PLWHA with TB-HIV co-infection
- Absence of integration of HIV/AIDS prevention into HBC
- Absence of care and support for orphans and vulnerable children (OVC)
- lack of focus on gender and caregiver burn-out
- Limited training and education
- Absence of eEffective linkages and referral systems
- Lack of strong pain control in HBC for PLWHA
- Poverty
- Stigma

4.2 Phase Two

Phase Two, as mentioned above entailed a home base care (HBC) situation analysis in four African countries (i.e. Malawi, Tanzania, Kenya and Zambia)
Data from various respondents in each service was transcribed under that service, keeping the thematic areas in mind. Thereafter, the transcribed information was analysed following the thematic areas for the review. The analysis was continued at the national level following thematic areas. The findings at the national levels from the four focus countries were aggregated into one report. Transcribed qualitative data was subjected to manual content analysis and descriptive presentation based on the main thematic areas.
Results were organised according to the four themes drawn from the assessment obejctives.

Models of home based care services in the four project countries.

Five models of HBC were identified

- Community Home-Based Care (CHBC)
- Integrated Community-Based Home Care (ICHC)
- Government District-Level Home-Based Care Services (GDL)
- Hospital-Supported Home Based-Care Services (HS)

- Home Visiting (HV)

Hospice care with HBCmodel and outreach Services which include HBC model were not found in the review.
Determination of the home based care models of programmes was based on the categorisation in the HBC literature review which is described in Phase One above.

Strengths and gaps for palliative care provision within current home-based care delivery models for PLWHA.

The leading overall strengths of HBC found were:

a) The "integration" principle, i.e. the effectiveness and sustainability of HBC programmes as a result of collaboration by stakeholders. This was noted best in the ICHC model.
b) An enabling environment in all countries due to government policies and political will.
c) Existing teams/systems that could be used to integrate palliative care (PC) in HBC.
d) Most human resource cadres were willing to learn, understand and implement PC in HBC. Service delivery was going on despite limited resources.

The leading gaps found were:

a) A general lack of understanding of what palliative care meant and how it could be integrated in HBC.
b) A lack of resources and generally inadequate capacity to mobilise financial resources.
c) Limited access to opiates / strong pain killers.
d) Inadequate monitoring and evaluation of programmes.
e) Failure to give adequate attention to spiritual care in HBC programmes.

Best HBC Practice model:

Similar to the literature search, the best HBC practice model was identified as the to be ICHC. It had the following characteristics:

- It had the capacity to provide a comprehensive list of HBC elements, including palliative care. This was possible through collaboration and networking of various stakeholders. For example in western Kenya, there was Siaya HBC which was classified as ICHC. Siaya had synergy between the efforts of Mildmay which provided training and capacity building, while the government provided management infrastructure including human resources. The CBOs such as Nyamulerwa delivered HBC to the PLWHA in the area served by Siaya HBC. A similar situation was found in the case of Lighthouse trust programmes in Malawi.

- ICHC was more sustainable due to utilisation of larger sections of each of the three pillars, as highlighted in the concept (Figure 1). ICHC called into play a wider list of stakeholders. This integration made such a model more effective and more sustainable.

- Issues of capacity building, including training and resource mobilisation, were best addressed in the ICHC model; this was also possible because of bringing together resources and skills from the various stakeholders for example governments provided technical people to facilitated trainings and provided infrastructure such as hospital facilities while donors such as CDC equipped the hospital facilities particularly the patient support centres (PSC).
- It provided a natural direction of growth for other models. It was assessed that all models could potentially grow into ICHC, by applying the principle of "integration", whatever their foundation may have been.

5.0 Recommendations

5.1 Phase One

The literature review made the following recommendations:

Training and Education

- It is essential to increase palliative care training and education efforts for HIV/AIDS care (10, 12, 13, 22, 24, 25, 26, 49, 66, 82, 97, 99). To further palliative care integration into HBC for PLWHA, palliative care training itself is of critical importance for all stakeholders.
- The range of stakeholders for whom palliative care training and education efforts should be developed and directed should include nurses, doctors, nursing and medical students, volunteers, allied health professionals such as social workers and counsellors, programme managers, funders, supervising nurses, families, PLWHA, policymakers, narcotics control boards, traditional healers, and pharmacists. Any of these stakeholders can play a role in supporting or delivering palliative care within the context of HBC for PLWHA. Especially for those directly involved in palliative care provision, refresher training is necessary. Focusing on training trainers is also important.
- In addition to training about palliative care principles and methods, education and sensitization is needed to dispel myths which exist among many stakeholders about pain relief through opioids. They can be roadblocks for palliative care expansion, and therefore need to be addressed sensitively and effectively.
- To facilitate access to palliative care training, a variety of training programs are necessary that meets needs of trainees in terms of program timeframes, locations where training is provided, costs, and types of qualifications available.

Supportive and Policy Environment

- One of the best ways to ensure a supportive policy environment for palliative care is through national palliative care guidelines (24), as well as supportive

structures in place such as a national palliative care task force and a national palliative care association with government links. Government support ensures financial support of palliative care. In addition, national commitment to palliative care provides further basis for maintaining and improving quality of care standards. Issues affecting access to pain relief – such as expanding the types of health care workers who have prescriptive authority for morphine to include specially trained and qualified nurses in palliative care – are in a more favourable place to be addressed if palliative care receives national support.

Morphine –related recommendations

- Addressing morphine access and usage in palliative care training and education to the wide range of stakeholders is an important way to increase morphine availability for PLWHA in HBC settings.
- Supporting policy changes that increase morphine access is necessary, such as policies allowing palliative care nurses to prescribe morphine. Policy-level changes can help to change overly strict regulations set forth by narcotics control boards and similar regulatory agencies.
- Morphine accessibility can also be problematic due to high costs. Powdered morphine is generally less costly compared to injectable and liquid morphine, for instance.

Mentoring

- Hospices well-established in the ICHC model mentored other hospices to become established in ICHC through a process that involved active participation between mentor hospices and mentored hospices. An evaluation of the ICHC model indicated that it was suitable for replication in other resource-constrained settings in Sub-Saharan Africa (92). The ICHC model should be scaled up and replicated through the ICHC mentorship program in areas where there is a hospice presence.
- Refresher training and support supervision of community volunteers through mentorship…as in Uganda and many other African countries has proved useful for gradual integration of PC in existing HBC services**.**

Linkages and referrals

- Linkages and referrals are critical components of comprehensive care for HIV/AIDS care in HBC settings (14, 66, 82, 99). One organization alone typically cannot provide the full range of care and support services needed to PLWHA and their families.
- Developing and maintaining strong linkages between HBC programs and palliative care providers is important for better integration of palliative care into their HBC service delivery, especially when hospice is not well-developed in a given area.

Evaluation and Research

- Evaluation and research results can be used to inform programming about integration of palliative care into HBC for PLWHA. Examples could include

research about whether health care workers support prescriptions for oral morphine in HBC settings (49), development and adaptation of pain assessment instruments for use by different HBC workers (12), research about types of pain and symptoms experienced by different patient populations in home settings (12), and incorporation of results from caregiver evaluations into the caregiver training programmes (82). These are not the only examples; research and evaluation about many other relevant topics can also be beneficial for the overall aim of integrating palliative care into HBC for PLWHA.

Advocacy

- Advocacy about integration of palliative care into HBC for PLWHA is essential for informing the wide range of stakeholders about why and how to take steps towards improving the quality of life of people in their communities (31).

5.2 Phase Two

The following recommendations for integration of all aspects of PC into HBC were made based on the results of the in-country review:

- The practice of 'integration' in HBC programmes for PLWHA be promoted by APCA. This will make it easier to integrate all aspects of palliative care in HBC programmes for PLWHA.
- The best practice model identified was ICHC. The practice of 'integration' in existing ICHC models such as the Lighthouse Trust, should be benchmarked by other HBC models.
- APCA works to influence governments to adjust policies to include adequate guidelines for PC in HBC and to enable easier access to strong pain killers. There are lessons to learn from the Ugandan and Zimbabwe experiences of allowing other cadres other than doctors, to prescribe opiates.
- APCA advocates for capacity building in HBC and PC. Specific emphasis to be put on transferring palliative care and HBC skills to lay people in the communities.
- That programmes of HBC design/develop strategies that address economic empowerment of PLWHA, their extended families and communities.
- That HBC programmes strengthen operational research, including M&E of HBC and PC.
- That APCA facilitates the establishment of standards for the provision of HBC/PC by programmes.
- That APCA and programmes establish an inventory of HBC and PC services in member countries.
- That stakeholders work to integrate PC more intentionally into HBC programmes

6.0 The Full Report

The section below provides a detailed report of Phase one –the literature review and Phase Two -the situation analysis. It provides the detailed methodology, results, recommendations and conclusions.

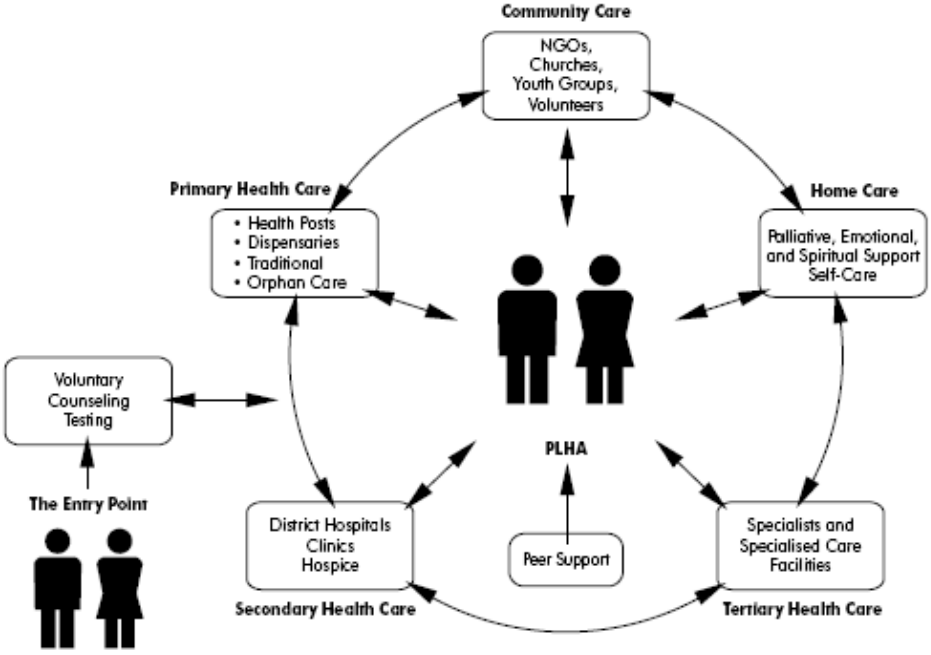
6.1 Phase One

6.1.2 Introduction

Palliative care is defined by WHO as "an approach that improves the quality of life of patients and their families facing 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 physical, psychosocial and spiritual problems" (8).

Palliative care is an essential element of HBC in resource-constrained settings, according to WHO (99). Community home-based care (CHBC) has been broadly defined as care provided to the ill in their homes (99) or more generally, in their natural environments (30), by families and available community resources. Care encompasses a comprehensive spectrum of patient needs: physical, spiritual, palliative, social, and material. The mutually reinforcing nature of palliative care and HBC is evident in the similarities of their definitions. Within HIV/AIDS-related care, Figure 1 shows how palliative care can fit into HBC.

Figure 1: HIV/AIDS Continuum of Care across Community Settings



Source: (24) Gwyther L., Merriman A., Mpanga Sebuyira L., & Schietinger H. APCA, FHSSA, NHPCO. *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS in Sub-Saharan Africa.*, 2006.

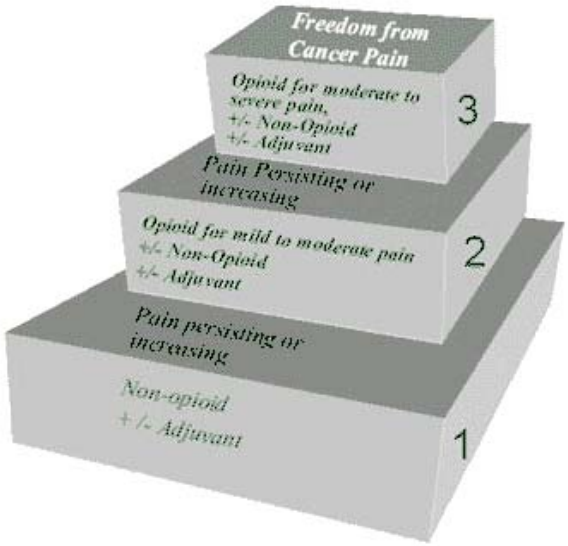
Of the 39.5 million people living with HIV/AIDS around the world, approximately 24.7 million people (63%) are in Sub-Saharan Africa (88). The need for HBC within the context of HIV/AIDS in Sub-Saharan Africa is well-documented (9, 24, 25, 29, 30, 65, 77, 82, 95, 97, 99). In response, various degrees of HBC service provision have been adopted by many HIV/AIDS-affected communities in Sub-Saharan Africa. HBC is essential in addressing HIV/AIDS-related care and support for two reasons in particular:

- Health care facility-based resources are overburdened by the demand for HIV/AIDS care and support services.
- HBC better parallels cultural values in many settings for care of the ill and dying at home.

Studies also indicate good ART compliance among HIV-infected individuals in HBC programs (4, 23, 94), including an HBC program for PLWHA in rural Uganda.

Despite the need, many HBC programs in Sub-Saharan Africa do not provide the full range of palliative care as part of HBC services (26). HBC programs might choose certain elements of palliative care to integrate into their services, such as spiritual or social care. Often, however, a full range of pain control options (Figure 2) is not part of the HBC service package for PLWHA and other HBC recipients. Several reasons exist for this, but the absence of strong pain relief options reduces the potential for HBC to improve the quality life for PLWHA.

Figure 2: WHO Pain Relief Ladder*



Sources: 1) WHO, 2007. http://www.who.int/cancer/palliative/painladder/en/
2) (24) Gwyther L., Merriman A., Mpanga Sebuyira L., & Schietinger H. APCA, FHSSA, NHPCO. *AClinical Guide to Supportive and Palliative Care for HIV/AIDS in Sub-Saharan Africa.*, 2006.

Of several models of HBC for PLWHA in Sub-Saharan Africa (described in Section 3.1), CHBC and integrated community-based home care (ICHC) integrate palliative care into service provision. Within these 2 models, ICHC is a best practice of HBC for PLWHA, according to the South African National Department of Heath's HIV/AIDS/TB/STI Directorate (24). An evaluation of the ICHC model indicated that it is feasible to replicate this model in resource-poor settings (92).

Strategies for integrating palliative care into HBC for PLWHA involve the following:

- training and education,
- a supportive policy environment,
- morphine-related issues,
- mentoring,
- linkages and referrals,
- evaluation and research,
- 7) advocacy.

All of these issues are inter-connected and can simultaneously affect the capacity for palliative care to be integrated into HBC for PLWHA.

6.1.3 Methodology

A comprehensive literature review was conducted about HBC for PLWHA in resource-constrained settings, especially Sub-Saharan Africa.

Literature reviewed included systematic reviews, academic reviews, economic evaluations, guidelines and manuals, qualitative studies, policy reports and papers, program evaluations, programs assessments, program case studies, program appraisals, tools, randomized controlled trials, controlled clinical trials, cohort studies, case control studies, cross-sectional studies, controlled before and after studies, and conference proceedings.

Several biomedical databases were searched including MEDLINE (PubMed), Cumulative Index to Nursing & Allied Health (CINAHL – till 2004), Cochrane Library (Issue 3, 2006), TRIP Data base, BioMedCentral. We also used the following search engines: Google Scholar, AEGiS Search Engine (for searching abstracts from major AIDS conferences). More than 150 relevant websites were visited to gather appropriate literature for this review. Some of these websites include WHO, HIV InSite, AJOL, UNAIDS, UNICEF, IAHPC, NHPCO, HPCA-SA, HRSA, CDC, APCA, AIDSinfo, and Women, Children and HIV.

Examples of keywords and their combinations used for searching databases and web-sites include HIV, AIDS, home care, home based care, services, Africa, Sub-Saharan Africa, and tools, as well as the names of specific countries used in combination with above terms, as well as the name of specific programs or models. For searching PubMed we additionally used Clinical Queries and Health Services Research Query filters.

Reference lists from pertinent articles, books, review articles and programmatic literature were scanned to identify further studies for possible inclusion.

Inclusion criteria for literature in this review were the following:

- Geographic and development level restrictions = only Sub-Saharan Africa, developing & developed countries
- Language restrictions = English only
- Date restrictions = only published during or after 1997
- Subject matter = questions posed in Section 1.8, in addition to research methodologies and tools about HBC for PLWHA

Literature that met these inclusion criteria was subdivided according the questions in Section 1.8, research methodologies and tools about HBC for PLWHA, and geographic area. The strength of a given piece of literature's capacity to answer the relevant questions of this literature review determined if it was included in the final selection of references. When information was too little or otherwise insufficient, that literature was excluded.

7.0 Results

7.1 Home-Based Care Models in Sub-Saharan Africa

Several HBC models are utilised in Sub-Saharan Africa to provide care at home for PLWHA and others with chronic, life-threatening conditions (24, 51, 65, 82, 105). While some models primarily focus on HBC provision, others incorporate HBC into a wider range of services – such as inpatient hospice care, OVC care and support, the range of clinical services offered by various departments in hospitals, and other care.

According to the literature, the following HBC service delivery models are present in Sub-Saharan Africa:

- Community home-based care (CHBC)
- Integrated community-based home care (ICHC)Hospice care with HBC services
- Hospital-supported HBC services
- Outreach services which include HBC

The ICHC model (in which hospice plays a main role) is a best practice according to the South African Department of Health (14, 24, 82). It is considered feasible and appropriate for replication in other resource-challenged settings within Sub-Saharan Africa (92).

The CHBC model is noted for its comprehensiveness of care (99). Examples in this report if where CHBC is implemented include South Africa (e.g. Highway Hospice and Tanzania (e.g. Tutunzane program).

Home visiting is a general aspect of all HBC service delivery models. Counselling and basic care are part of home visits (9, 65). Volunteers sometimes assist with transporting patients to clinical facilities for appointments and may arrange for material support to be provided to homes. In addition, volunteers might help with household tasks such as cooking, cleaning, and tending to errands.

Also based on the literature are models focusing on *who* the main providers and/or supporters of HBC services are in Sub-Saharan Africa, such as the following:

- CBOs, NGOs, FBOs, and hospices (community-based)
- Hospital-supported HBC services

There is a strong overlap between the types of HBC services provided (e.g. CHBC, ICHC, etc.) and who provides the HBC services. For instance, community-based NGOs, CBOs, and FBOs can be the providers of CHBC services. Another example is that hospitals are the basis for hospital-supported HBC services. The HBC program examples selected for countries addressed in this report are first classified by the type of service provider (e.g., NGOs/CBOs/FBOs, etc.), and the service description that follows further describes the services provided. In this regard, it should be noted that hospices frequently provide HBC services, but that hospices themselves are often NGOs or hospital-based.

Most HBC services for PLWHA in Sub-Saharan Africa are provided or supported primarily by CBOs, NGOs, FBOs, and hospices (24). Table 2 discusses possible advantages and disadvantages of different types of HBC service providers / supporters.

Palliative care is not always a part of HBC services, although integrating palliative care into HBC would further increase the ability of HBC services to meet the comprehensive needs of PLWHA. In some organizations, palliative care is sometimes grafted onto the existing services (24). Recommendations for integrating palliative care into HBC for PLWHA are discussed in this document.

7.1.1 Community home-based care (CHBC)

Community home-based care (CHBC) has been broadly defined as care provided to the ill in their homes (99) or more generally, in their natural environments (30), by families and available community resources. Care encompasses a comprehensive spectrum of patient needs: physical, spiritual, palliative, social, and material. Physical care includes clinical care, while spiritual care often addresses religious concerns about illness and dying. An important component of palliative care is effective pain management. Examples of social support include addressing legal matters and facilitating access to government assistance programs. An example of material care is food provision.

The ability of patients and families to maintain self-sufficiency to the extent feasible and attain the best quality of life possible are the overall goals of CHBC. Also essential is to provide care in a framework that respects the dignity and sensitivities of patients and their families. Overall, CHBC is a comprehensive model of HBC care when all of its constituent elements are incorporated into service delivery.

Within the context of HIV/AIDS, CHBC aims to mitigate the impacts of HIV/AIDS on patients, families, and communities. CHBC has been adopted by many communities in Sub-Saharan Africa and has become an essential component in the response to HIV/AIDS for two reasons in particular: 1) facility-based community resources are overburdened by the demand for HIV/AIDS care and support services, and 2) CHBC better parallels cultural values in many settings for care of the ill and dying at home.

Many CHBC programs are initiated or coordinated by NGOs, CBOs, FBOs, or hospices (24). Patients needing CHBC are identified by relatives, self-referral, or hospital staff around the time of discharge from hospitals (97). Alternatively, community health workers identify people in need of CHBC. Patients are then referred to community-based CBOs, NGOs, or FBOs providing CHBC.

Government departments at national, district, and local levels can also play a role in CHBC, such as by promoting supportive CHBC policy environments, determining how to channel national CHBC funds to local efforts, or by committing resources to CHBC service provision.

Essential elements of CHBC in resource-constrained settings identified by WHO (99) are listed in Table 1.

Table 1: Essential elements of CHBC

Category	Subcategory
Provision of care	Basic physical care Palliative care Psychosocial support and counselling Care of affected and infected children
Continuum of care	Accessibility Continuity of care Knowledge of community resources Accessing other forms of community care Community coordination Record-keeping for ill people Case-finding Case management
Education	Curriculum development Educational management and curriculum delivery Outreach Education to reduce stigma Mass media involvement Evaluation of education
Supplies and equipment	Location of the CHBC team Health centre supplies Management, monitoring and record-keeping Home-based care kits
Staffing	Supervising and coordinating CHBC Recruitment Retaining staff
Financing and sustainability	Budget and finance management Technical support Community funding Encouraging volunteers Pooling resources Out-of-pocket payments Free services
Monitoring and evaluation	Quality assurance Quality of care indicators Monitoring and supervision Informal evaluation Formal evaluation Flexibility

Source: (99) WHO. *Community Home-Based Care in Resource-Limited Settings: A Framework for Action,* 2002.

CHBC programs that address all essential elements listed in Table 1 represent the ideal in comprehensive CHBC programming. However, aiming to implement all elements together might not be possible because of resource constraints.

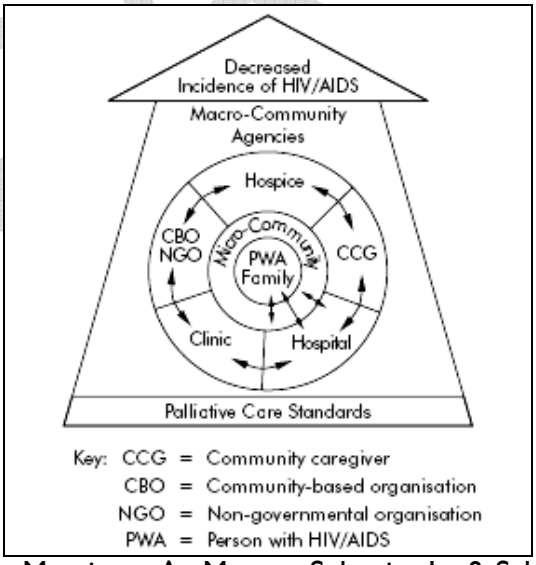
For CHBC programs operating within the context of HIV/AIDS, the continuum of care can range from HIV/AIDS prevention to bereavement counselling (30). PLWHA may not necessarily need continuous CHBC, as the nature, severity, and timeframe of HIV/AIDS' effects can vary by person. Critical areas of care and support for PLWHA include ART provision and adherence support, as well as treatment of OIs and management of other HIV/AIDS-related conditions. Psychosocial and spiritual care are important aspects of CHBC in general, especially for HIV/AIDS-affected households that might have the added burden of dealing with HIV/AIDS-related stigma.

7.1.2 Integrated community-based home care (ICHC)

In response to the impact of HIV/AIDS in rural KwaZulu Natal (South Africa), South Coast Hospice developed and implemented the integrated community-based home care (ICHC) model in 1996-1997 (14, 24, 82, 93). Palliative care is an integral part of the ICHC model, whereas palliative care can be but is not necessarily part of other HBC models. Since pilot testing the model, the Hospice and Palliative Care Association of South Africa (HPCA-SA) actively promotes ICHC.

The ICHC model is a best practice model according to the South African National Department of Heath's HIV/AIDS/TB/STI Directorate. Figure 3 shows the ICHC model.

Figure 3: ICHC model



Source: (24) Gwyther L., Merriman A., Mpanga Sebuyira L., & Schietinger H. APCA, FHSSA, NHPCO. *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS in Sub-Saharan Africa.*, 2006.

The primary goal of ICHC is to meet the needs of PLWHA and their families in a continuum of care (24). Nursing care, psychosocial support, social support, and clinical management including pain control are all part of the ICHC model (43).

Figure 3 emphasizes the inter-connectedness of several stakeholders in providing the continuum of care. Collaboration and networking are essential among ICHC partners and other community resources which can be brought into the ICHC model in a given community.

Hospices play a key role in the ICHC model. In addition to being one of the service providers, hospices are the overall managers of the ICHC model (82) and a main reason why palliative care is integrated into home care services. Being already established in communities, as some hospices are, is advantageous because coordinating mechanisms would already be developed, compared to beginning the process of their development as services would have to do that are not already established in the community (26, 82).

