THE UNITED REPUBLIC OF TANZANIA

MINISTRY OF HEALTH AND SOCIAL WELFARE

NATIONAL GUIDELINES FOR HOME BASED CARE SERVICES

National AIDS Control Programme
(NACP)

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ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral Drug
CBO	Community-Based Organization
CCHP	Comprehensive Council Health Plan
CHMT	Council Health Management Team
CTC	Care and Treatment Clinic
FBO	Faith-Based Organization
GDP	Gross Domestic Product
HBC	Home-Based Care
HIV	Human Immunodeficiency Virus
IMCI	Integrated Management of Childhood Illnesses
NACP	National AIDS Control Programme
NGO	Non Governmental Organization
OI	Opportunistic Infection
OVC	Orphans and Vulnerable Children
ORS	Oral Rehydration Salts
PHDP	Positive Health, Dignity and Prevention
PLHIV	People Living with HIV
PMTCT	Prevention of Mother-To-Child Transmission of HIV
RCH	Reproductive and Child Health
RHMT	Regional Health Management Team
TB	Tuberculosis
WDC	Ward Development Committee
WHO	World Health Organization

FOREWORD

The HIV and AIDS epidemic continue to pose a challenge to all sectors in Tanzania. For the past 24 years of HIV epidemic, the country has responded in several ways, including putting in place a series of strategic plans and prevention interventions.

In 1996, the first National Home Based Care Guidelines (HBC) were developed, aiming at providing guidance to managers, health care providers and Home-Based Care providers in the community. In 2004, the National Care and Treatment programme was established, aiming at providing care and treatment to People Living with HIV and AIDS (PLHIVs) in the country. The main focus of the programme is to improve access to ARVs and Home based Care (HBC), for as many PLHIVs as possible. The establishment of HIV care and treatment programme in the country, improved significantly the health of many people living with HIV and AIDS. This is evidenced by a significant decrease in the number of bedridden clients, who need home based care services. These changes in the development and experience in the field of HIV and AIDS care, treatment and support, has deemed necessary for the country to review the HBC guidelines, to reflect the changes that have taken place.

In this edition, all sections have been reviewed to include new information. These sections includes; Introduction to home-based care services, Home Based Care services, Palliative care and chronic disease management, Home Based Care and the continuum of care, roles and responsibilities of different actors, special issues, recording and reporting systems, and referrals system. The section on special issues includes the following sub sections; Prevention, Positive Health, Dignity and Prevention services, gender equity and code of ethics.

These guidelines are intended for a multifaceted audience, that include managers at different levels, health care providers, Governmental and Non- Governmental Organizations and workers from Community Based Organizations (CBOs) and Faith Based Organizations (FBOs). This guideline intends to be used as a reference for those caring for chronically ill patients at home, including People Living with HIV and AIDS.

The Ministry of Health and Social Welfare urges all stakeholders providing Home Based Care services, to use these national guidelines, to ensure that there is the standardization of HBC services in the country and that, they contribute their comments for future improvement of this document.

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SECTION 1: INTRODUCTION TO HOME BASED CARE SERVICES

1.1 Background and target group

Home-based care (HBC) is defined as any form of care given to chronically ill people in their homes. It includes activities that provide physical, psychological, social, and spiritual support (WHO/GPA, 1993). Families are the central focus and form the basis of community HBC.

HBC targets chronically ill patients: those who continue to be ill for more than one month and who need continuous medical attention and management. Chronically ill patients may include adults and children with cancers, HIV and AIDS, sickle-cell disease, cardiovascular diseases, diabetes, and cerebral palsy.

HBC draws on the strengths of families and communities. Its goal is to provide hope through good-quality and appropriate care that helps patients and families maintain their livelihoods and the best possible quality of life (WHO, 1999). Various studies confirm that most people would rather be cared for at home, and that effective home care improves the quality of life of chronically ill people and their family caregivers (WHO, 2000; E. Lindsey, 2002).

For persons with chronic illnesses, a well-functioning HBC programme provides a continuum of care that extends from a healthcare facility to home settings. To be effective, HBC programme must be linked with and integrated into existing district healthcare delivery systems and plans. Effective HBC programmes are also results-based, and the inputs of families, communities, and healthcare systems are essential.