Recruitment and training of community caregivers is primarily undertaken by the hospice (82). Training addresses general and clinical aspects of HIV/AIDS, palliative care, nursing skills, hygiene, counselling, and bereavement. Supervised by supervisory registered nurses (82), community caregivers provide care and to PLWHA and their families, as well to the general micro-communities where they reside. Community caregivers are sometimes involved in TB care as well (93).

Social work is an important component of ICHC. When ICHC teams are faced with households in dire poverty or experiencing other social issues, they can refer these situations to a community social worker who is part of the ICHC team (14). For every five ICHC teams, there is one community social worker.

An evaluation of the ICHC model indicated that it is feasible to replicate this model in resource-poor settings (92). Though ICHC began as a rural model, the evaluation indicated that it is feasible to replicate the ICHC model in urban and peri-urban settings, too (82).A strong network of ICHC partners and a very capable management structure were indicated as crucial to the success of ICHC. Other results of the evaluation were that PLWHA and their families reported satisfaction with the ICHC model, though some PLWHA reported more satisfaction with their community caregivers than with hospitals and clinics in their local ICHC network. Community caregivers were generally satisfied with the support they received in the ICHC model, and noted that hospices were the main sources of support.

As of 2006, more than 40 hospices in South Africa were ICHC providers (24).

7.1.4 Palliative/Hospice care with HBC services

Hospice aims to provide care and support to patients and their families that meet physical, psychosocial, and spiritual needs. Physical care includes clinical care, while

spiritual care often addresses religious concerns about illness and dying. Examples of social support include facilitating access to government assistance programs. Hospice services also include palliative care, of which an important component of palliative care is effective pain management.
While some of the earlier-established hospices in countries such as Zimbabwe and South Africa were based on the inpatient model of care, the HIV/AIDS pandemic in Sub-Saharan Africa made many hospices adapt their services to better meet the needs of PLWHA and their families (43, 47). One major adaptation has been to provide hospice services through HBC. For many hospices in Sub-Saharan Africa, HBC is a main model/approach used for providing care. Several hospices also have outpatient clinics and supportive services such as day care centres.

Inpatient hospices are generally not a sustainable model of care in Sub-Saharan Africa. Compared to HBC, inpatient hospices are usually more expensive to operate (24). In addition, cultural norms in Sub-Saharan Africa more often value caring for ill and dying family members at home, not in inpatient hospices and similar facilities. However there are situations when inpatient hospice care has been advantageous compared to HBC. In Zambia, for instance, traditional support networks for the dying were disrupted as many men became employed in copper mines away from their families (46). Thus, inpatient hospices sometimes provided terminal and palliative care to these men. Another reason for the relatively higher occurrence of inpatient hospice service utilization in Zambia is connected to the need for strong pain control in chronic conditions such as HIV/AIDS – due to very strict morphine regulations in Zambia, morphine is best available at services such as inpatient hospices.

Though hospices are a central part of the ICHC model, all hospices with HBC services are not necessarily part of the ICHC model because their services might not be as integrated and comprehensive as hospices providing services in accordance with the ICHC model. .

7.1.5 Hospital-supported HBC services

In this model, government and non-government hospitals support HBC services, which are directly connected to the hospitals. Examples can include hospitals making HBC one of their approaches to service delivery, HBC-providing NGOs being based in hospitals, or other formal links between hospitals and HBC services. Hospital-based HBC service staff such as nurses and community health workers follow up hospital patients with HBC referrals from hospital wards to their homes. Nurses and volunteers are part of HBC teams. HBC services can also be linked with community-based services to ensure patients receive continuity of care and support. Referrals are made as needed to community-based healthcare services or back to the hospitals.

Sometimes, hospitals have palliative care teams to follow up patients with palliative care referrals while patients are still at the hospital (24). In such cases, palliative care teams are part of hospital staff, and they liaise with community-based services to ensure patients receive continuity of care after discharge from the hospital (24, 65).

Government hospitals work in collaboration with multi-sectoral stakeholders (82). Doctors, nurses, and social workers in hospital-based frameworks coordinate HBC services at the district level. The literature available does not provide examples of government hospitals providing HBC services at a district level.

7.1.6 Outreach services which include HBC

In order to increase services' geographic coverage, this model utilizes outreach teams to provide services in areas away from the main base of services (24). Staff see patients on a walk-in basis in outreach area clinics, in addition to providing home care for patients who are unable to attend the clinic. Sometimes, outreach teams and clinics are preceded by roadside clinics, in which staff provide care to patients along the roadside or other transportation routes where patients and staff can meet relatively easily. This type of service provision over a period of time can justify the need to start outreach teams and clinics.

Table 2: Possible advantages and disadvantages of the main HBC providers / supporters

HBC provider / supporter		Possible Advantages	Possible Disadvantages
Community-based providers: CBOs, NGOs, FBOs, hospices		• Awareness of specific community needs and relevant responses. • Can be flexible, adaptive, accessible, more affordable, have good coverage, and sometimes better able to provide comprehensive care. • Utilises existing community resources, such as volunteer community-based caregivers. • Could address other chronic health issues in addition to HIV/AIDS. • Sense of community ownership can facilitate resource development and sustainability.	• Weak links with hospitals, referral systems, and medical supplies. • Insufficient program management capacity and technical input. • Sustainability, especially if funding is primarily from external donors or if donor base is not diverse. • If FBO-supported, might increase HIV/AIDS-related stigma by moralizing.
Hospitals	**government and non-government**	• Good access to supplies, referral systems, and professional staff.	• Costly • Inadequate focus on non-clinical needs of PLWHA and families.

		• Easy supervision and monitoring.	• Low coverage and frequency of home visits.
	government	• Sustainability • Potential for greater service coverage, depending on location.	• Relatively inflexible policies and procedures. • Needed changes in service delivery can sometimes take a long time to implement.

Adapted from:

▪ (18) Family Health International, USAID. *Monitoring HIV/AIDS Programs: A Facilitator's Training* Guide – A USAID Resource Guide for Prevention, Care, and Treatment. Module 4: Monitoring and Evaluating Community Home-Based Care Programs, 2004.

▪ (51) Lamptey P, Gayle H. *HIV/AIDS Prevention and Care in Resource-Constrained Settings: A Handbook for the Design and Management of Programs, 2001*.

7.2 Home-Based Care in different resource-constrained countries

HBC is an important care and support delivery mechanism for PLWHA in Sub-Saharan Africa. This section discusses different models of HBC for PLWHA in Kenya, Tanzania, Zambia, and Malawi, as well as Uganda, South Africa, Zimbabwe, Lesotho, and Botswana. Outside of Sub-Saharan Africa, the discussion includes HBC for PLWHA in India, Cambodia, Viet Nam, Papua New Guinea, and Nepal.

Each country's discussion begins with a country-specific background about HBC and HIV/AIDS, followed by a HBC models section. For most countries, successes and strengths are addressed next, and the discussion ends with challenges and recommendations.

To note is that HBC service examples highlighted from each country are only examples and not the only such services. The literature available often did not directly address the standard of HBC services provided in a given country, but the information in this section provides a description of HBC services per country based on the information available.

7.2.1 Malawi

In Malawi, HBC is part of the overall national response to HIV/AIDS (54). Beginning in 1992-1994, the Government of Malawi established District AIDS Coordinating Committees (DACCs) to facilitate and implement multi-sectoral responses to HIV/AIDS (76). It took several years to strengthen the overall concept and structure. DACC members include government ministries (health, gender and community services, children's affairs, education, agriculture, youth-sports-culture), NGOs, CBOs, FBOs, and individuals. DACCs form Technical Subcommittees (TSCs), of which one is HBC. Regular interaction is expected between DACCs and TSCs. DACCs are further subdivided into Community AIDS Committees (CACs), which have their own TSCs. Around 1995, Village AIDS Committees (VACs) were initiated and incorporated into the overall already-existing government structure by the STEPs program (Scaling up HIV/AIDS Interventions Through Expanded Partnerships). The Malawi office of Save the Children Federation implemented STEPs – a multi-sectoral, community-based program for OVC and others affected by HIV/AIDS. HBC was one program area of STEPs, and VACs enhanced the ability to meet program beneficiaries' needs.

DACCs, CACs, and VACs are integral elements of Malawi's HBC provision. VACs have HBC committees supporting local HBC service provision. Other committees address the issues of orphans and vulnerable children (OVC), youth, and high risk groups. However, in a Malawi HBC service assessment conducted by the Umoyo Network in 2000 (54), most high risk group committees were found to be inactive. This could in part be due to committee members wanting to avoid stigma they might face if their involvement in high risk group committees is perceived to be motivated by their own involvement in high risk activities. A recommendation was made to re-name these committees prevention committees.

Malawi's original National AIDS Commission (NAC) operated from 1987-2001, but in 2001, NAC became a Trust (61). In 2004, the National HIV/AIDS policy was implemented, and Malawi's ART program was initiated to provide free ART to 50% of HIV+ people (42). In 2005, the National Community Home Based Care Policy and Guidelines were finalised with palliative care included as an element of a comprehensive community HBC package (i.e. 7.6 pp. 10)[1]. Palliative care is also included in the minimum package for CHBC and the holistic approach to care including palliative care is highlighted as a guideline to CBHC (i.e. 11.1 pp. 16). The guideline states that all patients who are suffering from life threatening diseases and ultimately incurable illness shall be provided with palliative care with the aim of achieving the best quality of life (pp.18).

According to a 2004 report by the International Observatory on End of Life Care (42), five organisations provide palliative care in Malawi, of which two provide home care services, too.

[1] Republic of Malawi Ministry of Health/National AIDS Commission National Community Home Based Care Policy and Guidelines, December 2005

From Table 8:

Country	Models / service providers of HBC for PLWHA		HIV/AIDS statistics		
	CBOs, FBOs, NGOs, hospices	Hospitals: government and non-government	Estimated Adult Prevalence (%)	Estimated # PLWHA	# deaths (adults & children)
Malawi	X	X	11.9%	930,000	68,000

Source: 2008 Report on the global AIDS epidemic, UNAIDS/WHO, July 2008.

HBC models

According to the literature, two main models of HBC are present in Malawi:

- CBO-/NGO-/FBO-/hospice-supported programs
- Hospital-supported HBC programs

CBO-/NGO-/FBO-/hospice-supported programs

FBO-supported HBC programs are typically implemented by member agencies of the Christian Hospital Association of Malawi (CHAM) (54). Community-based volunteers provide services in HBC programs supported by CHAM member organizations. Volunteers are managed by supervisors, and hospital-based staff are sometimes able to provide support.

When NGO- or CBO-supported, HBC is provided by community-based volunteers connected to NGOs and CBOs with HBC services (54). Volunteers are usually part of the local AIDS committee. Volunteers are managed through NGO-employed coordinators.

An example of this overall model in Malawi is the Lighthouse, which is a WHO case study (103). In 2001, the Lighthouse Trust was established to improve quality of life for PLWHA, as well as to provide a continuum of care and counselling. Demonstrating governmental support of the response to HIV/AIDS, the Vice President of Malawi opened the Lighthouse Centre in 2002.

Many services are provided for PLWHA at the Lighthouse, such as community home-based care (CHBC) mostly in Lilongwe city (42). In 2004, the Lighthouse had a HBC team consisting of professional staff and approximately 300 volunteers (42). Volunteers and professional staff work closely together, meeting regularly. Volunteers identify patients in their communities who need HBC and can refer them directly to the Lighthouse clinic as needed. In 2003, approximately150 HBC patients were served per month.

Palliative care is provided (103). Morphine is available, and the Lighthouse was instrumental in the introduction of oral morphine into the government's morphine supply (42). In the Lighthouse, morphine prescriptions are written by clinical officers. Nursing staff includes at least one nurse specifically for palliative

care, as well as supervision. In addition to providing palliative care training throughout Malawi, the Lighthouse also offers ongoing palliative care training to its staff (42).

The Lighthouse offers CHBC refresher courses, as well as activities to retain volunteer motivation such as annual social events and opportunities to visit other programs (103). The Lighthouse maintains close links with Lilongwe Central Hospital.

Further details specifically about CHBC services provided by the Lighthouse are not described in the available literature..

Hospital-supported HBC programs

HBC services supported by St. Anne's Hospital are an example of hospital-supported HBC services in Malawi. This hospital in Nkhotakota provides HBC through the community-based volunteers it trains (42). Three health centres are present in the district, and volunteers work within the health catchment areas.

St. Anne's Hospital also has a palliative care unit which provides most palliative care medication free of charge to patients, but a full range of pain control options is not necessarily part of HBC (42). HBC volunteers provide basic medication to patients.

Strengths and Successes

- HBC **volunteers' assessments of patient needs** (physical, emotional, household help, basic commodities, and social services) are generally good, tending to correlate with what patients themselves report as needs, according to the Malawi HBC services assessment conducted in 2000 (54).

Challenges and Recommendations

- Strong referral systems are crucial for effective HBC programs. In the Umoyo Network's assessment of HBC service provision in Malawi (2000), it was found that referral systems between HBC programs, hospitals and other community resources/organizations were weak (54). Referral systems should be strengthened for patients discharged from hospitals to HBC programs, as well as for HBC patients needing referrals to health care facilities and other services.

  In addition, the work of HBC volunteers makes them aware of not only patient needs but also the diverse needs of patients' families. These include caregiver respite, as well as OVC care and support. HBC programs' referral systems must include links with community and government services for PLWHA's families.

- Increased collaboration among HBC-providing entities and related programs would further strengthen the response to PLWHA (54). With TB being a leading

cause of mortality among PLWHA, collaborative efforts between HBC programs and the National TB Control Program could help to bridge the gap between services for PLWHA and TB patients. Other useful collaborations for HBC programs to pursue include those with the STI Control and Prevention Program and reproductive health programs.

- In Malawi, food security has been heavily affected by droughts and poverty. Especially within the context of HIV/AIDS and ART, food is very important not only for better ART effectiveness but also for general nutritional status. Patients and volunteers report needing more food, and HBC programs must seek to address this basic need to the extent possible (54), whether through referrals, food provision, or other means. While food aid can be costly for programs and lead to dependence by recipients, food aid could be used as a short-term measure while longer-term measures are explored and implemented.

- Volunteer training and supervision needs should be better addressed.

  In the Umoyo Network's assessment of HBC service provision in Malawi (2000), approximately 23% of HBC volunteers reported receiving no training, whereas others reported receiving insufficient training in certain areas, such as counselling and nursing skills (54). HIV/AIDS prevention training is also important. Refresher training should be part of training provided by HBC programs.

  In addition, HBC volunteers report wanting more supervision than they currently receive. Supervision systems exist in the three models of HBC services in Malawi, but the expressed needs of HBC volunteers should be explored further to better understand and respond to HBC volunteers' supervision needs.

- Transportation can be problematic for HBC volunteers who must travel in order to reach patients' homes, as well as for HBC patients needing to go to hospitals or clinics for care (54). Public transportation can be expensive, unreliable, or too infrequent to adequately meet travel needs. Transportation in rural areas can be especially challenging. Some HBC programs provide bicycles to their volunteers to facilitate service provision, though management of bicycle provision can have challenges as well. Overall, adequate support of transportation is an important facilitative aspect of HBC service provision that HBC programs should consider.

- HBC kits are an essential component of HBC, but based on an assessment of Malawi's HBC services in 2000 (54), HBC volunteers are too often not equipped with HBC kits which contain basic nursing supplies, pain relief medications, and antibiotics. Replenishing HBC kits regularly is key, in addition to providing patients and families with basic supplies to use in between visits from HBC volunteers.

7.2.2 Zambia

A multi-sectoral approach to HIV/AIDS that includes HBC was established in 1999 by the National AIDS Council (63). Improved HBC for PLWHA was a high priority area in the 2001-2003 HIV/AIDS/STD/TB Strategic Framework (63), and HBC remains part of Zambia's response to HIV/AIDS. Health-related HIV/AIDS activities are the responsibility of district health management teams, which are divided into district AIDS task forces. Community representatives, the general public, and NGOs can partner with district AIDS task forces to increase access several HIV/AIDS-related services, including HBC.

Recent events include the development of the Zambia National Minimum Standards for Community and Home-Care Organisations. This was completed in June, 2007 by the National AIDS Council Technical Working Group on VCT/HBC and the HBC Forum.[2] These standards are based on the National HIV/AIDS policy framework that is implemented through the Zambia AIDS Strategic Framework (ZASF). In this framework, the need to improve and standardize the quality of palliative care is highlighted as a key issue to achieving strategic objectives and management of pain (pp. 31), psychosocial support and physical care (pp.29) are key standards relevant to palliative care.

According to a 2004 report by the International Observatory on End of Life Care (46), six organisations are listed as providing palliative care in Zambia, and all six provide home care services, too.

From Table 8:

	Models / service providers of HBC for PLWHA		**HIV/AIDS statistics**		
Country	**CBOs, FBOs, NGOs, hospices**	**Hospitals: government and non-government**	**Estimated Adult Prevalence (%)**	**Estimated # PLWHA**	**# deaths (adults & children)**
Zambia*	X	X	15.2%	1,100,000	56,000

Source: 2008 Report on the global AIDS epidemic, UNAIDS/WHO, July 2008.
* Inpatient hospices are also common in Zambia (46). Though this model is different from HBC, inpatient hospices sometimes provide HBC services as well.

HBC models

According to the literature, two main HBC models are present in Zambia:

- Hospital-supported HBC programs

[2] National AIDS Council (2007), Zambia National Minimum Standards for Community and Home-Based Care Organisations, first version June 2007

- CBO-/FBO-/NGO-/hospice-supported HBC programs

Inpatient hospices are also common in Zambia. Though this model is different from HBC, some inpatient hospices also provide HBC services.

Hospital-supported HBC programs

According to available literature, hospital-supported HBC programs are implemented either by government hospitals or NGO hospitals, of which most in Zambia are faith based. Several hospital-based HBC programs started in 1987. In the Southern Province at Chikankata, the Salvation Army Hospital began a home care unit (5), and the Churches Medical Association of Zambia (CMAZ) initiated a similar effort (63). In Lusaka, an HBC program was implemented at the University Teaching Hospital through the Family Health Trust, a local NGO with an office in the hospital. Some years later in 1992, a HBC unit began in at the Copperbelt's Ndola Central Hospital. By the mid-1990s, the number of HBC programs had risen to approximately 100, according to the Ministry of Health (5). Further details specifically about HBC services provided by these hospitals are not described in the available literature, but general components of hospital-supported HBC programs are described in this report in Section 3.1.4.

Several hospitals have HBC departments, which are staffed with nurses and others. When patients with HBC referrals are discharged from hospital wards, a core team of trained professionals receive referrals and initiate regular HBC visits for patients.

CBO-/FBO-/NGO-/hospice-supported HBC programs

CBOs, FBOs, NGOs have started CHBC programs in Zambia. They were originally established when the limitations of hospital-based programs became clear, at which point hospitals themselves began to link with CBOs to be partners in HBC service provision (5).

Examples of FBO-supported HBC for PLWHA in Zambia include the Lusaka Change Programme, which began in 1999 and is part of the Salvation Army, and the Ndola Catholic Diocese, which provides HBC services in the Copperbelt region (5). Community organizations approach the Ndola Diocese with HBC support requests. The Diocese and the respective CBO then collaboratively discuss what can be done, including roles and responsibilities of each organization. HBC services implemented by Diocese nurses, volunteers, spiritual staff, and administrative staff include nursing and spiritual care, psychosocial support, and counselling (63). Nurses can provide care at community clinics or in the home setting, where they are usually able to treat conditions such as oral thrush, diarrhoea, malaria, various skin conditions, and some sexually transmitted infections. The government district health system provides TB drugs for directly observed treatment – short course (DOTS). Volunteers provide emotional and spiritual support, as well as practical assistance such as facilitating transportation to and from clinics. Nurses and specially trained volunteers offer counselling

before and after HIV testing. The literature available does not indicate if morphine is available for HBC patients.

Finally and according to report by the International Observatory on End of Life Care (46), many inpatient hospices are present in Zambia. Reasons proposed for their existence include the fact that traditional support networks for the dying were disrupted as many men became employed in copper mines away from their families. Another reason is connected to the need for strong pain control in chronic conditions such as HIV/AIDS: due to very strict morphine regulations nationwide, morphine is best available at services such as inpatient hospices. Based on selected inpatient hospices, bed capacity ranges between 12-26 per inpatient unit. Specific details of services are not described in available literature but in addition to palliative care, several inpatient hospices have HBC services as well.

Strengths and Successes

- Training constitutes an essential component of effective HBC programs. Mother of Mercy Hospice has a varied training program for staff and volunteers (46). Regular meetings present opportunities to discuss case studies based on patients and caregivers. Kara Counselling undertakes training and skills improvement for Mother of Mercy Hospice. To address HIV/AIDS, STIs, and TB, the Ministry of Health and the Zambian National AIDS Committee are involved in nursing and laboratory workshops. In addition, monthly meetings with the Palliative Care Association of Zambia (PCAZ) allow for interaction and sharing experiences.

- HBC volunteers reported satisfaction with their role in the community (63). In addition to being better able to educate patients and families about HIV/AIDS, basic nursing skills, and other issues, HBC volunteers felt their position is a respectful one in their communities. At the same time, they become someone community members can confide in.

Challenges and Recommendations

- Given that TB is a leading cause of mortality and morbidity among PLWHA, HBC programs have a role to play in TB care and support for PLWHA and their families. Doing so not only provides a needed service, but it can serve as an example to other HBC providers to integrate TB care and support into HBC. In Zambia's Copperbelt, the Home Care Program of Ndola district's Nkwazi township began providing TB care and support as part of HBC. The initial results were promising (59). However, based on an HIV/AIDS care and support assessment in 2002 that included TB care, 80% of HIV care providers do not provide TB care, stating insufficient supplies of TB drugs and a lack of guidelines/policy as the main reasons for not addressing these needs of their TB/HIV co-infected patients. In addition, the assessment found that a significant portion of TB physicians in assessed districts did not provide DOTS (63).

- HBC volunteers' high case loads could mean less quality time with patients and families (63). Though HBC volunteers averaged visiting 5 patients per day, half of the HBC volunteers averaged visiting approximately 10 patients per day in Lusaka. In addition to quality issues, high case loads could also lead to HBC volunteer burn-out. HBC programs' human and financial resource development efforts should plan for better distribution of patient case loads among existing volunteers, as well as recruitment and retention of new volunteers.

- Referral systems are not effectively in place for HBC patients' clinical and social support needs (63). Though health care workers reported strong networks within the communities for HBC patients' health-related needs, referrals outside communities were not common, and most referrals were within the health sector only. Establishing and maintaining strong, multi-sectoral referral networks at the local and district levels is important for communities to fully provide holistic HBC. National efforts should also be put in place to ensure effective referral systems for HBC patients and their families.

7.2.3 Tanzania

The Tanzania Commission for AIDS (TACAIDS) and the Zanzibar AIDS Commission (ZAC) were both established in 2000 (44). Both are multi-sectoral in scope.

National guidelines for HBC service have been developed by Tanzania's Ministry of Health and National AIDS Control Programme (86). The original version from 1999 was revised in 2005 due to changes in or introduction of companion documents such as the Health Sector Strategy for HIV/AIDS and the National HIV/AIDS Care and Treatment Plan. The (2005) *Guidelines for HBC Services* addresses a comprehensive range of HBC-related topics, such as the continuum of care, roles and responsibilities of stakeholders at different levels, and referral systems. These guidelines support palliative care as part of a minimum package of HBC services, indicating the palliative care role of HBC providers to include identification of symptoms and pain in patients, monitoring side effects of administered drugs, and making referrals as needed. The WHO pain ladder is part of these guidelines. In Tanzania, integration of HBC into health care systems is the responsibility of District Health Management Teams (DHMTs), and therefore, the Guidelines for HBC Services are meant to support DHMTs, as well as other HBC implementers such as NGOs, CBOs, and FBOs. An assessment by WHO in 2005 (97) indicated that though the Tanzanian health system is supportive of CHBC, it is mostly NGOs and other organizations that provide the bulk of CHBC in Tanzania (97).

According to a report in 2004 by the International Observatory on End of Life Care (44), four organisations are listed as providing palliative care, of which three provide home care services, too. A study in 2006 covering 5 regions in mainland Tanzania indicated that a total of 129 organizations provided HBC or HBC-related services in the 5 regions (70). However, the study was not able to fully identify which programs provided comprehensive HBC versus which ones provided home visiting.

From Table 8:

Country	Models / service providers of HBC for PLWHA		HIV/AIDS statistics		
	CBOs, FBOs, NGOs, hospices	Hospitals: government and non-government	Estimated Adult Prevalence (%)	Estimated # PLWHA	# deaths (adults & children)
Tanzania	X	X	6.2%	1,400,000	96,000

Source: 2008 Report on the global AIDS epidemic, UNAIDS/WHO, July 2008.

HBC models

In Tanzania, two main models of HBC are present according to the literature:

- Hospital-supported HBC programs
- CBO-/FBO-/NGO-/hospice-supported HBC programs

Hospital-supported HBC programs

Selian Lutheran Hospital, an FBO, is an example of this type of HBC service delivery model in Tanzania, where approximately 50% of health care is provided by hospitals with religious (especially Christian) affiliations (44). Already utilizing volunteer community health workers in addition to working in community health and HIV/AIDS prevention, Selian Lutheran Hospital reported that its transition into HBC provision was not very difficult. As of 2004 (44), approximately 120 volunteers were providing HBC to approximately 300 enrolled patients, and patients were visited once weekly. Oral morphine is available to HBC patients. Once prescribed by the medical team, volunteers and families can administer the morphine. Volunteers are supervised by a small core of clinical hospital-based staff. Health professionals receive training based on that provided by Hospice Africa Uganda and Nairobi Hospice. Spiritual and emotional care are part of HBC services.

Another example of this model is found in rural Muheza District at Muheza Hospice Care, which is part of Teule Hospital (44). Muheza Hospice Care is co-supported by the Tanzanian Ministry of Health and the Anglican United Society for the Propagation of the Gospel. Several services are provided through Muheza Hospice Care, including HBC by volunteers and village health workers who receive training in hospice, basic care, and counselling. The available literature does not further describe details of Muheza Hospice Care's HBC services.

At least three hospital-supported HBC programs are also present in Dar es Salaam in Temeke, Kinondoni, and Ilala municipalities (97). All hospitals facilitate referral to their HBC units of patients who are likely to benefit from HBC.

Aspirin and panadol are provided by HBC workers, and it is not clear whether stronger analgesics are also available for patients.

CBO-/FBO-/NGO-/hospice-supported HBC programs

Examples of CBO-supported HBC programs in Tanzania include PASADA (Pastoral Activities and Services for People with AIDS in Dar es Salaam Archdiocese) (44). Begun in 1992, care is provided by volunteers trained in basic nursing skills, counselling, and palliative care in this HBC program specifically for PLWHA. PASADA works in collaboration with the Diocesan Community Health Education Programme. As of 2004, approximately 600 families were reached by PASADA. Patients are visited approximately twice a week (97). WAMATA (Walioi Katika Mapambano na AIDS Tanzania) also focuses on PLWHA for its HBC services.

Another Tanzanian example of this model is Pathfinder's Tutunzane CHBC program (70). Begun in 2001, Tutunzane trains community health workers (CHWs) in palliative care within a HIV/AIDS context. In turn and in addition to care delivery, trained CHWs train and provide information to primary care providers (PCPs) of PLWHA about basic nursing care, infection prevention, and sanitation, as well as treatment adherence, PMTCT, reproductive health, and PLWHA self-care.

Strengths and Successes

- According to WHO, HBC is integrated into the Tanzanian health care system (98). The (2005) *Guidelines for HBC Services* addresses a comprehensive range of HBC-related topics, such as the continuum of care, roles and responsibilities of stakeholders at different levels, and effective referral systems (86).

- In a study by Pathfinder (70), it was found that CHWs generally have good rapport with places where they refer their patients for additional health care. Such working relationships contribute to the continued ability of HBC programs to meet the health needs of HBC patients and their families.

- PCPs of PLWHA and CHWs trained in HBC noted that they had a better understanding of HIV/AIDS (70). This in turn helped in caretaking because when periods of illness set in for PLWHA, PCPs and CHWs felt more empowered to handle what had arisen because of increased knowledge about HIV/AIDS.

Challenges and Recommendations

- PCPs, CHWs, and PLWHA in Pathfinder's Tutunzane program indicated that transportation costs, food needs, hospital/clinic fees, inadequate supplies, and insufficient allowances are very challenging issues (70). In short, poverty affected the CHBC program. Inadequate food supplies can negatively affect ART effectiveness. Insufficient transportation allowances can hinder HBC provision by volunteers and the ability of patients to get to clinics or hospitals for further care. HBC programs in resource-limited settings must address these basic needs

by collaborating further with other organizations that could provide assistance, in addition to re-examining their own resources to see if additional services that address these needs can be added to the program without severely compromising other aspects of the program or fostering a sense of dependency by those enrolled in HBC programs.

- Referral systems must better address legal needs of HBC patients and their families (70). Topics which PLWHA and their families needed legal information about included inheritance, employment rights, housing, and access to other resources.

- Though there was an increased knowledge base among PCPs and CHWs trained in HBC about HIV/AIDS, information about and supplies for infection prevention were insufficient and not well distributed or available in the program (70). Supplies include such items as gloves and condoms. While gloves were used in CHW demonstrations to PCPs and PLWHA, supplies of gloves were often not part of what CHWs left with families to use in caretaking in between CHW visits. More information about PMTCT and reproductive health would have also enabled PLWHA to be better informed in making choices about these issues.

7.2.4 Kenya

Kenya established an AIDS Programme Secretariat in 1985, and later instituted the National AIDS/STD Control Programme (NASCOP) in 1992 (58). NASCOP developed CHBC guidelines in 1993 (100). They have been revised, and the 2002 version of NASCOP's *National Home-Based Care Programme and Service Guidelines* are available (64). In addition, the 2002 version of the *National Home-Based Care Policy Guidelines* by the National AIDS Control Council (NACC) (58) are available, including a section for palliative and terminal care. The HBC policy guidelines define palliative care generally as care which keeps patients as healthy as possible to the longest extent possible through addressing physical, spiritual, emotional, and psychosocial needs. As such, the HBC policy guidelines also note that all of the care addressed in the document could be considered palliative.

According to the *National Home-Based Care Programme and Service Guidelines* (64), the most direct level of interaction between HBC programs and government structures takes place at the Constituency AIDS Control Committee (CACC) level. Above the CACC level and still within the overall framework of NACC are Provincial AIDS Control Committees (PACCs) and District AIDS Control Committees (DACCs). CACCs work at the community level and along with the other two AIDS Control Committees, CACCs are expected to work in close collaboration with District Home-Based Care Committees, District Health Management Teams (DHMTs), and community resources such as hospitals, NGOs, CBOs, FBOs, and others providing health care. Community involvement in developing HBC strategies and action plans are encouraged by the *National Home-Based Care Policy Guidelines* (58).

A 2004 report by the International Observatory on End of Life Care shows that seven organisations provide palliative care services, and all seven provide HBC as well (40). In addition, one hospital has three HBC programs.

From Table 8:

	Models / service providers of HBC for PLWHA		HIV/AIDS statistics		
Country	CBOs, FBOs, NGOs, hospices	Hospitals: government and non-government	Estimated Adult Prevalence (%)	Estimated # Adult PLWHA	# deaths (adults & children)
Kenya	X	X	6.1%	1,200,000	140,000

HIV/AIDS statistics source: (88) *AIDS Epidemic Update.* UNAIDS, Dec 2006 (WHO/UNAIDS database source: *2006 Report on the Global AIDS Epidemic*).

HBC models

According to the literature, there are two main HBC models present in Kenya:

- Hospital-supported HBC services
- CBO-/FBO-/NGO-/hospice-supported HBC programs

Hospital-supported HBC services

In rural Nyambene District in Kenya, the HBC programs within Maua Methodist Hospital are an example of a hospital-supported HBC model (40). The HBC programs were established in 2002 as part of Muau Methodist Hospital, which provides nursing, organizational, and medical support to the HBC programs. A doctor, clinical officer, nurses, and volunteers are part of the HBC service delivery team. ART is available for PLWHA, and for patients in need of it, morphine provision is part of HBC service delivery. In addition, community-based clinics have been established.

CBO-/FBO-/NGO-/hospice-supported HBC programs

Examples in Kenya of this model are Nairobi Hospice, Coast Hospice, Nyeri Hospice, Eldoret Hospice, Meru Hospice, Kisumu Hospice, and Mildmay International (40, O'Keeffe C, 2007).

Nairobi Hospice began in 1990. It provides palliative care within its HBC services. Bereavement and psychosocial support are available. Powdered morphine is imported from the UK, which is then made into liquid morphine and distributed throughout Kenya for use in hospices. Nairobi Hospice is recognized in Kenya as the main entity providing palliative care training. In addition, hospice teams visit hospitals, provide hospice care and counselling, and organise a day care service once weekly for adult patients which includes two meals cooked by volunteers. Most referrals to Nairobi Hospice are from Kenyatta National Hospital, and the majority of patients around Nairobi are from Kibera, the

largest slum in Sub-Saharan Africa. However, most of Nairobi Hospice's patient case load is from areas outside of Nairobi. Approximately 65% of patients with cancer are expected to be HIV-positive, while 25% of patients without cancer are HIV-positive.

Additional examples of this model include the Community-Based HIV/AIDS Prevention, Care, and Support Program (COPHIA) by Pathfinder International and Mildmay International's work in Nyanza Province (55, O'Keeffe C, 2007).

COPHIA's overall goals were 1) to strengthen HIV/AIDS-related capacity of local organizations, and 2) to increase the capacity of communities to identify, develop, and implement HIV/AIDS prevention, care, and treatment activities for PLWHA and OVC. Integral to these efforts was the work of trained HBC volunteer community health workers, who were part of CBOs in the overall COPHIA network of implementing agencies. Volunteer training included ART adherence, PMTCT, counselling, nutrition, VCT, basic care, hygiene, and stigma reduction. OVC care and support training for volunteers enabled them to identify and assess the needs of OVC in households where they provide HBC. For volunteers whose CBOs provided material support, part of volunteers' work was to identify those most in need and prioritize them for receiving material support. Referrals to health care facilities and other support were an important part of COPHIA.

Mildmay International in Nyanza Province works closely with the Ministry of Health and the Kenya Medical Training College (KMTC) to deliver integrated HBC services to PLWHA and others. A two-way referral system is a key component of this programme, with referrals possible between CBOs and health facilities, as well as between CBOs and community-level social support structures for patients and families. Within the Ministry of Health, support comes from the National AIDS Control Council and the National AIDS and STIs Programme. The Ministry of Health is the lead in divisional, district, and provincial levels. To enable HBC service delivery, community leaders and CBOs are partnered with district and divisional level Ministry of Health staff, who train CBOs' CHWs. These CHWs are also supported by the CBOs to which they are associated. Provincial level Ministry of Health staff receives training in KMTC's range of courses about HBC and palliative care. Regular technical support is provided to CBOs and CHWs by trained Ministry of Health staff, who also monitor use of HBC kits. This programme's HBC kits basic medications for pain and symptom control, emergency food supplies, and other supplies. APCA's African Palliative Care Outcome Scale was piloted in one district, where it showed improved quality of life through factors such as improvements in pain control and symptom control. As of August 2006, over 45% of patients in Nyanza Province had been reached by this programme, with CBOs actively providing care to more than 16,202 patients. Furthermore, 42% (more than 130,000) OVC had also been reached.

Nyatike Home-Based Care is an example of an FBO providing HBC services (48). Located in rural Nyanza Province, Nyatike Home-Based Care was established in 1999 by the Catholic Diocese of Homa Bay to provide HBC for PLWHA. Later, OVC care and support and material assistance were added. Community members chosen by the community are trained to become CHWs who provide HBC. In addition to their role as HBC service providers, CHWs provide HIV/AIDS-related education to communities, and this is noted to have resulted in changing community perceptions of PLWHA in positive ways.

Strengths and Successes

- Nairobi Hospice provides a range of palliative care training (48). A one-week training is available for community-based volunteers and health care professionals. A 14-month distance learning program for a Diploma in Higher Education Palliative Care has been offered since 2001. Four-week clinical placements at Nairobi Hospice are available for students from other hospices and colleges. Third year medical students can receive palliative care training from Nairobi Hospice at a teaching hospital. Also, Nairobi Hospice is working with the Ministry of Health to bring palliative care training into nursing school curricula.

- Together, the two **government HBC guidance documents** – *National Home-Based Care Programme and Service Guidelines* and *National Home-Based Care Policy Guidelines* (2002) – address a comprehensive range of HBC-related topics, such as HBC for PLWHA, palliative and terminal care, effective referral systems, and government policy for analgesics (64).

- UNAIDS noted Diocese of Kitui HIV/AIDS Programme for its work in eastern Kenya, which includes HBC (1999) (89). One aspect of this program is to actively recruit PLWHA as volunteers. Greater involvement of PLWHA is an important part of reducing stigma about HIV/AIDS (37, 90).

- In rural Nyanza Province, Nyatike Home-Based Care primarily serves PLWHA (48). Its community-chosen CHWs not only provide HBC, but also educate the community about HIV/AIDS**.** One result of community education has been increased knowledge by widows about the HIV/AIDS-related implications of a common cultural practice, wife inheritance. HIV/AIDS-related education at home and in the community can be mutually reinforcing, which is especially beneficial when applied to cultural traditions that play a role in HIV/AIDS transmission.

- Located in Kariobangi (outside of Nairobi) in the slum of Korogocho, the Community Health Programme was established in 1986 by the Medical Mission Sisters Health Programme to provide CHBC for PLWHA (91). It is a UNAIDS case study (2001). Its volunteer CHWs are from Korogocho, and their training takes place in Korogocho at a local school. PLWHA and their families could feel a greater sense of identification with CHWs who are from the communities they serve, which in turn can affect the perceived quality of receiving HBC services.

Challenges and Recommendations

- Dependence solely on external funding sources and dependence on too few donors can render programs vulnerable to unstable financial resources. This was noted as a challenge by Miwani Home-Based Care in rural Nyanza Province (48) and the Community Health Programme in Korogocho slum outside of Nairobi (91). Given the importance of maintaining HBC services for PLWHA, it is essential for HBC programs to actively explore ways to ensure sustainability.

- The Diocese of Kitui HIV/AIDS Programme in eastern Kenya noted insufficient collaboration among government services, NGOs, communities, and its own program (89). Often, one service by itself is unable to provide a comprehensive range of services for PLWHA and their families. Therefore, it is crucial for HBC programs to spread their professional networks and collaborative efforts into the immediate and larger areas they operate within.

- A CHBC study by WHO in 2001 revealed major challenges to include inadequate HBC training among HBC service providers (100).

  Ongoing HBC training of staff, volunteers, and caregivers should be a priority in HBC programs. It is core to providing quality, multidisciplinary HBC services. Refresher training is important for skills to be retained, as well as for new information to be incorporated into skills sets. Trainee feedback in training program evaluations can enable trainings to better address needs of a given HBC program.

7.2.5 Lesotho

According to a CHBC rapid appraisal in 2004 (7), there is no official CHBC policy or strategy in Lesotho. However, national stakeholders in CHBC include the Lesotho AIDS Programme Coordinating Authority (LAPCA), the Ministry of Health and Social Welfare – Lesotho (MOHSW) AIDS Unit, and the Department of Social Welfare. CHBC implementation is coordinated by LAPCA in conjunction with MOHSW AIDS unit, which developed the *Lesotho Community Home Based Care Training Manual* in use by many CHBC programs and partners. The Department of Social Welfare provides CHBC support as one of several services. The MOHSW has trained approximately 6000 community health workers in HBC, though none are also trained in palliative care, perhaps in part because formal palliative care does not exist in Lesotho (41).

At the district level, District AIDS Task Forces (DATFs) are linked to LAPCA (7). DATFs are the main entities coordinating HIV/AIDS-related activities in districts, and CHBC is a main responsibility of DATFs within that overall context. DATFs are headed by District AIDS Coordinators, with constituencies including district nursing officials, chiefs, police, and representatives from NGOs and CBOs.

From Table 8:

Country	Models / service providers of HBC for PLWHA		HIV/AIDS statistics		
	CBOs, FBOs, NGOs, hospices	Hospitals: government and non-government	Estimated Adult Prevalence (%)	Estimated # PLWHA	# deaths (adults & children)
Lesotho	X		23.2%	270,000	18,000

Source: 2008 Report on the global AIDS epidemic, UNAIDS/WHO, July 2008.

HBC models

At least one HBC model is present in Lesotho, according to the literature:

- CBO-/FBO-/NGO/hospice-supported HBC programs

CBO-/FBO-/NGO-/hospice-supported HBC programs

At the time of the 2004 CHBC assessment, CARE Lesotho was providing small grants to nine CHBC programs as part of supporting the strengthening of their CHBC services (7). Of the CHBC programs appraised, volunteers were utilized to provide to CHBC services, and they were trained in CHBC, counselling, and nutrition. None of the volunteers had official employment elsewhere. In one of the programs, teams of 2-3 volunteers provided CHBC to 3-4 households per day, approximately four days per week.

Referrals were an important aspect in CHBC service provision. Referral clinics were located in each general area where CHBC volunteers worked. They received approximately 2-3 referrals per month from CHBC volunteers.

Strengths and Successes

- Lesotho has a strong culture of communities caring for their ill members at home. These values form the foundation of CHBC provision in Lesotho (7).

- CHBC programs that were part of the appraisal in 2004 (7) met with each other once weekly to debrief about the week's cases, lessons learned, challenges, and topics of particular interest. When CHBC programs meet with each other on a regular basis, it can facilitate stronger links, collaboration, and networking among CHBC programs.

Challenges and Recommendations

- Lesotho's CHBC efforts are in critical need of technical support on a national level. Such technical support would include a national CHBC mapping exercise to ascertain more information about CHBC coverage in Lesotho, assistance in scaling up the national CHBC response, development of a national CHBC coordinating structure, and development of a national CHBC policy and strategy in Lesotho (7).

Can share the APCA assessment report

- DATFs are the government structures with primary responsibility for CHBC. In addition to national level technical support, technical support to DATFs needs to include assistance for more clearly defining the CHBC strategy and implementation plan (7).

- **HBC kits** are an important element of CHBC provision, and volunteer caregivers in the appraised CHBC programs considered HBC kits an essential component of their work (7). Yet, too few HBC kits were available for volunteer caregivers. In addition to increasing the number of HBC kits to at least be equal with the current number of volunteer caregivers, the HBC kits' supplies should include items such as pain medication, simple curative medication, bandages, thermometers, and other basic items (7, 69).

7.2.6 Botswana

Botswana's original national HIV/AIDS plan in 1993 was revised in 1998 to include CHBC. The current National Strategic Plan on HIV/AIDS (2003-2009) is multi-sectoral in scope (38). The literature available did not indicate if palliative care was part of either plan. A national ART plan was implemented in 2002. The Ministry of Health has a HBC training program which is operationalised by city councils. The National AIDS Council's CHBC program began in 1995 and is linked to the National Strategic Plan on HIV/AIDS (78, 97). The CHBC program has its own committees and is situated within the AIDS-STD Unit, which has a national coordinator. At the district level, HBC coordinators are part of teams consisting of a nurse, social worker, and volunteers.

According to a report in 2004 by the International Observatory on End of Life Care, three organisations are listed as providing palliative care in Botswana, and all three provide home care services, too (38).

From Table 8:

	Models / service providers of HBC for PLWHA		**HIV/AIDS statistics**		
Country	**CBOs, FBOs, NGOs, hospices**	**Hospitals: government and non-government**	**Estimated Adult Prevalence (%)**	**Estimated # PLWHA**	**# deaths (adults & children)**
Botswana	X	X	23.9%	300,000	11,000

Source: 2008 Report on the global AIDS epidemic, UNAIDS/WHO, July 2008.

HBC models

Two main models of HBC are present in Botswana, according to the literature:

- CBO-/FBO-/NGO/hospice-supported HBC programs
- Hospital-supported HBC services

CBO-/FBO-/NGO-/hospice-supported HBC programs

An example of this model is seen in Gaberone at the Holy Cross Hospice (38). Established in 1994, HBC for PLWHA was part of its mission from the beginning. It has since added a day care and an outpatient centre to its services, as well as some care and support of deceased hospice patients' orphaned children. Services are provided free of charge. Though this facility is a hospice, only mild pain relievers such as paracetamol are available. The literature does not provide much more information about services provided, but does indicate (as of 2004) having the following as full-time staff members: 1 director / health administrator, 3 nurses; 1 day care manager who is trained as a nurse, 2 social workers,3 drivers, 1 accounts officer, 1 receptionist, 1 administrative assistant, and 1cleaner. In addition, two volunteer doctors are available at the day centre's clinic and are on call as needed. Fifteen volunteers receive stipends for their work in the centre kitchen and in the community.

Hospital-supported HBC services

An example of this model in Botswana is Ramotswa Hospice at Home, which is part of the faith-based Bamalete Lutheran Hospital (38). Established in 1992, this hospice was initially intended to serve the chronically ill and elderly, but PLWHA soon became part of the patient population as well. Ramotswa Hospice at Home provides HBC, and for PLWHA, ART adherence support as well. Once per week (as of 2004), a physician prescribes morphine to patients as needed. Services are free of charge. In addition to HBC, a day care centre is open twice weekly to patients, and income-generating activities such as beadwork are available.

Strengths and Successes

- Botswana was the first country to implement **ART accessibility on a wide scale** (97). In addition, the national list of essential drugs corresponds with WHO standards for HIV/AIDS management.

Challenges and Recommendations

- **Staff shortages** are a critical issue for CHBC programs and the health system in general (78, 97, 98). In particular, there are too few registered nurses and social workers to meet the need for their services. Furthermore, recruiting new staff is difficult. Reasons for sub-optimal staff retention rates need to be further explored. Solutions to consider could include supporting adequate training, managing workloads better, offering competitive wages to the extent possible, and providing incentives.

- There are increased rates of **caregiver burnout and high burden of care** (98). Volunteer CHBC caregivers in a rural area of Botswana noted the emotional toll of working in an area of high HIV/AIDS prevalence and its associated deaths (78). Caregivers of PLWHA are burdened with increased caretaking responsibilities, which are even more challenging to handle in a framework of poverty. CHBC programs should strive to meet the respite needs of PLWHA caregivers by providing appropriate support interventions. Day care

centres for PLWHA provide respite for their household caregivers. Regularly-meeting CHBC volunteer support groups and careful attention to workload levels are examples of strategies that can be utilized to help manage the impacts of caregiving.

- When ill, seeking the advice of traditional healers and utilizing alternative healing methods were part of the response by some patients in rural Botswana (78). This is common in other parts of Sub-Saharan Africa as well. In contrast, Western/allopathic medical theory and practice generally underlie clinical responses to HIV/AIDS. Given that traditional medicine is important in the lives of many PLWHA and their families, **involving traditional healers** in HIV/AIDS-related efforts should be a part of community responses (7, 34, 45, 51).

7.2.7 Zimbabwe

Zimbabwe's *National Community Home-Based Care Standards* were developed in 2001 by the National AIDS Council and several partners, including the Hospice and Palliative Care Association of Zimbabwe (HOSPAZ) and Island Hospice (57, 98). In this document, palliative care training for multi-disciplinary staff is mentioned within an objective about psychosocial support, though palliative care is also mentioned in one standard (out of five total) about general HBC-related training, information, and education. Other national-level documents linked to CHBC include the Discharge Planning Guidelines and the National HIV/AIDS Policy. In addition, training and guidelines about the terminally ill are available. According to an International Observatory on End of Life Care report in 2004, palliative care has historically been provided by hospices in Zimbabwe (47). Nineteen services providing palliative care also provide home care.

Morphine is one of the drugs addressed in Zimbabwe's Dangerous Drug Act (47). If supported by a hospice physician, nurses in Zimbabwe are allowed to prescribe morphine.

From Table 8:

	Models / service providers of HBC for PLWHA		**HIV/AIDS statistics**		
Country	**CBOs, FBOs, NGOs, hospices**	**Hospitals: government and non-government**	**Estimated Adult Prevalence (%)**	**Estimated # PLWHA**	**# deaths (adults & children)**
Zimbabwe	X	X	15.3%	1,300,000	140,000

Source: 2008 Report on the global AIDS epidemic, UNAIDS/WHO, July 2008.

HBC models

According to the literature, two main models of HBC are present in Zimbabwe:

- CBO-/FBO-/NGO-/hospice-supported HBC programs
- Hospital-supported HBC services

CBO-/FBO-/NGO-/hospice-supported HBC programs

Island Hospice is an example of this HBC model in Zimbabwe. Its original service in Harare was established in 1979, where it is still operating (47). Other branches opened in Bulawayo in 1981 and Mutare in 1985, as well as six other independent branches throughout Zimbabwe. Services were originally for patients with cancer and other terminal illnesses, but as the prevalence of HIV/AIDS rose in Zimbabwe, services were adapted to enable PLWHA to become part of Island Hospice's patient population. Island Hospice provides HBC with palliative care, as well as basic nursing care. Services are provided free of charge to patients and their families. Island Hospice is a well-known provider of palliative care training.

The literature indicates that Island Hospice in Harare has a supply of morphine for patients (who are unable to get morphine from Harare government hospitals), but it also mentions that morphine supply is erratic (47). Neither Island Hospice Bulawayo nor Island Hospice Mutare prescribes morphine, though the one in Bulawayo facilitates morphine access through patients' physicians.

In 2003, Island Hospice Harare had full-time and part-time staff that totalled 85 volunteers, 14 nurses, 10 social workers, 10 administrative staff, 4 ancillary staff, 3 massage therapists, and 1 physician (47).

Another example of this HBC model in Zimbabwe is the Chirumhanzu Home-Based Care Project, which is a UNAIDS case study in 1999 (51, 89). Located in Midlands province, Chirumhanzu district is mainly an agricultural area where the prevalence of HIV/AIDS reached high levels after it was already high in urban areas. HBC for PLWHA and their families was a goal of this program from its inception in 1994. Most patients are identified in St. Theresa's Hospital, and many volunteer caregivers are themselves PLWHA. Patients are visited once per week by volunteers, whose reports help project coordinators decide if nurses also need to visit patients. The Ministry of Health provides HBC-related nursing materials and drugs. If patients are well enough to engage in any self-care, they receive training in hygiene, nutrition, and methods for treating common, simple HIV-related infections and conditions. Family caregivers are also trained in these areas. Chirumhanzu Home-Based Care Project hosts PLWHA support groups and conducts HIV/AIDS-related education efforts for the general public and higher risk groups through drama and skits.

Additionally, the Family AIDS Care Trust (FACT), which began in 1987, is an example of this model (47, Foster G et.al, 1999). In 1990 upon request by St. Joseph's Tuberculosis Hospital, FACT began providing HIV test counselling to patients. In response to some patients requesting care after discharge, FACT's

home care program began, with a nurse to coordinate the program starting in 1992. A church coordinator was also appointed to increase church involvement in home care. HBC service components include training family caregivers about nutrition, infection control, and basic nursing. Patients and families are also educated on several aspects of HIV/AIDS. Psychosocial support and spiritual care are part of HBC, as well as some material and logistical assistance. Patients are referred when needed. In 2004 and with the supervision of a volunteer doctor, three trained nurses could prescribe morphine.