1.2 Rationale for home-based care

The number of people living with HIV and AIDS who require medical attention continues to increase steadily, due to related diseases and conditions and the need to follow up treatment. Among adult patients in medical wards in Tanzania, between 50% and 60% were admitted for HIV-related causes. Other chronic conditions, such as diabetes, hypertension, and cancers, are also on the increase. Many health professionals and public healthcare facilities are overburdened, and it is becoming increasingly difficult for them to provide quality care. In addition, studies among patients with advanced HIV disease showed that many preferred to be nursed at home.

The introduction of antiretroviral therapy (ART) required links to be established with successful HBC programmes that would increase patient identification, adherence to treatment, and patient follow-up. Many patients on ART feel more comfortable discussing adherence issues in their home environments and express a preference for less frequent clinic visits.

A significant number of patients were referred to HIV care and treatment clinics (CTCs) in an effort to provide comprehensive support across a continuum of care.

Tanzania's *Health Sector HIV and AIDS Strategic Plan II, 2008–2012* calls for the provision of quality HBC services in all districts. National HBC guidelines focus on provision of quality care to PLHIV and other chronically ill patients, outlining the establishment and management of HBC services, a training curriculum for service providers, supportive supervision tools, and a monitoring system.

Intensified efforts must be made to identify PLHIV in need of services to meet the goals of the National HIV and AIDS Care and Treatment Plan. People in both urban and rural areas need to be sensitized on HIV testing and counselling so that those in need of care, treatment, and support can be linked to appropriate services, including HBC.

1.3 Benefits of home based care

Quality HBC at various levels provides many benefits for individual patients, families, and communities.
HBC helps health facilities to provide their services more efficiently and effectively, facilitating patient follow-up and adherence support and enabling health facility staff to maintain strong links with patients and with care-providers in communities.

HBC clients receive care and treatment in a familiar, supportive environment that promotes self-care and prevention. They can continue to participate in family matters, and they maintain a sense of belonging within their social groups. At the same time as HBC strengthens family ties and family attachments, it helps family members to accept the patient's condition. Through HBC, family members learn about chronic illnesses and how to provide care and support. They also learn about ways that they can reduce medical and other care-related expenses.

Within communities, HBC promotes care and support for people with chronic illnesses as well as awareness of how to prevent ongoing infection. HBC programmes help community members to understand HIV and other diseases, correct myths and misconceptions about HIV and chronic illnesses, and works to reduce stigma. Community support also encourages sustainable care and support services.

1.4 Guiding principles

The following are considered as essential to the design, implementation, recording, and reporting of HBC programmes, which should target all people who are chronically infected, ill or bedridden to avoid discriminating by patient categories and stigmatizing PLHIV.

- HBC programmes should be *comprehensive.* They should include medical and nursing care, legal advice, referrals, and emotional, socioeconomic, and spiritual support.
- HBC programmes should be *provided along a care continuum* and linked with facility-based and other related services. A continuum of care provides comprehensive care and support and links health-facility services with services in the community and in the home.
- HBC programmes should be *integrated with appropriate prevention activities*. These include the provision of Positive Health, Dignity and Prevention packages (PHDP) for PLHIV and care services for orphans and vulnerable children.
- HBC programmes should be *family-centred.* Family or household members are key actors and they are supported by the programmes.
- HBC programmes should be *owned by communities.* Community members are involved in the programmes and participate fully in their planning, implementation, and monitoring.

1.5 Overview of HIV and AIDS

1.5.1 Epidemiology

HIV and AIDS are a major global health problem. Worldwide, an estimated 33.2 million people were living with the infection at the end of 2007. Sub-Saharan Africa is the world's most severely affected region, where 1 in 12 adults is reported to be HIV-positive. Though the region has only 10% of the world's population, it shelters about two-thirds of the global number of people living with HIV and AIDS. Though there are now reports of declining trends in HIV incidence in a number of countries—presumably due to changes in behaviour and prevention programmes—the number of PLHIV continues to rise with population growth and the life-prolonging effects of ART.

After the first three AIDS cases were reported in Tanzania in 1983, the HIV epidemic spread rapidly to all districts and communities and affected all sectors of the society. In 2003, a total of 18,929 AIDS cases were reported to the National AIDS Control Programme (NACP) from 21 regions, bringing the cumulative total of reported cases to 176,102. In 2007, about 2 million persons in Tanzania were estimated to be living with HIV and AIDS and approximately 600,000 (or 30%) were in need of ART.