FACT saw an increase of HBC volunteers from 4 in 1993 to 125 in 1998, in addition to the number of HBC visits from 562 in 1993 to11,623 in 1998. In 2004, FACT had 600 volunteers (47). In 1993, FACT's Family, Orphans and Children Under Stress (FOCUS) programme was initiated, which works with FBOs to identify households where for OVC care and support are needed (DeJong J, Population Council, International HIV/AIDS Alliance, 2001).

Hospital-supported HBC services

An example of this model is available in Morgenster Mission Hospital, which began in 2003 and provides HBC (47). As of 2004, this hospital had one doctor and one administrative staff, as well approximately 400 trained volunteers and links with 10 district nurses in 5 clinics. No social workers are on staff. Morphine is not available from Morgenster Mission Hospitals to its HBC patients.

Strengths and Successes

- In Zimbabwe, **palliative care training** is available primarily from Island Hospice Harare. Its palliative care training is offered to several different types of stakeholders in CHBC such as volunteer caregivers and other community volunteers, nursing and medical students, nurse aides, pastors, NGOs that work with OVC, HIV/AIDS support organizations, and HBC organizations.

Challenges and Recommendations

- There is a **lack of supplies and equipment**, including of basic materials and drugs (97). This is a major problem that needs to be addressed system-wide.

- **Staff shortages** are a critical issue for CHBC programs and the health system in general (97). The effectiveness, quality, and sustainability of CHBC programs can suffer without the staff needed to implement care, support, and management. Reasons for sub-optimal staff retention rates need to be further explored, in addition to considering solutions for these human resource challenges such as supporting adequate training, managing workloads better, offering competitive wages to the extent possible, and providing incentives.

7.2.8 Uganda

Uganda's effective responses to HIV/AIDS are well-documented. In 1986, an AIDS Control Program was established within the Ministry of Health (87). By 1992, the

Uganda AIDS Commission (UAC) was established within the Office of the President. UAC is responsible for overall planning, coordination, and oversight of HIV/AIDS prevention, care, and support activities in Uganda. It was a main stakeholder in developing the *Revised National Strategic Framework for HIV/AIDS Activities in Uganda: 2003/04-2005/06*. HBC is identified as a gap and emerging issue within these guidelines. Palliative care is highlighted in national HIV/AIDS framework and HBC guidelines

According to a report by the International Observatory on End of Life Care (45), eight organizations provide palliative care in Uganda, of which home care services are part of seven of those organizations.

From Table 8:

	Models / service providers of HBC for PLWHA		**HIV/AIDS statistics**		
Country	**CBOs, FBOs, NGOs, hospices**	**Hospitals: government and non-government**	**Estimated Adult Prevalence (%)**	**Estimated # PLWHA**	**# deaths (adults & children)**
Uganda	X	X	5.4%	940,000	77,000

Source: 2008 Report on the global AIDS epidemic, UNAIDS/WHO, July 2008.

HBC models

According to the literature, two main models of HBC are present in Uganda:

- CBO-/FBO-/NGO-/hospice supported HBC programs
- Hospital-supported HBC services

CBO-/FBO-/NGO-/hospice-supported HBC programs

Hospice Africa Uganda was established in 1993 to provide palliative care and support to PLWHA and cancer patients within a 20-kilometer radius of the main site in Kampala (21, 26, 34, 45). HBC is a main delivery model which Hospice Africa Uganda provides, and morphine is available for HBC patients. In addition to the main site, Mobile Hospice Mbarara and Little Hospice Hoima are part of Hospice Africa Uganda. Both began providing services in 1998. Hospice Africa Uganda has a wide variety of training programs for professional and volunteers at different levels of palliative care provision.

Another example of this model is found in The AIDS Support Organisation (TASO) was established in 1987 (45). In addition to other services, TASO provides HBC to PLWHA and their families within 35 kilometres of TASO clinics (81). The home-based caregiving team is typically constituted of a nurse, a client counsellor, and either a medical assistant or doctor. TASO is training

community health workers to be part of HBC teams as well. Nutrition, hygiene, skin care, counselling, and clinical care are part of HBC services.

Kitovu Mobile Home Care is an additional example of this model (45; O'Keeffe C, Mildmay International, 2007). Kitovu Mobile Home Care was established in 1987 by the Medical Missionaries of Mary and provides care to patients in their homes, as well at health centres. It operates in Masaka, Rakai and Ssembabule districts. Nurses, community volunteers, add coordinators are part of the staff. Medicines used by volunteers and nurses include those needed for treatment for HIV-related opportunistic infections and malaria. TB identification and treatment, counselling, HIV testing, HIV/AIDS awareness education, and psychosocial support are part of home-based and centre-based services. In 2000, palliative care was added to services. A physician was appointed for palliative care services, TB services, and complicated referrals from nurses. Morphine is available in HBC and health centre settings.

A final example of this model is The Partnership for Home-Based Care in Rural Uganda, a UNAIDS case study (91). The partnership began in 1993 and is comprised of the Family Life Education Program (FLEP), Pathfinder International, The AIDS Support Organisation (TASO), and the AIDS Information Centre (AIC). All partners are well-established in Uganda. Together and with HBC as a central component, the partnership works to improve the quality of life of PLWHA and communities affected by HIV/AIDS, in addition to promoting HIV/AIDS prevention. Village health workers, nurses, and supervisors in rural areas are trained and supported in their HBC work. To facilitate streamlining of HIV/AIDS care and support in rural areas, the partnership aims to bridge gaps among providers of home-based care, community-based care, clinic-based care, and self-care (by PLWHA). HBC services provided by volunteers include basic care and counselling, as well as increasing the capacity of family caregivers and patients by teaching them about HIV/AIDS, nutrition, hygiene, and treating simple conditions and infections. STI and HIV testing are available. Psychosocial and spiritual support are part of services provided, though referrals are made as needed in these areas of care, as well as for legal needs and more complicated health situations.

Hospital-supported HBC services

Lira Regional Referral Hospital's Palliative Care Unit provides an HBC service for areas within a bicycle ride of the hospital (45). The palliative care unit is a 1-bed facility. It is not clear from the literature whether caregivers in the HBC services are palliative care unit staff, trained volunteers, or both.

Strengths and Successes

- Uganda's national health plan includes palliative care, which is expected to result in palliative care eventually being available throughout the nation (45, 97). The integration of palliative care into the national health plan has begun to improve morphine availability. For instance, morphine is available free to PLWHA and cancer patients. In addition, training for health care students, professionals, and others at different levels of care provision has improved. Palliative care is integrated into HBC policies and training.

- Palliative care nurses and clinical officers specially trained in clinical palliative care (9-month course) have authority to prescribe morphine (26, 45). This is the result of a Statutory Instrument approved by the Ministry of Health in 2004. In many settings, only medical doctors are allowed to prescribe morphine, but with prescriptive authority extending to nurses as well, the potential opens for increased access to morphine by patients – including PLWHA in HBC settings – who need it for effective pain relief.

- Hospice Africa Uganda has a wide variety of training programs for professionals and volunteers who are involved at different levels of palliative care provision (34, 45). A nine-month clinical palliative care course is required for health care professionals to be palliative care nurses and palliative care clinical officers, of which both can prescribe morphine. Curricula have been revised to better incorporate HIV/AIDS care, HIV/AIDS prevention, and related issues. Community volunteer workers receive training about HBC and palliative care. In addition to courses in Kampala at the Hospice Africa Uganda site, training is provided in areas outside of Kampala, and distance learning courses are offered. Hospice Africa Uganda has also held training outside of Uganda in Malawi, Zambia, Kenya, Tanzania, and other African countries.

  Also known for its national and international training programs is The Mildmay Centre, which began in 1998 and is a UNAIDS case study (45, 91; O'Keeffe C, 2007). On-site training is conducted at The Mildmay International Study Centre (MISC), which aims to build capacity in delivery of comprehensive palliative care to PLWHA. Trainees have included health care and ancillary staff – such as doctors, nurses, counsellors, social workers, volunteers, and community health workers, government staff – including policy makers, NGO staff, students and teachers, PLWHA – including children, family caregivers, businesses, journalists, religious leaders, and traditional healers. Off-site training occurs through the mobile training team (MTT), which builds the capacity of health workers to care for PLWHA in rural settings.

Challenges and Recommendations

- Though many CBOs provide HBC for PLWHA, strong pain relief drugs such as morphine are not necessarily included in HBC. For instance, a WHO assessment found that while HBC is provided in Tororo district by TASO, oral morphine is not available to those who need it for effective pain relief (97). The Mildmay Centre – a UNAIDS case study for HIV/AIDS palliative care (91) – and the

government of Uganda are training TASO about morphine. However, other HBC-providing organizations also need to be trained and sensitized about providing stronger pain relief drugs for PLWHA and other HBC recipients who need it.

- Poverty affects the lives of many PLWHA and their caregivers. Basic items such as food, money, soap, salt, and paraffin were indicated as needed by households in a WHO assessment (97). These needs affect HBC for PLWHA as well. For instance, adequate nutrition is necessary for ART to be more effective, but when food security is a problem in an HIV/AIDS-affected household, ART effectiveness can be compromised for PLWHA in that household. Poverty alleviation is an important element of the overall response to HIV/AIDS, and Uganda's Poverty Eradication Action Plan is part of its national HIV/AIDS strategy (87).

- HIV/AIDS-related stigma remains a challenge. In an assessment of societal acceptance of PLWHA and HIV/AIDS, respondents were asked several questions related to stigma (97). One question addressed respondents' willingness to care at home for a relative living with HIV/AIDS. Only one of ten women and men indicated willingness. Stigma from neighbours was a problem indicated by families caring for PLWHA at home.

7.2.9 South Africa

In South Africa, it was mainly CBOs, NGOs, and FBOs which initially began community-based care and support efforts, according to an assessment in 2000 (74). Since then, hospices have also taken an active role in HBC, a specific form of community-based care.

Based on research by the Department of Health and Social Welfare, CHBC was identified in 2001 by South Africa's Cabinet as a priority area (85). In that year, national guidelines were developed for CHBC (17), and palliative care is included as one of the principle elements of CHBC . The 2000-2005 HIV/AIDS/STD Strategic Plan for South Africa included specific objectives for CHBC (56). In 2002, the Ministry of Health through the Chief Directorate: HIV/AIDS, STIs, and TB convened the first national conference about CHBC (85). The conference reported that 464 CHBC programs and at least 8000 trained caregivers were in South Africa. Palliative care was on the conference agenda as a critical issue of CHBC implementation.

From Table 8:

Country	Models / service providers of HBC for PLWHA		HIV/AIDS statistics		
	CBOs, FBOs, NGOs, hospices	Hospitals: government and non-government	Estimated Adult Prevalence (%)	Estimated # PLWHA	# deaths (adults & children)
South Africa**	X		18.1%	5,700,000	350,000

Source: 2008 Report on the global AIDS epidemic, UNAIDS/WHO, July 2008.
*** The literature available indicates that there are hospital-based palliative care services in South Africa, but it is not clear whether there are hospital-based HBC services (43).

HBC models

According to the literature, there are two main HBC models in South Africa:

- CBO-/FBO-/NGO-/hospice-supported HBC programs
- ICHC – see Section 3.1.2 for more discussion about this model

In addition, there is the UNAIDS case study of Bambisanani, a partnership of several different types of organizations (91). HBC is a main component of this partnership.

The literature indicates that there are hospital-based palliative care services, but it is not clear if there are hospital-based HBC services (43).

CBO-/FBO-/NGO-supported HBC programs

Highway Hospice is an example of this HBC model in South Africa. Located in KwaZulu Natal, Highway Hospice offers its services to residents of the eThekwini Municipal Area (84). Originally begun as an inpatient service in 1982 (43), Highway Hospice evolved to meet the needs of the communities it serves by including CHBC in its services. PLWHA make up a significant proportion of the patient population. Professional nurses coordinate HBC services, which includes supporting volunteer caregivers. Social workers are part of the home care team. Pain relief, symptom management, spiritual care, and emotional care are part of home care teams' work. Highway Hospice also has several day care centres (83).

A UNAIDS case study, Tateni Home Care Services, is another example of this model (89). Begun in 1996, Tateni Home Care Services serves Mamelodi, a former township located outside of Pretoria. Early on, it formed a link with Directorate for AIDS and Communicable Diseases while also maintaining close links with other community-based resources and organizations. Professional nurses and social workers provide training for CHWs. In turn, CHWs train PLWHA and their families about self-care and caregiving, respectively, as well as providing care. Referrals are made as needed to and from Tateni Home Care

Services, the government health system, and other health care services. As of 1999, Tateni Home Care Services was funded by the provincial government and local donors.

In addition, there is Bambisanani, UNAIDS case study (2, 91). Begun in 2000 in the Eastern Cape Province, this public-private partnership is comprised of the following stakeholders: Bristol Myers Squibb, Gold Fields Ltd, the National Union of Mineworkers, South Coast Hospice and Transkei Hospice, Anglo Gold, the Mineworkers Development Agency, Harmony, Planned Parenthood Association of South Africa, and the EQUITY Project. Bambisanani's goal is to improve the quality of life of PLWHA, their families, and their communities by providing comprehensive care that meets physical, social, emotional, and spiritual needs. Trained community caregivers provide HBC, teach households about basic care, and also provide households with home care kits. OVC care and support is coordinated by Care and Support for Children in Distress (CINDI). Support groups and income-generating activities are part of Bambisanani's efforts.

Strengths and Successes

- ICHC is a best practice model, according to the South African National Department of Health's Directorate for HIV/AIDS/STIs (14, 24). An evaluation of the model indicated that it is possible to replicate this model in resource-poor settings (92). The ICHC model is further discussed in the section of this document about Home-Based Care Models in Sub-Saharan Africa.

- In a study of the ICHC model (93), supervision and support to community caregivers were noted as strengths. Community caregivers reported that their supervisory nurses, and the director or social worker at the Hospice and Palliative care Association of South Africa played an important role in community caregivers' continued ability to carry out their work.

Challenges and Recommendations

- **Sustainability** is a challenge for HBC programs in South Africa. Though government support has increased for CHBC, more resources are needed for CHBC programs to be able to sustain themselves in the longer term (16). Smaller CHBC programs often have inadequate internal capacity to strategically seek funding and develop resources (74). In addition, there is insufficient recognition by the formal sector about palliative care as a professional service (82), which could not only have implications for sustainability of palliative care in general but also for its provision in HBC settings. In addition to increasing advocacy efforts, more capacity building is essential for CHBC programs to seek and utilize funding.

- An ICHC assessment included examining the effects on different ICHC model stakeholders of participating in the ICHC model (92). Though there were several

positive comments by hospitals, clinics and hospices, one challenge is that workload significantly increased by participating in the ICHC model. Examples of responsibilities for hospices (the main managers of the ICHC model) which were more time-consuming that anticipated included data collection, supervision, and securing social grants for patients and their families.

7.2.10 India

The National AIDS Control Organisation (NACO) is part of the Ministry of Health and Welfare of the Government of India (62). NACO has the responsibility of coordinating and directing India's national response to HIV/AIDS. State AIDS Control Organisations are also key stakeholders in this effort. As part of NACO's goals to expand care and support, it is recognized that HBC for PLWHA needs to be further developed and supported.

Table 3 provides HIV/AIDS-related statistics about India from July 2007.

Table 3: HIV/AIDS in India

	HIV/AIDS statistics	
Country	**Est. Adult Prevalence**	**Est. # Adult PLWHA**
India	0.36%	2,500,000

Source: (60) UNAIDS, WHO. AIDS Epidemic Update, December 2007.

HBC models

According to the International Observatory on End of Life Care, there are some hospice-related centres which provide services to PLWHA, but there is insufficient information about whether these sites also provide HBC for PLWHA. Cross-referencing these sites with HBC services in the report reveals that none of the PLWHA service providers are also listed as HBC providers (39). While many hospice services and some HBC services exist in India, many of them are for cancer patients. As such, the development of palliative care in India has mostly been based around cancer (79). HBC was recommended for PLWHA with cancer by Bansal et al. (3), but there was no information about HBC for PLWHA without cancer.

In spite of the strong connection to cancer only, there is a relatively small amount of literature indicating that that there are two models of care with HBC for PLWHA:

- Programs with HBC services connected to palliative care centres/clinics
- CBO-/FBO-/NGO/hospice-supported programs with HBC services

Programs with HBC services connected to palliative care centres/clinics

In the South Indian state of Kerala, the Neighbourhood Network of Palliative Care (NNPC) was established in 2001. It provides comprehensive long term care and palliative care to its patients, which include PLWHA (50, 68). NNPC

primarily operates in northern Kerala but is expanding to other areas of Kerala as well. NNPC is closely linked with palliative care centres/clinics, which are often part of hospitals.

Community-based volunteers who can devote approximately two hours per week caring for chronically ill people in their communities are trained by NNPC. This training is conducted by health care professionals and includes the following areas: introduction to palliative care, home care, HIV/AIDS, cancer, patient assessments, nursing care, communication, the role of communities, and care of the terminally ill. After successful completion of training, NNPC supports the development of home care programs by groups of 10-15 volunteers. This facilitates the direct involvement of volunteers in program design, implementation, monitoring, evaluation, and revision. NNPC supports these home care programs, and local palliative care centres are also directly linked to these home care groups. Volunteers identify the needs of chronically ill people in their communities, and patient management plans are developed for each patient in consultation with health care workers. Volunteers follow up visits to patients by palliative care teams, in addition to facilitating follow up of social and spiritual needs of patients and their families.

Overall, NNPC has trained at least 3000 community-based volunteers, established at least 40 home care programs, cares for at least 3000 patients and their families in their communities, and conducts at least 350 household visits per week.

CBO-/FBO-/NGO-/hospice-supported programs with HBC services

Examples of CBO-supported HBC services for PLWHA include the Pathway project, a CHBC initiative funded by CDC and implemented by Project Concern International. Begun in 2001 in one state, the project has since grown to providing services in 5 states (71). The Pathway project's objectives include proving CHBC to PLWHA and their families, as well as psychosocial support and income-generating activities. Given the importance of referral systems for the CHBC model, the Pathway project also focuses on strengthening the referral system. Home-based care teams are trained by the Pathway project. Care provided for PLWHA includes TB screening and DOTS provision, ART monitoring and adherence support, treatment for OIs and other infections, self-care skills for PLWHA and caregiving skills for family caregivers, and nutritional support (72).

The Pain and Palliative Care Society (PPCS) in Kerala is an NGO that provides HBC among other services, but it is not clear from the relatively small amount of literature available whether PLWHA are part of the patient population in PPCS's HBC services (6, 30, 68, 79).

Strengths and Successes

- NNPC has a relatively stable degree of **financial stability and sustainability** due to its strong roots in community participation (50, 68). Approximately 80% of NNPC's operating budget is the result of NNPC's work in fundraising for the program through community-based donations and local government support. The advocacy role of NNPC volunteers helps with raising funds from the community for NNPC. A system of donating approximately one rupee (approximately USD 0.03) or less per day by shopkeepers, bus operators, households, students, and others has been established, which is proving to be very successful. When external funding is sought, it is for start-up costs, and programs have so far shown their ability to become self-sufficient within 2-3 years by community-based fundraising.

Challenges and Recommendations

- HIV/AIDS-related **stigma** remains a major issue in India (39), which in turn can seriously affect the quality of, access to, and availability of HBC for PLWHA and their families. For instance, if building owners renting living spaces find out that a tenant is getting HBC because of HIV/AIDS, the PLWHA and their family can be at risk for getting evicted, if not also being socially ostracized by neighbours (33).

  While stigma reduction is one of NACO's activities (62), several CBOs are also working to address this critical issue. Among them is the Indian Network for People Living with HIV/AIDS (INP+). INP+ is nationally and internationally known for its work, which includes activities known to help reduce HIV/AIDS-related stigma, such as promoting greater involvement of people living with HIVAIDS in prevention, care, treatment, and support (35, 62, 90).

7.2.11 Cambodia

The National Centre for HIV/AIDS, Dermatology, and STDs (NCHADS) was established in 1998 by the Ministry of Health, and the National AIDS Secretariat was also established in 1999 for the national response to HIV/AIDS (104). The Strategic Plan

for HIV/AIDS and STI Prevention and Care (2001-2005) included HBC within the AIDS Care section. There were HBC-specific goals, as well as recommendations for HBC expansion and coordinating mechanisms to support HBC implementation. Inclusion of HBC in this strategic plan was based in part on the results of an HBC pilot project, which is described further below. By September 2005, PLWHA care and support was included in the 261 HBC teams throughout Cambodia which covered "350 health centres in 52 operational districts of 17 provinces" (Cambodia Ministry of Health and NCHADS, 2006). Members of the Ministry of Health's national-level CHBC sub-committee are from NCHAD's AIDS Care Unit, and they provide technical guidance for CHBC guideline reviews. In 2006, NCHADS and the Ministry of Health released the *Standard Operating Procedure for Implementing Community Home-Based Care in Cambodia*. Care and support for PLWHA are throughout the overall document, and in the section for new roles of the CHBC programme, ensuring palliative care and end-of-life care for PLWHA are briefly mentioned.

Table 4 provides HIV/AIDS-related statistics about Cambodia.

Table 4: HIV/AIDS in Cambodia

	HIV/AIDS statistics		
Country	**Est. Adult Prevalence**	**Est. # PLWHA**	**# deaths (adults & children)**
Cambodia	0.8%	75,000	6,900

Source: 2008 Report on the global AIDS epidemic, UNAIDS/WHO, July 2008.

HBC pilot project

This HBC pilot project started in 1998. It was coordinated by WHO and implemented by the Ministry of Health and several NGOs (51, 104). The goals were to pilot HBC for PLWHA and people with chronic illnesses, as well as to bring the Ministry of Health and NGOs together in a strong public-private partnership for HBC. NGO partners included the Khmer HIV/AIDS NGO Alliance (KHANA), World Vision, Maryknoll, and several local NGOs. This pilot project took place in Phnom Penh. A separate pilot project occurred in Battambang.

In this model, health centres chosen by the Municipal Health Department were the main base of home care teams, which were comprised of nurses from 8 health centres and staff from 7 NGOs. Teams were carefully chosen, trained, and supervised supportively. In Phnom Penh, the teams were based from Municipal Health Centres. They provided HBC services to patients within the catchment areas of their respective health centres. Volunteers were also an important part of home care teams. Individual home care teams together comprised the Home Care Network, which was well-resourced and supportive of health care teams and the pilot project's goals in general. Using home care kits, teams provided basic clinical care, which included treatment of HIV-related infections and conditions. Psychosocial support was provided. Health education for

family caregivers and patients addressed hygiene, nutrition, HIV/AIDS prevention, and infection control. Most patients were visited once weekly. The literature indicates that palliative care and terminal care were provided, but the literature does not elaborate further.

The Ministry of Health took over coordination of the project after the pilot project ended in 1999. Responsibilities for implementation were given to the AIDS Care Unit of NCHADS. KHANA provided technical and financial resources to local NGOs, as well as maintaining the partnership with NCHADS. The home care teams continued to provide HBC to PLWHA, who made up approximately 80% of the patient population.

Strengths and Successes

- Inclusion of HBC in the Strategic Plan for HIV/AIDS and STI Prevention and Care was based in part on the results of this HBC pilot project (104). The Ministry of Health decided to expand HBC nationwide. Different options were presented in the assessment for replication of models adapted for provinces.

- PLWHA noted improvements in their quality of life connected to home care team visits (104). In-depth interviews included questions based on quality-of-life indicators. Sixty-two percent (62%) reported having a better perspective about the future, seventy-two percent (72%) reported increased well-being, and eighty-five percent (85%) felt more capable of self-care.

- An effort was made by home care teams to link prevention and care (104). According to questionnaires, the majority of community leaders indicated that home care teams were enabling greater knowledge in communities about HIV/AIDS prevention methods. Two community leaders in particular reported that most of the local knowledge about HIV/AIDS and STIs was due to the work of home care teams.

Challenges and Recommendations

- One recommendation by the assessment team was that the home care project's systems for monitoring and evaluation needed strengthening (104). After the pilot project was over, a group representing NCHADS, the Municipal Health Department, KHANA, health centre managers, and local NGOs undertook the M&E component of the program.

- A pilot project recommendation was that the HBC care kits' drugs should be part of the Ministry of Health's essential drugs list (104). With HBC already being part of the national HIV/AIDS strategy, HBC's place in HIV/AIDS care would be further strengthened if HBC care kits' drugs were in the national essential drugs list.

- Refresher trainings and orientations need to be offered on a regular schedule, according to the assessment (104). This would be an effective way to incorporate new knowledge and emerging issues into the knowledge and skills base of home care teams.

7.2.12 Viet Nam

In 2004, Viet Nam launched its *National Strategy on HIV/AIDS Prevention and Control in Viet Nam until 2010 with a vision to 2020*, which is multisectoral in scope (The Socialist Republic of Viet Nam, 2008).

In the same year, funding from the President's Emergency Plan for AIDS Relief influenced changes in Viet Nam's HBC model (PEPFAR FHI doc). The five main changes were as follows:

1. "Basing HBC teams at HIV out-patient clinics so that they were included as part of the clinic team, participating in morning case conferences and client follow-up care planning
2. Altering the composition of HBC teams to ensure they included both PLHA and healthcare workers – who were then trained together in core HBC skills
3. Developing a core HBC training which included essential skills in symptom care, self care and adherence counseling, care of HIV-exposed and infected children, how and when to refer, psychosocial support and end-of-life care
4. Identifying a formal HBC supervisor, based at the outpatient clinic, who could mentor and support the HBC teams, and putting in place HBC standards and QA/QI systems
5. Supplying HBC teams with a regular stock of symptom management medicines including those to manage mild to moderate pain".

In 2005, the Viet Nam Administration for HIV/AIDS Control (VAAC) was formed.

In 2006, the HIV/AIDS care and treatment plan included the importance of palliative care (22), and in the same year, the Ministry of Health made available the Guidelines on Palliative Care for Cancer and AIDS Patients (49). The guidelines include paediatric palliative care and home-based care, among other topics. Also in 2006, the Therapy Department within the Ministry of Health began work towards developing a national opioid policy.

During 2006-2007, Provincial AIDS Centres were established to implement HIV/AIDS care and support activities at local levels, while simultaneously placing HIV/AIDS on the agenda of local and provincial governments. Provincial AIDS Centres are present in approximately 58 out of 64 provinces. Being relatively new, Provincical AIDS Centres have limited resources and need capacity building. Also during 2006-2007, Viet Nam began to implement the 'three ones' – i.e., one national HIV/AIDS coordinating body, one HIV/AIDS national framework, and one national monitoring and evaluation system.

In 2007, Viet Nam's National TB Programme and VACC began developing national procedures for collaborative work.

Table 5 provides HIV/AIDS-related statistics about Viet Nam.

Table 5: HIV/AIDS in Viet Nam

	HIV/AIDS statistics		
Country	Est. Adult Prevalence	Est. # PLWHA	# deaths (adults & children)
Viet Nam	0.5%	290,000	24,000

Source: 2008 Report on the global AIDS epidemic, UNAIDS/WHO, July 2008.

Palliative care rapid situation analysis in 5 provinces

In 2005, a rapid analysis about palliative care in Viet Nam was conducted by the Ministry of Health's Therapy Department in cooperation with international partners (22). The rapid analysis was held in 5 provinces: Hanoi, Hai Phong, Quang Ninh, HCMC, and An Giang. Its objective was for findings and recommendations to further inform the development of national palliative care guidelines, education and training, and service delivery.

Main findings

- "Severe, chronic pain is prevalent among people with cancer and HIV/ AIDS". Of the 81% of participants who indicated experiencing pain since their diagnosis, 53% reported it occurred always or once weekly, and 57% reported that the last time they experienced pain, it was severe or very strong.
- There is support for home-based provision of pain relief medications. Approximately 52% of health care workers in the rapid analysis supported home-based provision by trained health care workers of oral morphine prescriptions to PLWHA and people living with cancer.
- Policy makers expressed that pain is not well-addressed in PLWHA and people living with cancer.
- There is limited access to pain control and other palliative care medication, in addition to barriers such as availability and cost in accessing services.
- Palliative care training for health care workers is inadequate.
- Family care givers need psychological support.

Recommendations

- Develop national palliative care guidelines, and finish development of the national opioid control policy. Widely disseminate the guidelines and policy, including to HBC services.
- "Upgrade and expand availability of palliative care education, training, and certification in accordance with national guidelines.

- Scale-up national, provincial and local palliative care programs, support development of model palliative care programs, including community provision of oral morphine by trained health workers". This includes expanding coverage and increasing quality of HBC programs to better meet palliative care needs of PLWHA and people living with cancer, as well as improving HBC service provider training and facilitating adequate stocks of palliative care medications.

7.2.13 Papua New Guinea

In Papua New Guinea, most HIV+ people are not aware of their status (Papua New Guinea National AIDS Council Secretariat et al, 2007). HIV/AIDS care and support services are available in some areas of the country and can range from PLWHA support groups, and NGO-run care centres, and HIV clinics that are hospital-based or NGO-based.

However, many parts of the country do not yet have HIV/AIDS care, support, and treatment services. In response, the National AIDS Council Secretariat and the National Department of Health aim to achieve universal access to HIV/AIDS care, support, and treatment services by 2010. Scaling up of these services through community-based care is part of the National AIDS Council Secretariat's *National HIV and AIDS Strategic Plan (2006-2010)*. The National Gender Policy and Plan on HIV and AIDS 2006-2010 was developed to be a companion document to the 2006-2010 national HIV/AUDS strategy (Papua New Guinea National AIDS Council Secretariat and partners, 2008).

Table 6 provides HIV/AIDS-related statistics about Papua New Guinea.

Table 6: HIV/AIDS in Papua New Guinea

	HIV/AIDS statistics		
Country	**Est. Adult Prevalence**	**Est. # PLWHA**	**# deaths (adults & children)**
Papua New Guinea	1.5%	54,000	<1000

Source: 2008 Report on the global AIDS epidemic, UNAIDS/WHO, July 2008.

Community and home-based palliative care needs assessment

At the beginning of a CHBC program in National Capitol District and Central Province for people living with HIV, their children, and their caregivers, a needs assessment was undertaken by Family Health International, local health authorities, Friends Foundation Incorporated, and Igat Hope in August 2007 among PLWHA and their caregivers (Papau New Guinea National AIDS Council Secretariat et al, 2007 and Papua New Guinea National AIDS Council Secretariat and partners, 2008). The needs assessment aimed to inform further development of the CHBC program.

Focus group discussions, key informant interviews, a desk review, mapping, and a structured questionnaire were the methodologies utilised. Participants included PLWHA, their caregivers, local health workers, and representatives from the National AIDS Council Secretariat, Department of Public Health, PLWHA groups, and NGOs.

The program's aim is to expand CHBC access. Family Health International and Friends Foundation Incorporated are in a partnership to implement the program, which is operational in 23 sites and had reached 409 people by the end of 2007. Services provided include management of pain and other symptoms, ART adherence counseling, OVC care, end-of-life care, spiritual support, emotional support, and referrals.

Key findings

- "Pain is prevalent and under-treated." Since being diagnosed with HIV, 83% of PLWHA reported experiencing pain.
- "CHBC services are in high demand." Approximately 95% of PLWHA and 93% of caregivers interviewed indicated a need for CHBC services.
- Many PLWHA prefer home as the location for HIV-related care.
- "Distressing symptoms are common." Since being diagnosed with HIV, 93% of PLWHA interviewed indicated experiencing one or more distressing symptoms such as weight loss (71%), fever (55%), cough (53%), headache (53%), diarrhea (42%) and insomnia (42%).
- "PLWHA are experiencing significant emotional suffering." Approximately 67% of PLWHA reported being unhappy or very unhappy, with women (69%) more likely to suffer from severe emotional distress than men (40%). Fear of the future (their own or their children's future), as well as rejection by others were common causes of unhappiness.
- "PLWHA caring for children need help. All PLWHA interviewed with children stated they needed some form of help including schooling assistance, food, health care, and support in identifying a future caregiver for children."
- The majority of family caregivers indicated wanting to care for their loved ones but being sad and stressed by the care they provided. Only a small minority of caregivers had received caregiver training.
- Health care workers are ready to help and recommend that they receive HIV care training to better enable them in providing care to PLWHA.
- The majority of PLWHA interviewed indicated that hunger and poverty were serious problems for them.

Recommendations

- "CHBC teams need to be responsive to care needs over the entire course of disease.
- Train providers in palliative care. Improve access to codeine and morphine. Ensure that CHBC and ART go hand-in-hand.
- Develop formal linkages between CHBC teams and HIV out-patient clinics.
- Operationalize a continuum of care.
- Build capacity of PLWHA and families.

- Provide family focused care.
- Support women with HIV to access care services.
- Identify ways to address financial and food security needs of PLWHA.
- Conduct focused community sensitization.
- CHBC teams need to respect client wishes for discrete services.
- Measure results in order to scale up CHBC services.
- Develop national palliative care guidelines and standard operating procedures."

7.2.14 Nepal

Among several HIV/AIDS-related measures, Nepal has adopted the 'three ones' – i.e., one national HIV/AIDS coordinating body, one HIV/AIDS national framework, and one national monitoring and evaluation system (Nepal Ministry of Health and Population, 2008). The National Center for AIDS and STD Control (NCASC) recognized the need for community and home-based palliative care in its National Strategic Plan for HIV/AIDS Control 2002-2006, which includes steps for CHBC service delivery (NCASC et al, 2007). . There is a national CHBC training certification program. The draft National Strategic Plan for HIV/AIDS Control 2006-2011 addresses the need for comprehensive CHBC.

Table 7 provides HIV/AIDS-related statistics about Nepal.

Table 7: HIV/AIDS in Nepal

	HIV/AIDS statistics		
Country	**Est. Adult Prevalence**	**Est. # PLWHA**	**# deaths (adults & children)**
Nepal	1.5%	54,000	<1000

Source: 2008 Report on the global AIDS epidemic, UNAIDS/WHO, July 2008.

Community and home-based palliative care review

By 2010, NCASC aims to achieve universal access for HIV/AIDS care and support services, according to the draft strategy for 2006-20011 (NCASC et al, 2007). Expansion of home-based palliative care has an integral role in meeting this aim. HIV care and support services have increased in Nepal, and simultaneously, CHBC programs have increased to a current total of 18 programs throughout Nepal which serve several hundred PLWHA.

In June 2007, an review of 9 CHBC programs was conducted by NCASC, Family Health International, and the United States Agency for International Development. The review's objectives were to assess program quality levels and determine the how appropriately they met needs of PLWHA and their families. Methodologies utilized included focus group discussions, questionnaires, guided interviews, observations, and a desk review. Participants included CHBC providers, managers, key informants, PLWHA, and family caregivers.

Key findings

- "CHBC services are highly valued and appreciated by PLHA, families and hospital-based HIV care service providers.
- The CHBC service model is appropriate and effective but there are missed opportunities.
- There is good coordination between CHBC services and hospital HIV clinics but less links with other services". Formal referral systems between CHBC programs and hospitals were not present in several areas. In addition, referrals between crisis centers and communities were less effective than they could have been because of inadequate coordination between CHBC programs and crisis centers.
- The lack of national CHBC policies or guidelines contributes to programs operate with varying quality of care standards instead of a common standard and that there is no common standard to use when assessing quality of care.
- "A national CHBC training certification package is important to providing quality care.
- There is an inconsistent availability of CHBC kit supplies and currently no national standardized CHBC formulary in place.
- There is a need for further supervision support.
- There is a lack of coordination between CHBC programs and the District Health Office, District AIDS Coordination Committee, and community level public health services despite relatively strong relationships between the CHBC teams and hospitals."
- Clients have high expectations for CHBC services to address their multiple social and economic needs.
- Though PLWHA were involved in every CHBC program in the assessment, the level of involvement varied. For instance, PLWHA were equal partners or in leadership roles in some CHBC programs, but this was not so in other programs.
- Though all CHBC programs assessed were aware about the benefits of greater community involvement in their work, most programs had so far not initiated mobilization efforts for community, local government, and NGO services.
- There was limited knowledge and skills in PMTCT and caring for HIV exposed, infected, and affected children.

Recommendations

- "Increase access to CHBC services and explore new service delivery models.
- Provide guidance and a policy framework for CHBC.
- Develop a CHBC drug supply chain management system.
- Integrate CHBC into the national HIV M&E system.
- Establish closer relationships between CHBC services and District Health Offices, District AIDS Coordination Committees, and the local public health sector.
- Improve supervision and quality assurance / quality improvement systems.
- Increase PLHA and community involvement in CHBC.
- Increase diversity of referral relationships to address social and economic support concerns of clients.
- Train and support CHBC teams to provide family-centered care."

7.2.15 Summary

Section 3.0 discussed HBC models / service provision for PLWHA in the four focus countries of APCA's assessment – Kenya, Tanzania, Zambia, and Malawi, in addition to Uganda, South Africa, Zimbabwe, Lesotho, and Botswana. Outside of Sub-Saharan Africa, the discussion included HBC for PLWHA in India and Cambodia.

Table 5 below shows HIV/AIDS statistics and different types of models / service providers of HBC for PLWHA in the Sub-Saharan African countries addressed in this literature review.

Table 8: Service providers / models of HBC for PLWHA
& HIV/AIDS statistics in selected Sub-Saharan African countries

	Models / service providers of HBC for PLWHA		**HIV/AIDS statistics**		
Country	**CBOs, FBOs, NGOs, hospices**	**Hospitals: government and non-government**	**Estimated Adult Prevalence (%)**	**Estimated # PLWHA**	**# deaths (adults & children)**
Malawi	X	X	11.9%	930,000	68,000
Zambia*	X	X	15.2%	1,100,000	56,000
Tanzania	X	X	6.2%	1,400,000	96,000
Kenya**	X	X	6.1%	1,200,000	140,000
Lesotho	X		23.2%	270,000	18,000
Botswana	X	X	23.9%	300,000	11,000
Zimbabwe	X	X	15.3%	1,300,000	140,000
Uganda	X	X	5.4%	940,000	77,000
South Africa***	X		18.1%	5,700,000	350,000

Source: 2008 Report on the global AIDS epidemic, UNAIDS/WHO, July 2008.
* Inpatient hospices are also common in Zambia (46). Though this model is different from HBC, inpatient
hospices sometimes provide HBC services as well.
**Source: HIV/AIDS statistics source: (88) *AIDS Epidemic Update.* UNAIDS, Dec 2006 (WHO/UNAIDS database source: *2006 Report on the Global AIDS Epidemic*).
*** The literature available indicates that there are hospital-based palliative care services in South Africa, but it is
not clear whether there are hospital-based HBC services (43).

Table 5 indicates that in this literature review, the majority of HBC models / service providers for PLWHA are **CBOs, NGOs, FBOs, and hospices,** since all countries addressed have this HBC model / service provision. Simultaneously, all countries have serious HIV/AIDS epidemics, as shown in the HIV/AIDS statistics.

Table 5 also shows that all except two Southern African countries in this literature review (Lesotho and South Africa) have **hospital-supported HBC services**. In Lesotho, the lack of hospital-supported HBC services might be connected to the fact that HBC itself is not well-developed (see Section 3.2.5). In South Africa, the literature available indicates that there are hospital-based palliative care services in South Africa, but it is not clear whether there are hospital-based HBC services. All East African countries in this literature review have hospital-supported HBC services. It should also be noted that some hospices are part of hospitals, such Muheza Hospice and Selian Hospital Hospice in Tanzania.

Comparatively, there was a relatively small amount of literature about India indicating what models of HBC service provision were available for PLWHA. Though many hospice services and some HBC services exist in India, many of them are for cancer patients, not necessarily for PLWHA. Nevertheless, there were examples of HBC models / service providers for PLWHA through at least 2 non-hospital HBC service providers. A pilot project in Cambodia brought together NGOs and the government in HC provision to PLWHA.

HBC service staffing in all countries of this literature review include volunteer care providers, upon whom HBC programs generally rely a lot in carrying out HBC service delivery for PLWHA and their families. Volunteer responsibilities entail various degrees of psychosocial care, material and logistical care, basic nursing care such as wound cleaning and simple medication administration, training family caregivers about caring for PLWHA, and when possible, educating PLWHA about self-care. Nurses are also often utilized by HBC programs, not only for nursing care and for referral of cases by volunteers but also to serve as coordinators and administrators of HBC programs. Compared to nurses and volunteers, the literature did not elaborate as much about allied health professionals, such as social workers and counsellors. Still relative to nurses and volunteers, few physicians are full time staff members of HBC programs, although they sometimes work in senior management roles. Their medical skills are utilised with some frequency on a part-time basis (paid or volunteer), and physician approval is often needed for nurses to prescribe strong pain relief medications to HBC patients. A notable exception to this situation is found in Uganda, where specially trained palliative care nurses and clinical officers have authority to prescribe morphine.

National level HBC guidelines mention palliative care in several countries of this literature review, including the four focus countries of APCA's assessment: Malawi, Zambia, Kenya, and Tanzania. Furthermore, three of the four countries have at least one example of HBC service provision which includes morphine access for patients. Such is the case with the Lighthouse Centre in Malawi, Nairobi Hospice in Kenya, and Selian Lutheran Hospital in Tanzania. Uganda and Zimbabwe also include palliative care in their national HBC guidelines, and in Uganda, Kitovu Mobile Home Care is an example of an HBC service providing morphine to patients, while FACT is an example in Zimbabwe.

In addition to the challenges discussed in country sections, some cross-cutting themes and challenges of HBC for PLWHA are as follows:

- TB care for PLWHA with TB-HIV co-infection
- HIV/AIDS prevention integrated into HBC
- Care and support for orphans and vulnerable children (OVC)
- Gender and caregiver burn-out
- Training and education
- Effective linkages and referral systems
- Availability of strong pain control in HBC for PLWHA
- Poverty
- Stigma

TB care for PLWHA with TB-HIV co-infection

Rather than vertical programming, integrated HIV/AIDS programming more realistically mirrors the lives of PLWHA and their families. Tuberculosis is a leading cause of mortality among PLWHA, but many HBC programs do not address TB. Closer collaboration is needed among organizations providing TB care with those providing HBC for PLWHA to better meet patients' comprehensive needs (101).

HIV/AIDS prevention integrated into HBC

HBC for PLWHA presents a unique opportunity to address HIV/AIDS prevention with patients and their families (24). Information, practical recommendations, and necessary supplies (such as gloves and condoms) for HIV/AIDS prevention can help lower risks of HIV transmission.

OVC care and support

For many PLWHA, their children's present and future care and support is a significant source of worry (80), but HBC programs for PLWHA and OVC programs have sometimes evolved separately. However, many HBC programs for PLWHA have seen the need to integrate OVC care and support into their services, and are doing so. An example of integrated HBC/OVC programming is seen in Kenya's COPHIA in Section 3.2.4.

Gender and care-giver burn-out

In many households in Sub-Saharan Africa affected by HIV/AIDS, women and girls are disproportionately burdened with caregiving compared to men (1, 36, 52, 97). In addition, many HBC volunteer caregivers are women. Volunteer caregivers have a critical role in direct service provision to PLWHA in home settings, and at the same time, there is a high risk of burn-out in these roles. Many HBC programs are aware of the effects of caregiver burn-out on service delivery, and some are actively trying to address the issue. Important considerations in caregiver support include the acceptability, accessibility, feasibility, and effectiveness of support interventions (27). Support mechanisms currently in use include support groups for HBC volunteers and day care centres

which provide care for patients and respite for caregivers (95). More support and involvement of men trained in caregiving is also necessary (75). Their active participation could play a significant role in decreasing the caregiving load women currently hold. In addition, it is possible in some settings that volunteer male caregivers might relate better to male HBC patients (75).

Training and education, effective linkages and referral systems, and availability of strong pain control in HBC for PLWHA

Section 4.0 discusses these topics in more detail. In particular, a weaknesses identified by WHO in 2002 (98) about strong pain control in HBC settings is that medical doctors are often the only health care workers with authority to prescribe opioids. This reduces accessibility to opioids for patients who need it for pain relief, whereas if nurses also had prescription authority, opioid coverage could expand to more people who need it, such as PLWHA in home settings.

Poverty

Poverty is a significant challenge in many HIV/AIDS affected countries, and its effects are felt in HBC for PLWHA (97, 99). Often, HIV/AIDS-affected households experience significant fluctuations in household income that can eventually lead to poverty. Other households are already in poverty when HIV/AIDS enters the home. HBC programs for PLWHA that link with poverty alleviation programs or which offer income-generating activities could be able to help households in longer term ways. It is not only HBC service recipients that are affected by poverty. HBC volunteers from poverty-affected communities could have difficulties providing services due to transportation costs and other issues.

Sections in this document about Uganda, Tanzania, and Malawi discuss poverty more generally.

Stigma

HIV/AIDS-related stigma is a serious issue in all HIV/AIDS work. Sections in this document about Uganda and India discuss some ways stigma affects HBC for PLWHA. Stigma can also affect specific program areas such as monitoring and evaluation in which HIV/AIDS-affected households might not want to provide information because of perceived stigma-related consequences (18). A study in Kenya's Nyanza province, however, suggests that despite significant challenges, HBC workers are having a positive impact on stigma reduction at individual and community levels because of training and educating community groups and individuals about HIV-related stigma (Waterman et. al, 2007).

7.2 Home-Based Care in Developed Countries: A comparison with HBC for PLWHA in developing countries

HBC is different in developed and developing countries, though there are also similarities. Within the context of HIV/AIDS, an important difference is that HIV/AIDS prevalence is lower in many developed countries, which in turn has meant that HIV/AIDS is typically not a major influence on HBC service expansion. In addition, ART is often more accessible, and health care delivery systems are generally better-resourced in developed countries.

HBC services in developed countries **tend** not to rely heavily on volunteer caregivers to the extent that many HBC services in developing countries do (19, 32, 67, 73, 96). Instead, HBC teams usually consist of health care professionals such as nurses and doctors, as well as nutritionists, social workers, physical therapists, and case managers. There are exceptions to the general trend about volunteers, such as a HBC service in rural, remote Alaska (USA) in which volunteers are one of the main HBC team members (13).

In addition to lesser dependence on volunteers overall, the responsibilities of HBC volunteers in developed countries are not necessarily the same as those of volunteer caregivers in many developing countries. For instance, whereas HBC volunteer caregivers' responsibilities in developing countries could include basic nursing care, these responsibilities would more likely be the work of HBC nurses and professional nursing support staff in developed countries.

Some services in developing countries such as Hospice Africa Uganda rely on health professionals for delivery of services to patients and families at home. They, however, work with community based volunteers in supportive roles. Others such as the ICHC in South Africa rely heavily on community based care givers with supervision from professional nurses.

HBC services are more costly in developed countries compared to developing countries. This is in part due to the direct costs of salaries for professionals such as doctors and nurses. Relying heavily on volunteers as many developing countries do results in lower operating costs for HBC programs. In some settings, influences which can indirectly affect the cost of health care in general as well as HBC programs can include issues such as budgeting for insurance against malpractice lawsuits from patients and families.

Related to HBC is that in developed countries, a wider variety of alternative placements can exist for patients who need more support than HBC can provide or when patients do not have a home where they can be based (67). Examples of alternative placements include assisted and independent living facilities and communities, as well as skilled nursing care facilities. In addition, there can be residential care facilities, including ones designed for care of PLWHA.

Finally, for many people and families in developed countries, HBC increases access to care. This is also true in developing countries. HBC can especially be important for rural communities where access to care can be especially challenging (11). HBC is sometimes the main access point for rural communities to health care and social services that they might not get otherwise.

7.3 Home-Based Care Research Methodologies

This literature review included identifying key methodologies and tools commonly used in research about HBC for PLWHA. Table 6 provides a summary of findings.

Table 6: HBC research methodologies from a literature review of HBC models for PLWHA

Ref. #	FGDs*	Interviews	Surveys, Question-naires	Sampling	Literature/ Document Review	Site Visits, Obser-vations	Data Analysis	Tools Available for Research about HBC for PLWHA
4			Y	Y		Y	Y	
20		Y			Y	Y	Y	cost analysis spreadsheets; tools for appraising management, quality of care, cost analysis
25					Y			
26					Y			
28					Y			
29			Y	Y			Y	
48	Y	Y				Y		
53					Y			
54	Y	Y					Y	questionnaires: patients, volunteers
55		Y				Y		
66		Y			Y	Y		questionnaires: home carers, FGD, quality of care
Waterman et. al, 2007	Y					Y	Y	
70	Y	Y			Y			
74		Y			Y	Y		
82		Y			Y			

92	Y		Y					
93		Y	Y			Y	Y	
94		Y	Y				Y	
97	Y	Y	Y	Y			Y	situation analysis guide, questionnaires: narcotic drug policy, urban patients, family caregivers, rural heads of household or caregivers of rural patients, programme managers, hospital medical super-intendents, FGDs, IDIs
100	Y	Y		Y				questionnaires: caregivers, FGD, IDI
104	Y	Y				Y		questionnaire: patients & families; interview guides: community leaders, home care teams

* FGDs = focus group discussions

Focusing mostly on quantitative research can often yield inadequate answers about the complex variables that comprise long-term care (53). A mixture of qualitative and quantitative research methods might be more appropriate when researching HBC.

The references in Table 6 show that quantitative and qualitative methodologies were utilised to research HBC for PLWHA. Most references used both types of research methodologies.

Interviews were the most commonly used method, with 14 out of 21 references utilising it for their research. FGDs were utilised in 8 references and site/visits observation were utilised in 9 references. Though these are notably less than the number of times

interviews were utilised, it is still slightly more than the number of times quantitative methods were utilised. There were no instances when only quantitative methods were utilised, though 3 references used only qualitative methods.

Literature reviews were used by 9 references.

Most references used 3 types of research methodology. Of those, the most commonly used research methodologies were interviews, FGDs, site visits /observation, and data analysis.

The reference using the greatest number of research methods was *A Community Health Approach to Palliative Care for HIV/AIDS and Cancer Patients in Sub-Saharan Africa*, a palliative care assessment conducted in 2005 by WHO of Botswana, Ethiopia, Uganda, Tanzania, and Zimbabwe.

Most of the tools available in references from Table 6 are questionnaires for a variety of audiences. The greatest number of questionnaires is found in the above-named palliative care assessment by WHO in 2005, which also contains a situation analysis guide. Interview guides are available in *An Evaluation of the MoH/NGO Home Care Programme for People with HIV/AIDS in Cambodia (*2000) by Wilkinson D and the International HIV/AIDS Alliance. Also to note are the cost analysis spreadsheets, as well as tools for appraising management, quality of care, and cost, developed in 2005 by the Gauteng Health Department and DFID for *A Participatory Rapid Appraisal Tool for the Appraisal of AIDS Home-Based Care Programmes*.

In particular, one of the references utilised a participatory action research (PAR) methodology to study the effects of HBC professionals' work in Kenya on HIV-related stigma (Waterman et. al, 2007). The aim of PAR is to foster collaboration and mutual participation between researchers and research participants. The study suggested that despite significant challenges, HBC workers are having a positive impact on stigma reduction at individual and community levels.

7.4 Discussion and Recommendations for Integrating Palliative Care into HBC for PLWHA

Palliative care is defined by WHO as "an approach that improves the quality of life of patients and their families facing 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 physical, psychosocial and spiritual problems" (8).

Palliative care is an essential element of HBC in resource-constrained settings, according to WHO (99). Within the context of HIV/AIDS, several issues can be addressed by palliative care such as pain associated with ART and OIs, various co-morbidities such as end stage liver disease, and HIV-related malignancies that have not declined despite ART uptake, such as non-Hodgkinson's lymphoma (24, 25, 28). In addition to pain relief and physical care, spiritual and social care are important elements of palliative care. Overall,

palliative care should be integrated into HIV/AIDS care and support (24, 25, 29, 73, 77, 82).

Despite the need, many HBC programs in Sub-Saharan Africa do not provide the full range of palliative care as part of HBC services (26). HBC programs might choose certain elements of palliative care to integrate into their services, such as spiritual or social care. Often, however, a full range of pain control options is not part of the HBC service package for PLWHA and other HBC recipients. Several reasons exist for this, but the absence of strong pain relief options reduces the potential for HBC to improve the quality life for PLWHA.

Within the different types of HBC models, ICHC already integrates palliative care into HBC for PLWHA (14, 24, 26, 43, 82, 93). This includes a full range of effective pain relief options. CHBC, being another comprehensive model of HBC for PLWHA, is positioned to integrate palliative care, especially as palliative care is considered an essential element of CHBC (99).

Recommendations for integrating palliative care into HBC for PLWHA are based on the following main categories:

- Training and education
- Supportive policy environment
- Morphine-related recommendations
- Mentoring
- Linkages and referrals
- Evaluation and research
- Advocacy

All of these issues are inter-connected and can simultaneously affect the capacity for palliative care to be integrated into HBC for PLWHA.

7.4.1 Training and education

It is essential to **increase** palliative care training and education efforts for HIV/AIDS care (10, 12, 13, 22, 24, 25, 26, 49, 66, 82, 97, 99). To further palliative care integration into HBC for PLWHA, palliative care training itself is of critical importance for all stakeholders. WHO asserts that palliative care is an essential element of CHBC (99). It is vital that palliative care training specifically addresses HBC for PLWHA.

The range of stakeholders for whom palliative care training and education efforts should be developed and directed should include nurses, doctors, nursing and medical students, volunteers, allied health professionals such as social workers and counsellors, programme managers, funders, supervising nurses, families, PLWHA, policymakers, narcotics control boards, traditional healers, and pharmacists. Any of these stakeholders can play a role in supporting or delivering palliative care within the context of HBC for PLWHA. Especially for those directly involved in palliative care provision, refresher training is necessary. Focusing on training trainers is also important. Trainings by Hospice Africa Uganda, Nairobi Hospice, The Mildmay Centre (Uganda), Island Hospice (Zimbabwe), and HPCA-SA are examples of reaching a wide variety of palliative

care stakeholders. All are described further below in this section about training and education.

In addition to training about palliative care principles and methods, education and sensitization is needed to dispel myths which exist among many stakeholders about pain relief through opioids. For instance, health care workers and families might believe that opioid use leads to addiction. This and other myths are roadblocks for palliative care expansion that need to be addressed sensitively and effectively.

To facilitate access to palliative care training, a variety of training programs are necessary that meets needs of trainees in terms of program timeframes, locations where training is provided, costs, and types of qualifications available.

Nairobi Hospice, which provides HBC for PLWHA, has a range of palliative care training opportunities available (48). A one-week training is available for community-based volunteers and health care professionals. A 14-month distance learning program for a Diploma in Higher Education Palliative Care has been offered since 2001. Four-week clinical placements at Nairobi Hospice are available for students from other hospices and colleges. Third year medical students can receive palliative care training from Nairobi Hospice at a teaching hospital. Also, Nairobi Hospice is working with the Ministry of Health to bring palliative care training into nursing school curricula.

Hospice Africa Uganda also provides HBC for PLWHA and has a wide variety of training programs for professionals and volunteers involved at different levels in palliative care provision (34, 45) such as health care professionals, volunteer caregivers, traditional healers, allied professionals, spiritual carers, medical students, nursing students, HIV/AIDS trainers, and clinical tutors. Curricula have been revised to better incorporate HIV/AIDS care, HIV/AIDS prevention, and related issues. In addition to courses in Kampala at the Hospice Africa Uganda site, training is available in areas outside of Kampala and has also been provided in Malawi, Zambia, Kenya, Tanzania, and other countries in Sub-Saharan Africa.

Also known for its national and international training programs is The Mildmay Centre, which began in 1998 and is a UNAIDS case study (45, 91; O'Keeffe C, 2007). On-site training is conducted at The Mildmay International Study Centre (MISC), which aims to build capacity in delivery of comprehensive palliative care to PLWHA. Trainees have included health care and ancillary staff – such as doctors, nurses, counsellors, social workers, volunteers, and community health workers, government staff – including policy makers, NGO staff, students and teachers, PLWHA – including children, family caregivers, businesses, journalists, religious leaders, and traditional healers. Off-site training occurs through the mobile training team (MTT), which builds the capacity of health workers to care for PLWHA in rural settings.

In Zimbabwe, palliative care training is available primarily from Island Hospice Harare (47). Its palliative care training is offered to several different types of

stakeholders in CHBC such as volunteer caregivers and other community volunteers, nursing and medical students, nurse aides, pastors, NGOs that work with OVC, HIV/AIDS support organizations, and HBC organizations.

HPCA-SA provides a 3-month HBC and palliative care training for caregivers (82). Topics covered include principles of palliative care principles and basic nursing care, nutrition HIV/AIDS, TB, sexually transmitted infections, social support, care of the caregiver, infection control, education and communication skills, and spiritual and cultural dimensions of care, Training includes 70 classroom hours of instruction and 160 hours of clinical work. Every six months, caregiver care is reviewed and results are incorporated into the training programme. The South African Nursing Council recognizes HPCA-SA's Short Course in Palliative Nursing for Professional Nurses, which is required for all ICHC nurses with supervisory responsibilities and is hosted by some ICHC sites. This course is also available to nurses in the general health system. In addition to the short course, an ICHC hospice – Pretoria Sungardens Hospice – developed a train-the-trainer programme about nutrition for caregivers and other community health workers.

7.4.2 Supportive policy environment

A supportive policy environment is vital for palliative care to be available and accessible to those who need it (12, 22, 24, 26, 45). PLWHA in HBC settings are among the many whose quality of life can be improved through palliative care.

In several countries, however, the policy environment is not at a supportive enough point.

In Zambia, very stringent regulations are in place by the Narcotics Control Board for importing and using morphine and other medication (63). While tablet morphine is sometimes available from donors in Zambia, it can not be dispensed in HBC settings. The University Teaching Hospital in Lusaka has powdered morphine, but only for cancer patients (46), not necessarily PLWHA. Some (relative) progress has been made in relaxing the degree of strictness posed by the Narcotics Control Board on morphine, but in general, morphine is still difficult to access.

In Botswana, only medical doctors can prescribe narcotics (97). There is a general lack of understanding in the health care community about palliative care, though the government is setting the conditions necessary for effective palliative care to me made available (97, 98). However, there is no government provision for providing PLWHA, cancer patients, and others with palliative care.

The government of Malawi is open to and recognizes the overall concept of palliative care, and the National AIDS Commission's Care and Support working group is developing National Palliative Care Guidelines. However, the government of Malawi does not yet support palliative care financially (26, 42).

One of the best ways to ensure a supportive policy environment for palliative care is through national palliative care guidelines (24), as well as supportive structures in place such as a national palliative care task force and a national palliative care association with government links. Government support ensures financial support of palliative care. In addition, national commitment to palliative care provides further basis for maintaining and improving quality of care standards. Issues affecting access to pain relief – such as expanding the types of health care workers who have prescriptive authority for morphine to include specially trained and qualified nurses in palliative care – are in a more favourable place to be addressed if palliative care receives national support. In Uganda, palliative care is in a more supportive policy environment than in many other places.

Palliative care is highlighted in national HIV/AIDS framework and HBC guidelines The integration of palliative care into the national health plan has begun to improve morphine availability. For instance, morphine is available free to PLWHA and cancer patients. In addition, training for health care students, professionals, and others at different levels of care provision has improved. With national health system support of palliative care (45, 97)., efforts to include palliative care in HBC might be more readily facilitated than before.

Specially trained palliative care nurses and clinical officers have authority to prescribe morphine (26, 45). This is the result of a Statutory Instrument approved by the Ministry of Health in 2004. In many settings, only medical doctors are allowed to prescribe morphine, but with prescriptive authority extending to nurses as well, the potential opens further for increased access to morphine by patients – including PLWHA in HBC settings – who need it for effective pain relief.

7.4.3 Morphine-related recommendations

Pain control is an integral part of palliative care (22, 24, 49, 66, 102). For PLWHA needing stronger pain relief in HBC settings than simple pain relievers can provide, morphine and other opioid-based pain relief methods are important aspects of effective pain relief. Examples in this literature review of HBC service providers which include morphine access for patients include the Lighthouse Centre in Malawi (see Section 3.2.1), Nairobi Hospice in Kenya (see Section 3.2.4), Selian Lutheran Hospital in Tanzania (see Section 3.2.3), Kitovu Mobile Home Care in Uganda (see Section 3.2.8), and FACT in Zimbabwe (see Section 3.2.7).

Nevertheless, regular morphine availability is difficult in several countries in Sub-Saharan Africa due to government regulations and costs, as well as resistance by policymakers and health care workers to increase morphine access. This is also discussed in Section 4.2.

Addressing morphine access and usage in palliative care training and education to the wide range of stakeholders is an important way to increase morphine availability for PLWHA in HBC settings. Section 4.1 addresses training and education in more detail.

At the same time, supporting policy changes that increase morphine access is necessary, such as policies allowing palliative care nurses to prescribe morphine. Policy-level changes can help to change overly strict regulations set forth by narcotics control boards and similar regulatory agencies. This is also discussed in Section 4.2.

Morphine accessibility can also be problematic due to high costs. Powdered morphine is generally less costly compared to injectable and liquid morphine, for instance. In the case of Hospice Africa Uganda, costs are kept low by trained staff mixing appropriate morphine dosages at Hospice instead of buying morphine in pre-prepared dosages (21).

7.4.4 Mentoring

Hospices providing HBC are more likely than other HBC models to have palliative care integrated into their HBC services. Hospice is a central stakeholder in the ICHC model, which was developed with palliative care integrated for HBC of PLWHA (14, 82).

Deemed as a best practice model by the South African Department of Health, the ICHC model was replicated in different parts of South Africa by HPCA-SA through a mentorship program (14, 15). Hospices well-established in the ICHC model mentored hospices to become established in ICHC through a process that involved active participation between mentor hospices and mentored hospices.

An evaluation of the ICHC model indicated that it was suitable for replication in other resource-constrained settings in Sub-Saharan Africa (92). Therefore, the ICHC model should be scaled up and replicated through the ICHC mentorship program in areas where there is a hospice presence.

7.4.5 Linkages and referrals

Linkages and referrals are critical components of comprehensive care for HIV/AIDS care in HBC settings (14, 66, 82, 99). One organization alone typically can not provide the full range of care and support services needed to PLWHA and their families.

Developing and maintaining strong linkages between HBC programs and palliative care providers is important for better integration of palliative care into their HBC service delivery, especially when hospice is not well-developed in a given area. Palliative care providers in linkages can be affiliated with hospitals or other clinical facilities. In South India, the NNPC program in Kerala successfully integrates palliative care into its HBC services through strong linkages to local palliative care units (50, 68).

Strong linkages and effective referral systems with palliative care services should be part of HBC services for PLWHA not only from the perspective of increasing pain control options, but also for increasing access to other aspects of palliative care that HBC programs might not be able to deliver to PLWHA and their families. The ICHC model, discussed in Section 3.1.2, emphasises effective, comprehensive referral networks for PLWHA and their families.

7.4.6 Evaluation and research

Evaluation and research results can be used to inform programming about integration of palliative care into HBC for PLWHA**.** For instance, a rapid situation analysis about palliative care in Vietnam within the context of HIV/AIDS revealed that a majority of health care workers supported prescriptions for oral morphine to be used in home settings (49). Such findings are relevant to programming about integrating palliative care into HBC for PLWHA. Other topics which link to programming include development and adaptation of pain assessment instruments for use by different HBC workers, as well as types of pain and symptoms experienced by different patient populations in home settings (12). Another example is found in HPCA-SA's caregiver training, which incorporates results of twice-yearly caregiver evaluations into the caregiver training programme (82).

7.4.7 Advocacy

Finally, advocacy about integration of palliative care into HBC for PLWHA is essential for **informing the wide range of stakeholders** about why and how to take steps towards improving the quality of life of people in their communities (31). As an example, Hospice Africa Uganda's advocacy efforts started in 1993 (173). Its advocacy reaches out to NGOs, CBOs, FBOs, hospices, patients, families, communities, and policymakers such as the Ministry of Health. Sustained palliative care advocacy by Hospice Africa Uganda and other HBC/palliative care providers in Uganda might be part of the reason why Uganda is steadily building its capacity to integrate palliative care into HBC for PLWHA.

8.0 Phase two- The Situation Analysis

8.1 Introduction

The situational analysis (SA) of HBC models for PLWHA in four African countries (i.e. Malawi, Tanzania, Kenya and Zambia) explored existing models of HBC for PLWHA, along with the current components of care they provide, the strength and gaps that exist so that palliative care standards that are relevant to various services are developed. The SA also provides a feel of the extent to which palliative care is integrated in HBC services and makes clear and practical recommendations for further integration.

8.2 Specific objectives of the situation analysis

These were:

- To establish the existing models of home-based care delivery for PLWHA.
- To determine the strength and gaps for palliative care provision within current home-based care delivery models for PLWHA.
- To identify best practice models for HBC for PLWHA that can be promoted by APCA across Africa.

- To establish some of the practical recommendations for the integration / implementation of all aspects of palliative within existing home-based care services for PLWHA.

8.3 Methodology

8.3.1 Design

The review of HBC models for PLWHA in Malawi, Kenya, Tanzania and Zambia was undertaken in two phases.

Phase One was a comprehensive literature review of existing HBC models in Resource-Constrained Settings discussed above and,

Phase Two was a country based review of HBC models for HLWHA in the four project countries. This was a cross-sectional study which used qualitative methods to explore the general picture of existing home based care models in the project countries. The SA intended to provide a picture of the services available rather than precise numbers. Thus, it may not be totally representative of home-based care services for PLWHA in each project country.

Preliminary activities

The African Palliative Care Association undertook preliminary visits and discussions about the proposed HBC review with the national palliative care associations i.e. Palliative Care Association of Zambia (PCAZ), Kenya Hospices and Palliative Care Association (KEHPCA), Tanzania Palliative Care Association (TPCA) and the Palliative Care Association of Malawi (PACAM). These were the principal local partners in the HBC SA exercise. Formal discussions were also held with focal persons in HBC Departments of the Ministry of Health in each country to ensure buy-in and participation. From these meetings, a set of HBC programmes for PLWHA were suggested to participate in the SA of HBC models based on the criteria below:

- A programme offering home based care with or without palliative care.
- In each country, attempt was done to include two programmes that are urban and two that are either rural or peri-urban.
- In each country, attempt was done to include two programmes that are private and two that are public.
- In each country, at least one hospital based home care programme was included in the sample.

Proposed programmes were formally contacted by the national palliative care associations for participation once ethical approval was obtained from the relevant national body. The National Coordinators of national palliative care associations were responsible for contacting the proposed sites and preparing them for the review of HBC models, with on-going technical support from the African Palliative Care Association.

8.2.2 Area and population of study

Within the four project countries of Malawi, Kenya, Tanzania and Zambia, the SA population constituted home-based care programmes for PLWHA. Within these programmes, the SA targeted operational level and managerial level staff; community volunteers/care givers; family care givers; beneficiaries of these programmes (i.e. PLWHA) and a national level policy maker within home based care department of the Ministries of Health.

8.2.3 Sample size and selection procedure

Purposive sampling used to select Home Based programmes to participate in this SA based on the pre-set criteria specified in section 3.2. In each project country, the African Palliative Care Association worked collaboratively with the national palliative care association and the Home Based Care stakeholders such as the Ministry of Health Home Based Care Programme to select the programmes to participate in the SA.

A total of four home based care programmes for PLWHA in each project country participated in this SA of home based care models.

In each country one policy level personnel from the Ministry of Health department of Home Based Care was selected purposively, with the facilitation of APCA and in collaboration with the national palliative care association, for in-depth interviews.

In each of the four programmes selected in each country, one staff in management and five formal care givers (health workers such as doctors or nurses/allied health workers such as social workers) were purposively selected and included in the sample. Also five community volunteers/ caregivers associated with the programme were included. These volunteers/caregivers improved the completeness of the picture of the home based care services available to PLWHA in the project countries as they are increasingly playing a central role in home based care. In consultation with the caring teams of each programme, four people living with HIV (PLWHA) and four family care givers to PLWHA were selected and included in the sample. Overall, the sample comprised of 308 respondents, as summarised in Table 9 below

Table 9 A: Summary of sample size in the four project countries

Country	Services	Policy makers	Managers	Formal Care-givers	Volunteer care-givers	Family care-givers	PLWHA	Total Respondents
1	4	1	4	20	20	16	16	77
2	4	1	4	20	20	16	16	77
3	4	1	4	20	20	16	16	77
4	4	1	4	20	20	16	16	77
Total	**16**	**4**	**16**	**80**	**80**	**64**	**64**	**308**

Table 10 B: Summary of the sample size for one project country

HBC Programmes	Policy makers	Managers	Formal care-givers	Volunteer care-giver	Family care-givers	PLWHA	Total respondents
1		1	5	5	4	4	19
2		1	5	5	4	4	19
3		1	5	5	4	4	19
4		1	5	5	4	4	19
Ministry of Health HBC department	1	-	-	-	-	-	01
Total	**01**	**04**	**20**	**20**	**16**	**16**	**77**

The total number of respondents in each project country was 77 respondents.

8.2.4 Recruitment plan and procedures for informed consent:

The national palliative care associations made initial contacts and preparations for data collection with identified sites. As part of this process, the sites were sensitised about the SA and helped to identify potential respondents within their organisations including managers, formal care-givers, volunteer care-givers, and service beneficiaries. Site managers and clinical staff working directly with PLWHA and their families had a central role in identifying individuals to participate in this review and shared all relevant details with them. Each respondent required to sign a written consent form or thumb printed it after full explanation and understanding of the SA of home based care models was about. A copy of the consent form is included (Appendix One.

National palliative care associations identified and trained local research assistants who helped with data collection. The local research teams worked with two consultants from the African Palliative Care Association in Uganda. Before data collection, both teams met and discussed the processes and tools for undertaking the review. The local teams also helped with translations into the local language(s).

In each country, data collection was done over a period of ten days. Data analysis and reporting was undertaken by the APCA consultants with input from the local research teams. Results from the four project countries were aggregated and presented in form of this research report which will be disseminated within project countries, the rest of Africa and internationally.

8.2.5 Research facilities:

In each country, this study was coordinated by the national palliative care associations, which are formal partners and member organisations of the African Palliative Care Association. APCA and these associations were already implementing other projects through different partnership arrangements in the development of palliative care in project countries. The national associations have well furnished offices in each country, under the leadership of the national coordinators, who were the local contact in relation to this review of home based care models for PLWHA.

At a regional level, this review was coordinated by the African Palliative Care Association which is a not-for profit non-governmental regional organisation mandated to promote and support affordable and culturally appropriate palliative care throughout Africa. The APCA Secretariat is based in Kampala and has a regional office in South Africa and small offices in Namibia, Lesotho and Swaziland. Two Uganda based consultants undertook the process of data collection, analysis and report writing with support from the APCA Secretariat in Kampala.

8.2.6 Data collection

Data collection was undertaken in four sites in each country selected by the local team based on the specified criteria. APCA consultants joined the local teams to undertake data collection from the four sites in each country. In each site data was collected from one manager, five formal care givers, five volunteer care givers, four family care givers and four people living with HIV. In-depth and unstructured interviews were undertaken

with site managers, people Living with HIV and family care givers by the reviewers (APCA Consultants and local teams) using interview guides. Focus group discussions were conducted with formal care givers and voluntary care givers using a guide. The national Palliative Care Associations oversaw the entire data collection process, including the selection of the local research teams.

A pre-test of tools by the APCA consultants in Uganda indicated that seven to ten days was appropriate for data collection from each country. The APCA consultants worked with local teams led by the national associations to collect data from only four sites/institutions/organisations in each country. The entire data collection process took 40 days.

The following list of tools, the details of which is in appendix one, were used to collect data from respondents. The tools were mainly composed of open ended questions.

- ***Tool 1:*** Interview guide for policy makers
- ***Tool 2:*** Interview guide for managers/ leaders of services
- ***Tool 3:*** FGD guide for formal care givers (Heath Care Workers)
- ***Tool 4:*** FGD guide for Community Volunteer / Care givers
- ***Tool 5:*** Interview guide for PLWHA
- ***Tool 6:*** Interview guide for Family care givers

The tools were developed through a process of comprehensive consultations with the project advisory committee which is made up of palliative care experts and HBC experts within and outside Africa. They were also shared with the national associations and Ministries of Health in the project countries for comment. The tools were administered by the data collection teams and were used as guides to the consultants and the local teams.

8.2.7 Data analysis and reporting:

Data from various respondents in each service was transcribed under that service with the thematic areas in mind. Thereafter, the transcribed information was analysed following the thematic areas for the review. The analysis was continued at the national level following thematic areas. The findings at the national levels from the four focus countries were aggregated into one report.

Qualitative data was followed by manual content analysis and descriptive presentation based on the main thematic areas.

Quantitative data was minimal and was presented using tables. A draft report was written by the consultants and submitted to APCA for preliminary review. The coordinator for this project at APCA shared the draft report with the APCA technical working group, the national palliative care associations in project countries and the project advisory committee for review and comments. The advisory committee was composed of expert individuals in home based care, palliative care and standards from within and outside Africa. Feedback was then provided to the APCA Consultants who,

thereafter, prepared a final report and submitted it to APCA for dissemination and use in the development of appropriate palliative care standards. Data from all the four countries was aggregated into a single comprehensive report.

8.2.7 Ethical considerations:

All information collected was confidential and aggregated to produce a review report based on findings from the four countries. Interviews with PLWHA were arranged through their service provider organisations. Participation was voluntary, with freedom to withdraw any time. Names or any other identification information were not required from individual respondents and no identifying features were utilised in writing the report.

8.2.8 Protection of Human Subjects

Written consent was obtained from all respondents participating in this review upon an explanation of what the study was about and upon checking their full understanding of the purpose and the process of the review of HBC models for PLWHA. A copy of the consent form and information sheet for participants is included in this report (Appendix oNE).

Consent for participation was sought at all the different levels of participation i.e. formal consent from the directors of participating sites and from the individuals participating from within each organisation. Health care workers, providing care to PLWHA and their families were best suited to explain this review to PLWHA because they were familiar to them and were aware of their different needs and were in charge of protecting these needs every day. They therefore guided the identification of PLWHA and family care givers who participated in this review. The reviewers were guided by the managers and operational health workers at the sites throughout the process of data collection to ensure safety of the respondents.

All information collected was confidential and aggregated to produce a review report based on four countries. Interviews with PLWHA were arranged through their service provider organisations. Participation was voluntary, with freedom to withdraw any time and this was explained to each potential respondent. Names or any other identification information were not required from individual respondents and no identifying features were utilised in writing up the report. A clear explanation was given to all potential respondents that their participation or non participation in this review would not affect the services they received through the study sites.

In compensation for participants' time and costs, refreshments, transport refunds where applicable and any other related aspects were provided based on local guidance.

8.2.9 Dissemination of Research Findings

There is a dissemination plan for the findings of this HBC review within project countries, within Africa and internationally.

With each project country, dissemination meetings and workshops will be organised for the Ministry of Health and other home based care stakeholders with coordination by the national palliative care association. Such meetings will aim to share results and recommendations of the review to ensure that they influence policy changes and improve service provision. Each participating programme will be entitled to the final review report. The national palliative care association and the local home based care stakeholders will have the freedom to prepare and submit articles to their national research bodies for review and publication in local peer reviewed journals. APCA too will prepare and submit articles for publication in regional and international peer reviewed journals.

Findings will be shared at local, regional and international health related conferences including national palliative care conferences and national AIDS conferences among others. The process for undertaking this review has already been disseminated to a wide audience through meetings and conferences.

The results will be used to guide the process of developing palliative care standards that meet needs of specialist palliative care programmes as well as home based care programmes, which is the ultimate goal of this entire review of HBC models for PLWHA. We also anticipate that findings will guide the designing of a technical assistance package for home based care programmes to implement the recommendations of this review.

8.2.10 Limitations

The tools used were developed without reference to the literature review which came later.

The tools were long and sometimes respondents became tired before the end of the interview. The interviewers learned to be fast and focussed on the questions most relevant to the themes of the review.

However, literature was very useful in describing models found in project countries.

Literature highlighted HBC classification criteria used by other researchers and this was adopted for naming the models found in the review.
There was no inventory of HBC services which could have been used as a sampling frame. In each country, the experience of local contact people was used to make decisions.

Local palliative care associations were the local partners in this review, which was not necessarily one of their priorities at that time. Data collection schedules therefore had to fit into work plans for the busy associations.

The sample was 'small' and was selected without reference to an inventory therefore mainly qualitative inferences can be made from it.

Ethical approvals took long to be obtained and this delayed the completion of data collection exercise. Each country had its procedures for obtaining ethical approval and ethical committee meetings were scheduled every 3 to 6 months. This caused the delay in obtaining ethical approval in some of the countries.

9 Results

9.1 Introduction

Results are organised according to four themes drawn from the HBC review objectives.

These themes are:

Theme I
Examining the home based care programmes for PLWHA and thus determining their models of service delivery.

Theme II
Examining the home based care models for PLWHA and understanding their strengths and gaps for palliative care provision.

Theme III
Discovering if there are any "best practice models for HBC for PLWHA" that could be promoted by APCA for adaptation by countries across Africa.

Theme IV
Determining practical recommendations that could be made for the integration of all aspects of palliative care into existing home based care services for PLWHA

9.1.1 Models of home based care services in the four project countries.

Criteria for determining model of services

To determine the home based care models of services the reviewers used the categorisation by the HBC literature review which had been undertaken during the first phase of the exercise. "Home-Based Care for People Living with HIV/AIDS in Resource-Constrained Settings" (APCA, 2007). According to the above categorisation, seven distinct models of HBC were described, namely:

- Community Home-Based Care (CHBC)

- Integrated Community-Based Home Care (ICHC)
- Government District-Level Home-Based Care Services (GDL)
- Hospital-Supported Home Based-Care Services (HS)
- Home Visiting (HV)
- Hospice Care with Home-Based Care Services
- Outreach Services which Include HBC

What follows below are definitions and descriptions of each of the seven models based on the literature review in chapter one.

9.1.2 Community Home Based Care (CHBC)

Community home-based care (CHBC) was broadly defined as care provided to the ill in their homes or, more generally, in their natural environments, by families, using available community resources (APCA, 2007).

The model uses volunteers to undertake most of the care provision work, but working closely with health care workers. There is also strong information awareness through this model. Examples of this model include: Walioi Katika Mapambano na AIDS Tanzania (WAMATA) and Kibera Integrated Community Self-Help Programme (KICOSHEP).

9.1.3 Integrated Community Based Home Care (ICHC)

ICHC were services characterised by strong networks between several stakeholders, ranging from community members to large donor organisations (APCA, 2007). They were services with well developed collaborations between a local health facility and the community in providing HBC. This networking and collaboration enabled them to provide a continuum of care to the sick in their homes. Networking also enhanced referrals to and from the community and health facilities.

The Integrated Home Based Care Model seems a very strong model which incorporates a wide range of service components, in addition to the use of functional linkages in service delivery including clinics and hospitals.

An example of ICHC model was the HBC programme under the Lighthouse Trust in Lilongwe, Malawi.

9.1.4 Government District Level HBC

Government District level HBC models were led by government district departments, for example health and/or social welfare, which in collaboration with multi-sectoral stakeholders provided HBC. Nurses and other technical persons within the district, coordinated the HBC activities. They worked with community volunteers to provide the HBC to the community members (APCA, 2007).

An example of government district level HBC was Kinondoni Municipality HBC in Dar es Salaam, Tanzania.

9.1.5 Hospital Supported HBC

Hospital supported HBC services were directly connected to and administered by a hospital. Technical people, such nurses and clinicians, in collaboration with community volunteers provided the services (APCA, 2007).

Out of the 16 services in the sample, one hospital supported HBC service was identified. This was Dowa Hospital HBC in Malawi.

9.1.6 Home Visiting HBC.

In this model volunteers provided home-based support to patients. Their services were not as comprehensive as in CHBC or ICHC models of care (APCA, 2007). Counselling and basic care were part of home visits.

One service was identified as home visiting. This was Foundation for Community Action (FOCA) in Lusaka, Zambia. The basic care consists of volunteers giving counselling, nursing care and the referral of patients.

9.1.7 Hospice Care with Home-Based Care Services

Hospices were described as institutions which aimed to provide pain and symptoms relief and support to patients and their families. The care was intended to meet patients' physical, social and spiritual needs. One major adaptation had been to provide hospice services through HBC. For many hospices in Sub-Saharan Africa, HBC was the main type of care provided. Palliative care was a part of hospice services (APCA, 2007).

In this review, this model was not identified.

9.1.8 Outreach Services which Include HBC

In order to increase services' geographic coverage, this model utilised outreach teams to provide services in areas away from the main base of services. Staff saw patients on a walk-in basis in the outreach area clinics. Staff also provided home care for patients who were unable to attend the outreach clinic itself (APCA, 2007).

This model was not identified in this review.

9.2 Models of HBC services seen in the four project countries.

Table eleven: Showing a summary of the distribution of HBC models in the project countries

ID	Model	Country Distribution	Frequency
1	CHBC	• Zambia 3 *(Ndola Catholic Diocese HBC, St Francis, Bwafwano)* • Kenya 2 *(KICOSHEP, Holy Cross)* • Tanzania 2 *(PASADA, WAMATA)* • Malawi 1 *(Dedza)*	8
2	ICHC	• Kenya 2 *(Siaya, Malindi)* • Tanzania 1 *(KIWAKKUKI)* • Malawi 1 *(Lighthouse)*	4
3	Government District level HBC	• Tanzania 1 *(Kinondoni)* • Malawi 1 *(Ndirande)*	2
4	Hospital Supported HBC	• Malawi 1 *(Dowa)*	1
5	Home Visiting with HBC	• Zambia 1 *(FOCA)*	1
6	Hospice Care with HBC	*None met*	0
7	Outreach services which include HBC	*None met*	0
	TOTAL		**16**

CBHC and ICHC were the commoner models found!

Table Twelve: A summary of HBC programmes which participated in the review by country

No.	Country	Name of Programme	Classification of Model
1.0	**Kenya**		
1.1		Kibera Integrated Community Self Help Project (KICOSHEP),	CHBC
1.2		Siaya District Hospital HBC,	ICHC
1.3		Holy Cross Catholic Diocese HBC,	CHBC
1.4		Malindi District HBC	ICHC
2.0	**Zambia**		
2.1		CHISILANO of the Ndola Catholic Diocese HBC in the Copper Belt	CHBC
2.2		St Francis HBC in Livingstone	CHBC
2.3		Bwafano in Lusaka	CHBC
2.4		Foundation For Community Action (FOCA) in Lusaka	Home Visiting
3.0	**Tanzania**		
3.1		Pastoral Activities and Services for People with AIDS Dar es Salaam Archdiocese (PASADA)	CHBC
3.2		Kikundi Cha Wanawake Wa Kilimanjaro Kupambana Na Ukimwi (Kilimanjaro Women's Group in the Fight Against AIDS (KIWAKKUKI)	ICHC
3.3		Kinondoni	Government District Level HBC
3.4		Walioi Katika Mapambano na AIDS Tanzania (WAMATA)	CHBC
4.0	**Malawi**		
4.1		Lighthouse Trust HBC,	ICHC
4.2		Dowa Hospital HBC,	Hospital Supported
4.3		Dedza Catholic Diocese HBC	CHBC

4.4		Ndirande HBC operating under the Blantyre City Authority.	Government District Level HBC

Table Thirteen: Intensity of components and elements in different models

ID	Component / Elements	Intensity in ICHC	Intensity in CHBC	Intensity in GDL	Intensity in HS	Intensity in HV
1	**Counselling / Psychosocial support**					
1.1	AIDS awareness	+++	+++	+++	+++	+++
1.2	Nutritional education	+++	+++	+++	+++	+++
1.3	Medical/nursing information e.g. drug adherence	+++	+++	+++	+++	++
1.4	Spiritual support	+	+	+	+	+
1.5	Other (e.g. Preparing a will)	+	+			
2	**Home visiting**	+++	+++	++	++	+++
3	**Nursing care & Treatment of opportunistic infections**					
3.1	Basic nursing care	+++	+++	++	++	++
3.2	Administering drugs	+++	+++	++	++	+
4	**Facilitation of IGAs**					
4.1	Sensitisation on IGA management	+++	++	++	++	+++
4.2	Initiation of IGAs	+++	+++	++	++	+
5	**Orphan support**					
5.1	Provision of fees and scholastic materials	+++	+++	++	++	+

5.2	Operating schools for orphans	-	++	-	-	-
6	**Referral**					
6.1	Referral for medical care	++	+++	++	++	+++
6.2	Referral to other organisations for other services not provided	++	++	+++	+++	+++
7	**Training/capacity building**					
7.1	Training of volunteers in HBC and other skills	+++	+++	+++	++	+
7.2	Training of formal carers in HBC	+++	+++	++	++	-
8	**Provision of food supplements**	+++	+++	++	++	+
9	**ART (referral)**	++	+++	++	++	+++
10	**Direct access to ART**	+++	++	++	++	-
11	**Access to simple pain killers only**	+++	+++	+++	+++	+++
12	**Access to strong pain killer with the prescription of a doctor**	+++	++	+++	+++	+

Key to table four

+++ Means element seen very frequently
++ Means element seen frequently
+ Means element seen less frequently
- Element not seen

9.2.1 A glance at HBC Models in Kenya

In Kenya the four programmes reviewed were:

- Kibera Integrated Community Self Help Project (KICOSHEP),
- Siaya District Hospital HBC,
- Holy Cross Catholic Diocese HBC,
- Malindi District HBC

Granting that type differences were not clear cut, KICOSHEP and Holy cross were classified as CHBC models. Siaya and Malindi were classified as ICHC models.

(i) CHBC Models

KICOSHEP was described as an example of CHBC models in Kenya.

KICOSHEP is an NGO founded by community initiative in 1991 and is based in Kibera, Nairobi, Kenya. It operates in five regions of Kenya, namely: Nairobi Province, Eastern Province, Nyanza Province, Central Province and the Rift Valley Province.

Kibera is one of the projects operated by KICOSHEP within Nairobi Province. It serves people in a slum in Nairobi city. It has formal care givers who provide training and technical support to community volunteers and families. The families and volunteers are the primary HBC care givers. KICOSHEP net works with several hospitals and health centres. It also collaborates with the provincial and district health offices as well as the MOH.

Some of the activities of Kibera project included the following; provision of psychosocial support through home visiting and counselling, treatment of opportunistic infections and linkage with hospitals in the area to provide ARVs. They also included facilitating/educating of families in income generation, as well as provision of material needs such as food supplements and scholastic materials.

Kicoshep operated a youth centre, orphans service centre and a hospice where palliative care was provided. Referrals were made to Mbagathi hospital and other health units in Nairobi. Volunteers, family care givers and patients were trained in patient care and support.

KICOSHEP had multiple sources of funding resulting from writing proposals. Major funders included Global fund, World Bank and MoH who gave training and supplies.

Volunteers contributed to the HBC through time, energy, bus fare, air time and these came from their personal resources.

(ii) ICHC Models

Siaya Hospital HBC was described as an example of ICHC in Kenya. It was found that Siaya District Hospital in Western Kenya collaborated with CBOs in Siaya District to provide HBC. In the hospital, health workers wrote discharge plans and clients were discharged through the Comprehensive Care Centre (CCC) (sometimes called Patient Support Centre PSC)). The CCC coordinated the hospital work with that of the community.

The CCC was jointly managed by formal care givers and volunteers. In the CCC, clients receive next appointment, ARVs and adherence counselling. The HBC service, managed by a CBO or FBO or NGO, collaborated with family care givers to provide HBC. Sometimes, formal care givers visited clients in the community. Clients were also referred to Siaya hospital from the community by volunteers working with a CBO or FBO or NGO.

Centre for Disease Control provided funds for some aspects of the CCC, including CD4 count. The MoH through the district hospital provided the rest of hospital funding. The CBO/FBO/NGO which collaborated with the district hospital through the CCC had their own sources of funding.

9.2.2 A glance at HBC models in Zambia

In Zambia, the four programmes reviewed were:

- Chisilano of the Ndola Catholic Diocese HBC in the Copper Belt
- St Francis HBC in Livingstone
- Bwafano in Lusaka
- Foundation For Community Action (FOCA) in Lusaka

Ndola, St Francis and Bwafano programmes were classified as CHBC models. FOCA was classified as Home Visiting model.

(i) Community Home Based-Care (CHBC) models in Zambia

Ndola Catholic Diocese HBC is described as an example of CHBC models in Zambia.

The Ndola Catholic Diocese supported CBOs such as Chisilano to provide HBC to the PLWHAs and their families. The Ndola Catholic Diocese recruited, trained and maintained formal care givers who in turn provided support supervision to volunteers belonging to various CBO/FBOs to glve the HBC. Activities of Chisilano HBC included; Physical support such as home visits, nutritional support, nursing care, medical care, physiotherapy, teaching relatives on care of clients and support at home as well training clients on how to take care of themselves.

Their psycho-social support activities included spiritual support, VCT, and linking patients with where they could find assistance.

The economic support included providing material needs (material and money at times), training /facilitating for IGAs, providing management guidance for small size enterprises and providing a small and medium size business consultation centre.

Sources of funding include Catholic Agency For Overseas Development (CAFOD), Christian AID, Catholic Organisation for Relief and Development AID (CORDAID), Irish Aid and Catholic Relief Services. The volunteers contributed their time, as well as cash, telephone air time, transport, etc.

(ii) Home Visiting

Foundation for Community Action (FOCA) is located at the out-skirts of Lusaka. FOCA is a community initiative in which community volunteers, with little external support, provided basic care at home. There was some networking with other service providers such the government health centre in the area. The volunteers conducted home visits and dealt with family needs such as food and scholastic materials for children. Occasionally, FOCA provided some end of life care services, IGA facilitation, transport to health facilities and training of volunteers.

FOCA did not have regular partners supporting it financially. It had been funded by MOH twice through the TB programme. Funding had once been obtained through CHAZ. Resources are a major constraint for FOCA. Due to resource constraints, the volunteers did not have much to offer and the visits were irregular.

9.2.3 A glance at HBC Models in Tanzania

In Tanzania, the four programmes reviewed were:

- Pastoral Activities and Services for People with AIDS Dar es Salaam Archdiocese (PASADA)
- Kikundi Cha Wanawake Wa Kilimanjaro Kupambana Na Ukimwi (Kilimanjaro Women's Group in the Fight Against AIDS (KIWAKKUKI)
- Kinondoni Municipality HBC
- Walioi Katika Mapambano na AIDS Tanzania (WAMATA)

PASADA and WAMATA were classified as CHBC. KIWAKUKKI was classified as ICHC and Kinondoni as Government District Level HBC.

(i) Community Home Based-Care in Tanzania

PASADA was described as an example of Community Home Based Care in Tanzania.

PASADA is a Faith Based Organisation (FBO) owned by Dar es Salaam Catholic Archdiocese. The HBC programme is located at the out skirts of Dar es Salaam city. It had a main centre and six outreach sites in the city. It had formal care givers called HBC nurses who provided technical support to community volunteers and families. These nurses had undertaken training in Palliative Care.

PASADA targets the poorest of the poor living with HIV and provide them with medical, social, psychological, material and spiritual support. PASADA networks with schools, health facilities from/to whom clients may be referred, MOH and donors.

The activities of PASADA included provision of medicines, training of technical people such as nurses on basic counselling to meet psychosocial needs. They also referred clients with psychosocial needs to social workers and to hospitals. It provided sensitisation of churches to help PLWHA, train family members about nursing care cleanliness and side effects of ARVs.

Activities also included facilitation of IGAs, pain management, provision of some material needs such as food and hospice services. They provided support for extended family members raising children whose parents or guardians had died from AIDS

Initial funding was by the Diana Fund but now, President's Emergency Plan for AIDS Relief (PEPFAR) funds medicines. The Stephen Lewis Foundation provided funding, particularly for salaries and other allowances.

(ii) Integrated Community Home-Based Care (ICHC) in Tanzania

KIWAKUKKI was classified as ICHC model

KIWAKKUKI is a nongovernmental organisation located in Moshi town in Northern Tanzania. Historically, it was founded by a group of women as a local initiative to fight HIV/AIDS. The women's group targeted the entire population in the community. It aimed to raise AIDS awareness, educate people about AIDS, help restore dignity, promote understanding, raise the status of women in the family, and share information on AIDS with other groups.

It grew to a level whereby training in home-based care of AIDS patients and their families was provided by a consortium of AIDS groups. The women's groups counselled families who neglected or discriminated against relatives with AIDS. The groups provided funeral expenses for abandoned persons with AIDS. The groups mobilised the support of the community in a variety of ways. KIWAKKUKI networks with Health Facilities such as Kilimanjaro Health Centre, Care Treatment Clinic (CTC). Referral is two way and is done through referral letters. Follow up on adherence is jointly done with hospitals.

The Government of Tanzania was responsible for providing medication but KIWAKKUKI helped in organizing provision of the medication to the clients. Through

World Food Programme (WFP), food was provided. Loans were provided to patients to facilitate their IGAs. KIWAKKUKI is donor funded. Major donors included the Government of Tanzania, Action Medior, Duke University, Women Front of Norway and Municipal Council of Moshi which provided HBC kits. WFP provided food to PLWHA.

(iii) Government District Level HBC

An example of Government District Level HBC in Tanzania was Kinondoni HBC. In Kinondoni Municipality, there was an HBC coordinator at municipality level. This person coordinated all the HBC activities in Kinondoni municipality and facilitated the HBC collaboration with existing health facilities. The technical people in the health centers collaborated with the community volunteers and home care givers to provide HBC.

Kinondoni Municipality had HBC groups working within its area, although some members also volunteered for NGOs such as Pathfinder. Its HBC teams check the health status of patients, distribute medicines (especially ART), offer counselling and provide food. They also educate communities on HIV/AIDS. Care is primarily for PLWHA. There are clear referral pathways for patients from volunteers to health workers at health facilities, and from there to hospitals. Referrals are made to ORCI for concerns about cancer patients. Although this sample site was selected for its 'hospital based' status as the outreach programme of Ocean Road Cancer Institute, this research exposed shortcomings and non-implementation of the palliative care programme described in Network 7 (APCA, 2007): 'In 2006 nurses working in home-based care programmes in the Kinondoni municipality of Dar es Salaam were intensively trained in a one week course which was supported by the Diana, Princess of Wales Memorial Fund. In March 2007, 33 heads of health facilities in the same municipality will attend a similar course. Plans are at an advanced stage to procure oral morphine for these facilities'.

The sources of funding for Kinondoni included the Municipal Council budget, WHO, PASADA and Pathfinder. Pathfinder provided training and municipality provided medicine.

9.2.4 A glance at HBC models in Malawi

In Malawi the four programmes reviewed were:

- Lighthouse Trust HBC,
- Dowa Hospital HBC,
- Dedza Catholic Diocese HBC and
- Ndirande HBC operating under the Blantyre City Authority.

Lighthouse Trust HBC was classified as ICHC. Dowa was classified as Hospital Supported. Dedza was classified as CHBC and Ndirande as Government District Level HBC.

(i) Community Home-Based Care in Malawi

The Community Home-Based Care model identified in Malawi was Dedza. It was led by an FBO owned by Dedza Catholic Diocese. The diocese recruited and maintained formal care givers. The formal care givers empowered and supervised the community volunteers to provide HBC.

Provision of HBC follows government policies and the Catholic Church ethical values. Government supports the HBC through provision of training, testing kits and HBC policies.

Activities of Dedza HBC included mobile clinics for medical needs, facilitation of volunteer groups offering psychosocial support and drilling bore holes. Dedza HBC also refered PLWHAs to hospitals for ART and TB treatment. It also offered training to volunteers (to monitor and ensure patient care). It also mobilised local resources to provide shelter and food supplements for PLWHA.

Dedza Catholic Diocese got its funding through writing grant proposals. The main donor was stated to be Catholic Relief Services (CRS). The Government of Malawi gave input through in-kind support, e.g. by conducting training or supplying HIV testing kits. The community volunteers contributed by using personal resources (e.g. farming) to supplement the funding.

(ii) Integrated Community Home-Based Care (ICHC) in Malawi

Integrated Community Home-Based Care model identified in Malawi was Lighthouse Trust. The Lighthouse Trust was started in 1997 by the staff of Lilongwe Central Hospital. It networks with existing community groups when providing HBC. It also operates a clinic where clients are provided with medical care. It collaborates with the Lilongwe General Hospital. Clients were referred to and fro between the community and the hospital.

Although Lighthouse was founded by staff of a government hospital, the organisation was essentially a private trust and only collaborated with government structures, donors and community volunteers when providing HBC. Lighthouse had grown to a level where it was considered by the government of Malawi to be an example and a breeding ground for best practices of HBC/PC provision.

Networking between many stakeholders enabled Lighthouse to provide an integrated and more complete HBC programmes that included palliative care.

Lighthouse HBC activities included training of volunteers and formal care givers, provision of food items, provision of nets, giving water guard and medical treatment of opportunistic infections. Other activities were home visiting, counselling on how to initiate IGAs, referral to Lilongwe Central Hospital and facilitation of formation of associations for PLWHA.

(iii) Government District Level HBC in Malawi

Government District Level HBC identified in Malawi was Ndirande. Ndirande is located in Blantyre city, southern Malawi. The HBC was initiated by Blantyre City Authority and there is close collaboration with Queen Elizabeth Hospital in Blantyre. The Blantyre City Authority systems support CBOs. The community volunteers who provide HBC, belong to CBOs. Government formal care givers empower and supervise the volunteers. Formal care givers belong to health facilities such as Tiyanjane. Government, through Blantyre City Authority, facilitates training, access to ARVs and HBC kits.

(iv) Hospital Supported HBC in Malawi

A hospital supported HBC in Malawi was the one led by Dowa Hospital. Dowa Hospital HBC is located more than 100 km North East of the capital Lilongwe. There was a coordinator for the various HBC programmes under the hospital. The coordinator gave support supervision to CBOs in the various operating areas. Occasionally, other formal care givers visited clients and provided technical support-supervision to volunteers and treated opportunistic infections. There were two way referral of clients to and from the community and the hospital. The volunteers belonging to the CBOs worked with home care givers to provide HBC.

Dowa Hospital HBC activities included nutritional counselling, giving food supplements, training and support supervision to volunteers. Other activities were management of opportunistic infections, ART, PMTC, referral and provision of transport to hospital.

10.0 Strengths and gaps for palliative care provision in the identified HBC models

10.1 Preamble

According to WHO (No date),

"Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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."

In order to articulate the strengths and gaps, there were questions about strengths and gaps to the respondents. Content analysis was done to the responses to find those gaps and strengths which were cross-cutting in models. The reviewers by observing the objectives, levels of performance and resources of the programmes, were able to form an opinion regarding the gaps and strengths of the programmes for palliative care provision.

10.2 Strengths and gaps for provision of Palliative Care within programmes categorised under the CHBC model.

a) Strengths CHBC

(i) It was noted that CHBC programmes were an initiative of the community and therefore, had strong community involvement and participation for provision of home based care including some aspects of palliative care.

(ii) Dedicated volunteers offered strength for the provision of PC. The volunteers and family care givers were pivotal to the success of CHBC.

(iii) CHBC also had boards of directors with membership from the local communities and with personal interest and commitment to the success of HBC.

b) Gaps CHBC

(i) A major gap was the lack of clear conceptualisation among the providers / volunteers as to what palliative care [especially holistic PC] meant and what role it played in HBC. For example, some respondents, including some policy makers, felt that palliative care was a sub set of HBC, while others thought that HBC was a subset of palliative care. On probing within the same interview, some respondents either changed their positions or lost any opinion.

(ii) Pain and symptom assessment skills were inadequate.

(iii) There was inadequate access to strong painkillers such as opiates.

(iv) There was little or no direct male involvement in the programmes. Men were, however, indirectly involved by allowing and sometimes facilitating their wives to volunteer in the programmes

(v) Some volunteers had become inactive. It was common to find a significant percentage (in some programmes more than 50%) of trained volunteers no longer actively participating in the service delivery. This was a cross-cutting gap in all the models.

10.3 Strengths and gaps for provision of palliative care within programmes categorised under ICHC model.

a) Strengths ICHC

(i) There was a two-way flow of client referrals between the community and the formal care services for HBC and for PC. This was achieved through the establishment of links in the Comprehensive Care Centres (or Patient Support Centres) in Kenya and Community Surveillance Assistants in Malawi.

(ii) There was involvement and participation of technical people working with health facilities. The nurses and clinicians contributed to the programmes.

(iii) There were networks between the different stakeholders particularly the community and health facilities. There were synergies in programmes due to each stakeholder contributing their input into the programme.
(iv) There existed strong government structures (such as structures for support supervision of HBC, training and human resource).
(v) There were capacity-building opportunities for both staff and community. For example, in Kenya, Mildmay provided various trainings of HBC for various cadres. In Malawi, Lighthouse Trust had a strong training component for formal carers and volunteers. They also conducted research and they developed best practices for other organisations to copy.

b) Gaps ICHC

(i) There was understaffing in the health facilities. Managers and staff of ICHC programmes highlighted the shortage of technical staff. The load of work in health facilities was more than the staff could adequately handle.
(ii) Transfer of technical staff without considering the roles they are playing HBC/PC skills was common. This was a problem particularly in government health facilities such as Siaya District Hospital, Kenya.
(iii) Another gap found was the inadequate capacity to write proposals and mobilise resources for provision of services.
(iv) Access to strong pain killers was also inadequate and this was attributed to restraining policies regarding the prescription of medicines. Doctors were few and yet they are the ones who were allowed to prescribe strong pain killers. This was the case in all the four countries.

10.4 Shared strengths and Gaps of CHBC and ICHC

a) Shared strengths of CHBC and ICHC

(i) *Teamwork:* Teamwork was a cross-cutting approach of delivering services to PLWHA. Volunteers at the community level worked in teams. Technical people also teamed up with volunteers to provide services. This was a common feature in all programmes in this review. This integration and teamwork had the potential to improve the efficiency and effectiveness in delivering palliative care. There were written material including policy guides and training manuals that provided guidance and policies for provision of HBC.
(ii) *Political good-will:* In all the four countries, there was evidence of political good will towards HBC. The policy makers supported HBC and palliative care. At the MoH level, there was always an officer responsible for coordination of HBC work.
(iii) *Strong support from CBOs,NGOs, FBOs and donors:* There was always strong support from members and leaders of CBOs, NGOs and FBOs at the

community level. These leaders had expertise in mobilising communities. The mobilisation was supported by the local political leaders who were involved in HBC work. Volunteers were pivotal in the continuity of the provision of HBC.

(iv) *There were* effort to facilitate IGAs. However, most IGAs seen included mainly petty trade in items such as tomatoes, fruits and maize flour.

(v) Networking was present between groups and monthly coordination meetings were organised. The meetings involved sharing of experiences, developing plans such as prevention of the duplication of services. Local governments were usually involved in the coordination meetings.

(vi) All programmes had some kind of ongoing training programmes for various cadres and the training consisted of workshops and hands-on experience in counselling, care of patients and IGA management.

b) Shared gaps of CHBC and ICHC

(i) Although some NGOs such as KICOSHEP, Bwafano, Siaya and Lighthouse had the capacity to write proposals and access funding, other programmes lacked resource mobilisation capacity and therefore could not use this approach to access funding.

(ii) All programmes were supported by donor input and would be challenged to operate without it. Donor dependence was a universal gap among programmes. Government input was not sufficient.

(iii) The IGAs facilitated were too small to make a meaningful impact on the economic welfare of clients. IGAs observed included selling tomatoes at a roadside kiosk in FOCA, one cow for a whole HBC programme in DOWA, necklaces and ornaments in Bwafano.

10.5 Strengths and gaps for provision of palliative care within programmes categorised under Government District Level (GDL) HBC.

b) Strengths of GDL

(i) There were viable district government structures. The reporting structures of local and national governments provided channels for implementing and support-supervising HBC and palliative care activities.

(ii) Technical people who could provide inputs in the HBC services were present. They needed only training, orientation and facilitation in order to deliver HBC and palliative care services.

c) Gaps of GDL HBC

(i) Understaffing in Government health facilities was an issue. It was reported that Government health facilities were understaffed even before HBC and

palliative care activities were introduced. Introduction of these programmes made the situation worse.

(ii) There was a motivational gap caused by the tendency by some technical persons to see HBC as secondary to their responsibilities.

(iii) While there was a general lack of skills among the staff in providing PC, the lack of skills for providing it within the home based care setting was even greater.

(iv) There was inadequate access to strong pain killers due to restraining policies on prescription.

10.7 Strengths and gaps for provision of palliative care within programmes categorised under Home Visiting (HV) Model of HBC

a) Strengths of HV

Home Visiting was a community initiative. The community were pivotal in HBC service provision. With little external support, but with a spirit of voluntarism, the community initiated and maintained HBC.

b) Gaps of HV

(i) Home visiting provided the least comprehensive HBC compared to all identified models. Their capacity was limited to providing home visiting and psychosocial support, but provision of other components of HBC such as treatment of opportunistic infections, spiritual counselling and training were minimal.

(ii) Gaps were noted also as lack of resources and skills being major challenges of the home visiting model, due to limited capacity of volunteers to mobilise them.

(iii) Lack of access to strong pain killers was more pronounced. These pain killers were available only through referral.

10.8 Strengths and gaps for provision of palliative care within programmes categorised under Hospital supported (HS) HBC model.

a) Strengths of HS

(i) Like in the case of government district level HBC programmes, there were strong management structures. Guidelines and protocols used in case management could be used to provide HBC and management of individual cases.

(ii) Technical people were available to give input in the provision of HBC and PC services.

(iii) Hospitals were resource intensive. These same resources were more easily accessed for HBC and palliative care provision.

(iv) There was good partnerships between volunteers and technical people. The synergy of volunteers and technical people working together contributed to a stronger potential for HBC and palliative care.

b) Gaps of Hospital Supported Programmes

(i) In this type of programme, there was a tendency to marginalise HBC when compared to other services of the hospital.

(ii) Not every technical person had received training in HBC. Therefore, there was lack of HBC skills in some of the technical people such as nurses.

(iii) Some medicines frequently used in treatment, for example those used for opportunistic infections, pain management and ARVs, were sometimes not consistently available.

(iv) Access to strong pain killers was restricted by policy which required prescription by a doctor.

Cross-cutting Strengths of all models reviewed (CHBC, ICHC, DDL, HV, HS)

(i) There were policies on HBC. The presence of these policies was an indicator that governments recognised the importance of HBC in the delivery of health services.

(ii) Governments in the four countries had policies for making ARVs more accessible.

Cross-cutting gaps of all models reviewed (CHBC, ICHC, DDL, HV, HS)

(i) The concepts of HBC and PC were not clear to most respondents. There was evidence of confusion of the meanings of palliative care and home based care. Home based care programmes and providers needed to understand palliative care and how it could be integrated in their work.

(ii) There was no researched information on HBC and PC issues. Many respondents' statements were based on their impressions. There was also a lack of inventory and documented resource information on HBC and PC.

(iii) It was noted that the needs for PLWHA had changed since the onset of HBC and including the better access to ARVs. Availability of ARVs had led to improved health of the PLWHA. However, there remained a more pressing need of economic empowerment and yet there were no strategies to address it.

11.0 Discussion of meanings of HBC and PC models, their strengths and gaps

11.1 Discussion of Classification of programmes

According to literature (APCA, 2007) HBC programmes were assigned to models based on 'who' offered the services and according to 'what' services were offered. In this review, models were assigned based on 'who' offered the service. This was because there was a lot of overlap in what services were offered by the various programmes. The components of HBC programmes reviewed are described in table four.

In the CHBC model, the community was the main service provider. In the ICHC model, services were provided by collaboration of a variety of stakeholders some of whom were based in facilities and others in communities. In the Government District level model, services were led by a government department collaborating with a community. In a hospital supported model, services were provided by a hospital in collaboration with community. In home visiting, service provision was led by community volunteers.

11.2 Discussion of strengths and gaps of CHBC models

The results showed that there was need to capitalise on the strengths of models and to manage their gaps in order to establish stronger CHBC. In so far as CHBC models were initiatives of the community, the capacity of the communities could be increased through promotion of the principle of "integration", strengthening awareness and building leadership. In this review, integration meant *collaboration between stakeholders who share resources and responsibility to achieve goals.*

The management of gaps could be improved through training, advocacy on policies and creation of appropriate incentives for volunteers.

11.3 Discussion of strengths and gaps of ICHC models

The key element of ICHC was the principle of "integration". The Integration principle should be recognised and maintained in the ICHC model. It can be increased by encouraging collaboration of partners and stakeholders.

Results showed that the strong partners included governments (both central and local) donors, NGOs, facilities such as hospitals and hospices, government departments, community leaders and volunteers.

11.4 Discussion of strengths and gaps of Government district level (GDL) HBC models.

GDL HBCs were strengthened by Government structures and availability of technical people for HBC service delivery. However, there was still a need to address the human resource and attitudinal gaps where by the staff and administration felt that HBC and PC was secondary to their primary jobs. Government facilities needed to give HBC fare share of resources.

11.5 Discussion of strengths and gaps of hospital supported (HS) HBC model

Hospital supported HBC was strengthened by the hospital/facility physical and management structures, including the availability of technical people who participated in the delivery of HBC. However, this model also needed to address its human resource issues, including the attitudinal issues of marginalizing HBC and PC.

11.6 Discussion of strengths and gaps of home visiting (HV) HBC model

Home visiting was the smallest unit of HBC/PC. A major gap identified in Home Visiting model was a lack of resources and skills to give a better package of HBC. Home visiting can offer more effective HBC if it utilises the principle of "integration" at its level.

11.7 Discussion of Components of HBC

The components listed in table four were present in all ICHC and CHBC programmes. Although there was no objective measurement of their presence, they were generally more visible in ICHC models. The same components were present in much less extent in government district level and hospital supported programmes. In home visiting model, only home visiting, counselling, basic nursing and referral were clearly visible.

In all programmes, spiritual care had not been given adequate attention. In general, clients were referred to their spiritual leaders for that service.

ARVs and treatment of opportunistic infections such as TB were provided by health units to which clients were referred. Follow up to the community level was relatively better whenever there was good integration such as in ICHC and CHBC models.

Simple pain killers were available to clients. However, interviews with policy makers showed that the process of clients accessing strong pain killers, was restrictive since only doctors were certified to prescribe them.

The components for HBC were essentially the same for all models (see table four). It was the capacity to deliver them that varied among the models. In this review, it was found that maximum capacity to deliver was in the ICHC model and minimum in the home visiting model. It was also noted that the higher the level of 'integration", the stronger was the capacity to offer HBC and PC components.

There was overlap in various models' capacities to offer HBC components for example KICOSHEP in Kenya could have been classified as either ICHC or CBHC.

Officially there were no programmes where strong pain killers were accessible through prescriptions by other cadres other than doctors.

Reviewers noted the similarity of components of HBC found as listed in table four and what WHO (No date) lists as components of palliative:
Palliative care:

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patient's illness and in their own bereavement;*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*

- *will enhance quality of life, and may also positively influence the course of illness;*
- *Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*

The World Health Organisation (No date) defined palliative care as "the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.

Palliative care is necessarily multidisciplinary. It is unrealistic to expect one profession or individual to have the skills to make the necessary assessment, institute the necessary interventions, and provide ongoing monitoring."

Comparing the list of components in table four, and components of palliative care as given by WHO above, shows that there is a similarity between the given components of HBC and those of palliative care. This similarity would seem to make integration of programmes of PC and HBC a strategic approach in health care.

11.8 Discussion on Policies of CHB/PC

The four countries reviewed had policies on HBC. The HBC policies included issues on palliative care. In Kenya, no direct reference was made about palliative care component (Home Care Handbook, 2006). In Malawi, there was a bullet about palliative care being included in the minimum package of HBC (HBC Policy and guidelines, 2005:11). In Zambia, there was no direct mention of palliative care as a component of HBC although they had several components of it in their programmes (HBC Care for PLWHA – Reference manual for care givers, 2004).

It was observed that the policies were not articulate about the role of PC in HBC.

Further, interaction with policy personnel in the countries indicated that the policies were restrictive on which cadres/s of service providers should prescribe and /or dispense strong painkillers.

11.9 Discussion of Research in HBC programmes

It was observed that the various programmes had raw data (e.g. Monitoring reports, records, statistics, outcomes and views) which had not been analysed so as to generate information for management of HBC programmes. The reviewers did not see sufficient evidence of formal operational research, surveys, programme evaluations and studies going on in the four countries. In the same vein, at the national level, there was a lack of inventory of HBC and PC programmes in the project countries. Therefore it was it was not clear whether planning and proactive implementation of activities was based on researched and documented information.

11.10 Discussion of the changing needs of PLWHA

The review showed that the focus of the patients' concerns had shifted from their direct health needs to their financial and material needs. In all services, the emphasis of HBC had been on health care including provision of ARVs. This emphasis had led to improved wellbeing of PLWHA. This improvement of health had resulted into a shift whereby the priority needs of the PLWHA changed from health needs to need for economic empowerment.

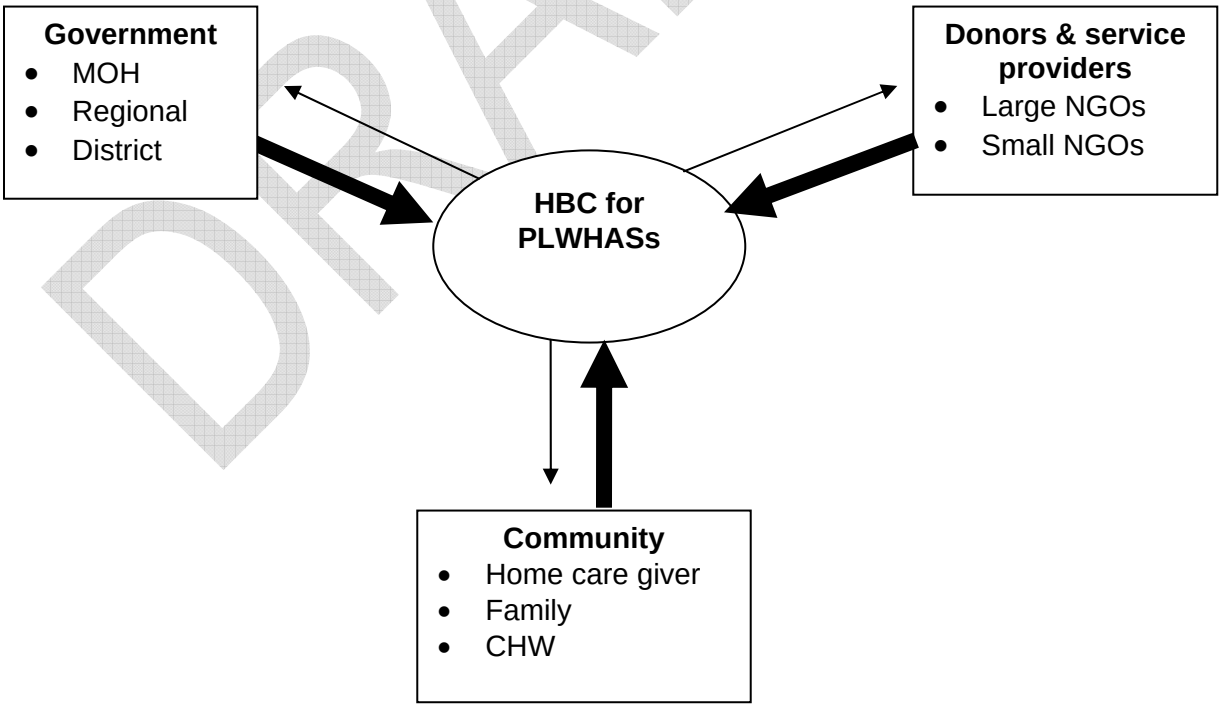
It seems logical, therefore, that HBC and PC stakeholders strategise to cater for economic empowerment of PLWHA as an emerging need. In the African context of collectivism, this would mean empowering PLWHAs' families and communities as well.

An assessment of "Best practice models for HBC for PLWHA" that can be promoted by APCA for adaptation by countries across Africa.

Criteria for identifying a best practice model

Determination of the a best practice model was based on the review finding that the strength of HBC for PLWAs and their families was heavily dependent on three pillars *(see illustration, Figure 4)*:

Figure 4: A Concept of pillars of HBC



Source: *M&BC Conceptualisation based on findings in the field*

(i) The pillar of community involvement and participation

This refers to the level at which community members, [i.e. home carers, individual volunteer care givers and groups, CBOs], were available and supportive to the clients.

It was noted that all categories of respondents said that home carers and community volunteers were pivotal in the delivery of HBC services. The home carers provided the actual service to the client while the volunteers provided support. Volunteers also formed a link with the health care services and NGO / CBOs serving the community.

(ii) The pillar of Government support

The national and local government organs were also a pillar in the provision of HBC. Governments created an enabling environment through policies and guidelines for HBC. Technical people, who were usually government employees, provided support supervision to NGOs, CBOs and community volunteers. The Governments provided empowerment through training of formal carers and volunteers. Clients were referred to government health care facilities. Governments also provided other resources such as HBC kits.

(iii) The pillar of Donors and NGOs

The support of donors and NGOs was a strong pillar in provision of HBC, since all the four project countries in the review were resource constrained and poverty was stated to be a major cause of suffering. HBC required resources [e.g. food supplements, medications and human resource] beyond what the local communities could provide. Donor support was considered to be a major pillar.

12.0 The model of Best Practice

- The best practice model was judged to be ICHC, based on the following supporting reasons:
- It had the capacity to provide a comprehensive list of HBC elements, including palliative care. This was possible through collaboration and networking of various stakeholders. For example in Siaya HBC which was classified as ICHC, there was synergy between the efforts of Mildmay which provided training and capacity building while government provided management infrastructure including human resources. The CBO (such as Nyamurerwa) delivered HBC to the PLWHAs. A similar situation was found in the case of Lighthouse trust programmes in Malawi.
- It was more sustainable due to utilisation of larger sections of each of the three pillars, as highlighted in the concept (Figure 1). Along each pillar, ICHC model

called into play a wider list of stakeholders. This integration and collaboration availed different sources of resources for sustainability.

- Through networking and collaboration, issues of capacity building, including training and resource mobilisation, were best addressed in ICHC model. This was because capacity building required skills and resources that were best provided through networking and collaboration.
- It provided a natural direction of growth for other models. All models could potentially grow into ICHC, whatever their foundation may have been. This was because the qualities of networking and collaboration could be learned and be given prominence in any one model.

13. 0 Conclusion

The following conclusions are made bearing in mind that the sample in this review was 'small' and was selected without reference to an inventory and those therefore mainly qualitative inferences could be made from it:

Overall, the review showed that programmes in the four countries were offering HBC to PLWHA despite resource limitations. The components of HBC observed in the reviewed programmes were similar to those provided in palliative care as defined by WHO).

The respondents testified that, whereas, PLWHA were benefiting from HBC services and their health had improved, as a consequence of improved health of PLWHA, there had been a shift of priority needs of PLWHAs from health to economic empowerment.

It was also found that the better model was ICHC because of its quality of 'integration' which gave it capacity for providing comprehensive services and a better potential for sustainability. The CHBC model was also noted to be effective at attracting community participation and ownership.

It was also found that the spiritual component HBC was not given adequate attention.

A critical gap observed in HBC programmes was the restricted access to strong pain killers for PLWHA.

The following strategic approaches will be required to strengthen HBC programmes:

(i) Enhancing capacity for resource mobilisation.
(ii) Integrating all aspects of PC in programmes of HBC including improved policy on access to strong pain killers.
(iii) Introducing standards that will enhance M&E of HBC and PC.
(iv) Enhancing the quality of 'integration' in all models of HBC.

14.0 Recommendations for integrating palliative care into home based care

14.1 Advocating for promotion of ICHC model which lends itself to more effective integration of PC into HBC.

ICHC model has the potential to provide PC in full. The ICHC model makes it possible to bring together the complementary strengths of community participation, NGOs, governments (including the health department) and donor support. Collaboration between government departments, community and the donors make this model more sustainable than the others. The synergy created increases effectiveness and efficiency.

The ICHC model was also recommended by the South African National Department of Health as stated by *Defilipi et el (2006:10)*:

"The Integrated Community-based Home Care (ICHC) model was developed in 1996 by South Coast Hospice in response to the HIV/AIDS epidemic in rural KwaZulu-Natal. It has been adopted by the Hospice Palliative Care Association of South Africa (HPCA) and written up as a best practice by the HIV/AIDS/TB/STI Directorate of the South African National Department of Health.
ICHC was subsequently piloted by HPCA in conjunction with the University of Natal and found to be replicable and flexibly effective in metropolitan, urban, peri-urban, and rural settings across South Africa."

Regardless of how HBC programmes start, they all have the potential to grow into integrated models.

It is recommended that the practice of integration in HBC programmes for PLWAs be promoted by APCA. This will make it easier to integrate all aspects of Palliative Care in Home Based Care programmes for PLWAs.

14.2 Influencing governments to adjust policies to include adequate guidelines for PC and to enable easier access to strong pain killers.

In all the four project countries, it was stated by policy personnel that only doctors were officially certified to prescribe strong pain killers such as morphine. The formal care givers confirmed this.

For easier access to better management of pain, other cadres of health workers, including nurses, midwives and clinical officers, should be trained and certified to prescribe strong pain killers such as morphine.

The World Health Organisation Report of 2006 classified the four project countries as some of those with a critical shortage of qualified human resources for health. In such countries, doctors were few. It was advisable to use other health cadres to prescribe and make easier access to strong pain killers as is the case in Uganda and Zimbabwe:

"In all African countries, doctors are scarce but are also the only prescribes of certain drugs, including morphine. For people in all communities to have access to effective pain management, nurses and clinical officers need to be trained and certified to prescribe morphine (see Chapters 4: Pain Management and Chapter 36: Drug Policy). This has been made possible in Zimbabwe as well as Uganda, where nurses and clinical officers with a 9-month course in palliative care can now prescribe morphine." (Defilipi et al, 2006:12)

This review, therefore, recommends that:

APCA advocates for changing policies to allow other cadres of health workers including nurses, midwives and clinical officers, to prescribe morphine and other currently restricted pain killers.

APCA advocates for provision of training and certification of nurses, midwives and clinical officers to enable them to prescribe morphine and other currently restricted pain killers

14.3 Advocating for capacity building in HBC and PC

As already pointed out the concepts of HBC and PC were not clear for most respondents. Knowledge of what constituted palliative care, and how it could work with HBC, was particularly lacking. This called for capacity building at all levels of HBC providers. Training should be provided to the community providers, technical people in the facilities and the policy level personnel.

In light of the human resources shortage in sub-Saharan countries (World Health Report 2006), which included the four project countries reviewed, capacity building was essential.

Defilipi et el (2006) asserted that the mainstay of many successful grassroots African programmes was the transference of skills to lay community caregivers.

Technical people need to be sensitised about the complementarity of home based and facility based health programmes. The community volunteers need ongoing training in basic nursing and other skills in health care provision within community setting. A key role by APCA should be facilitation of the development of standards for HBC and palliative care. Involving community in the provision of health care requires that standardisation of services be in place. This will enable monitoring of quality of services.

Defilipi et el assert that:

"In the interests of balancing coverage with quality care in this scenario, minimum standards must be complied with and monitoring and evaluation should become the norm rather than the exception."

It is thus recommended that APCA intensifies efforts to develop palliative care standards which can be used by service providers at all levels including the community.

14.4 Designing strategies that address economic empowerment of PLWHA, their extended families and communities.

It was noted that the needs and concerns of PLWHA were shifting from medical care to economic empowerment. This was echoed in all the programmes and at all levels in this review. All the four project countries were resource constrained. There was scarcity of basic needs including food, shelter and transport. These were mentioned as major concerns for PLWHA. While some food supplements were available in some of the programmes, there were no sustainable sources of food and other basic needs for clients.

The volunteers were also part of the same communities as the PLWHA and poverty hindered them from spending more time on voluntary activities. When asked to prioritise their needs, most PLWHA and volunteers listed economic empowerment on top.

Economic empowerment requires a different set of skills and resources. This makes it essential for HBC and PC programmes to collaborate with other sectors.

In the *national guidelines for HBC in South Africa*, it was stated that:

"Home-based care/community-based care cannot be accomplished by only one sector or one type of service."

It is thus recommended that:

HBC and PC programmes be helped in identifying and collaborating with other organisations whose core business is economic empowerment of local communities. One of the skills to be prioritised in training should be networking.

14.5 Strengthening operational research including M&E in the area of HBC and PC

In this review, it was noted that there were observations such as improved social, psychological and physical wellbeing of PLWHA, reduced death rates and reduced stigma. However, there was a universal lack of systematic examination of these observations. Some of the HBC services had even been started without any baseline surveys or situation analyses. The observed effects of HBC and ARVs on the wellbeing of the PLWHA were based on impressions of relatives and service providers.

This called for promotion of operational research including monitoring and evaluation activities in HBC and palliative care services. Results of M&E would be used to make informed decisions to improve the HBC and palliative care services.

Evaluation and research results can be used to inform programming about integration of palliative care into HBC for PLWHA (APCA 2007:55).

A requirement for monitoring and evaluation activities should be integrated in the palliative care standards.

14.6 Establishing an inventory of HBC and PC services in Africa.

There was a lack of sufficient inventory and/or resource information on which to base study population and sample in this review. It is recommended that surveys be conducted which will lead to establishing the information and working features of HBC and PC providers in Africa.

The results of these surveys will generate information that can be used in resource mobilisation and planning for the HBC and palliative care services at national level and local levels.

14.7 Establishing Standards

In all the HBC programmes reviewed in the four project countries, some components of palliative care, particularly social psychological support, pain relief using non-opioids and basic nursing care were offered to PLWHA. There, however, were no standards for measuring the extent to which palliative care had been integrated in the HBC services.

Given that the primary care givers of these services (i.e. the family care givers, community volunteers) were lay persons in the field of health care standards will enable technical people and policy makers to monitor the quality of palliative care administered in different services by different cadres of health workers.

"Minimum standards of Palliative care for People Living with AIDS (PWAs) need to be defined and tested for the protection of both clients and carers. … By making use of both the standards and the Audit Instrument, organisations can be assisted to develop and/or evaluate to what extent they are providing Palliative care (Maston 2000)."

It is recommended that palliative care standards be developed and implemented.

It is also recommended that in the process of developing standards, the fact that the primary care givers of palliative care in HBC services are lay people from the communities, should be taken into consideration.

14.8 Integrating PC more intentionally into HBC programmes

For palliative care access to be rapidly increased, existing HBC services should be guided to integrate all aspects of palliative care in their home based care package.
Defilipi et el state that:

"Many support organisations have networks into the communities and involve caregivers at the village level. Using these community-based organisations (CBOs) is obviously a way to rapidly scale up care of the critically ill and those at end of life within the community."

Existing HBC services provide networks that can be used to increase access to palliative care by communities.

The key role of APCA in facilitating integration of palliative care in HBC services will be the development and implementation of palliative care standards. HBC services can then be encouraged to follow the standards to integrate palliative care in HBC.

Building the capacity of HBC programmes to integrate and implement palliative care is essential.

15.0 Areas that need further studies

Exploring issues that lead to or hinder networking and collaboration in HBC programmes for PLWHA. This will yield information that can be used to develop strategies for integrating HBC and PC.

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