Sexual intercourse is the main mode of transmission. Recent data from household surveys estimate seroprevalence at 5.8% in adults ages 15–49, the most severely affected age group. There is wide variation across regions, and women are at higher risk of being infected than men.

In Tanzania, as in most sub-Saharan African countries, the HIV pandemic is recognized as a socioeconomic and development problem as well as a major public health concern. According to a study by the Adult Morbidity and Mortality Project, the leading causes of mortality in 2002 in the districts of Hai, Temeke, and Morogoro Rural were HIV/AIDS and tuberculosis (TB).

1.5.2 Impacts of HIV and AIDS

Health impacts: The HIV pandemic has had a profound impact on healthcare systems worldwide, but mostly on those in sub-Saharan Africa, reducing resources for other health problems and unfavourably affecting the quality of services.

HIV and AIDS have also escalated TB rates in sub-Saharan Africa and South East Asia over the past decade, and TB is now one of the principal causes of death in persons with HIV infection. Annual TB notification rates in many sub-Saharan African countries with well-organized programmes have increased fourfold since the mid-1980s, reaching peaks of more than 400 cases per 100,000 individuals. In some countries, up to 70% of patients with sputum smear-positive pulmonary TB are HIV-infected. In Tanzania, records indicate that 45% of HIV-infected individuals are also infected with TB. Most hospital admissions in sub-Saharan Africa are due to HIV-related conditions, and it is therefore very important that all HIV-infected patients be actively screened and promptly treated for TB.

Economic impacts: Poverty powerfully contributes to the spread of HIV and AIDS in Tanzania, and disadvantaged and marginalized groups, including women, youth, and children, are disproportionately affected.

Ill health and death due to AIDS have reduced the agricultural labour force, productivity, and disposable incomes in many families and rural communities. Data from Kagera, initially one of the most severely affected regions, indicated that the annual gross domestic product (GDP) declined between 1983 and 1994 from US$268 to US$91. Although this decline was multifaceted, AIDS is believed to be a major cause. Similar trends of declining GDP associated with reduced agricultural production and an increase in number of AIDS cases were observed in the coastal region of Tanga. Widespread use of and adherence to ART could reverse the economic effects, but data from Tanzania to substantiate this are not yet available.

Nutrition impacts: HIV and AIDS have significant impacts on nutrition at individual, household, and community levels.

At individual levels, HIV has negative effect on food intake, digestion, absorption, and metabolism. HIV-infection increases nutrient requirements and impairs the body’s immune system, thus increasing vulnerability to diseases. If not well managed, HIV infection creates the vicious cycle of malnutrition and disease.

At household levels, HIV and AIDS are likely to diminish the capacity to care for young children or HIV-infected members and the capacity to ensure food security. This, in turn, worsens a household's nutritional status.

At community levels, HIV and AIDS derail community-based interventions and make communities less able to promote sustainable agriculture, food security, and good nutrition. HIV and AIDS are more prevalent in populations where malnutrition is already endemic, so a renewed and priority focus on nutrition is called for. Monitoring and improving nutritional status is a critical challenge for care, treatment, and support programmes. Evidence-based nutrition interventions are a fundamental part of comprehensive packages of care and should form part of all national AIDS control and treatment programmes.

Social impact: HIV is widespread in both urban and rural communities and mostly affects persons at the peak of their sexual and productive lives. The death of a young adult often means loss of a family's primary income-generator. It is estimated that Tanzania has 2 million orphans by 2008

Studies conducted in the Arusha, Kagera, and Mwanza regions show a serious and growing breakdown of social networks that used to sustain African societies and that materialistic practices are on the increase. Orphans are not only subjected to material, social, and emotional deprivation, but they lack opportunities for education and healthcare. Widows and orphans are deprived of their inheritance rights by relatives of the deceased, often due to the application of outdated traditional practices and customary laws. Widows may also be blamed for the premature deaths of their husbands.

1.5.3 Tanzania's national response

The national response to HIV and AIDS has shifted from being solely based on prevention to include more emphasis on care, treatment, and support. In 2004, the Government of Tanzania, in collaboration with partners, initiated a national care, treatment, and support programme. By March, 2010, a total of 648,055 HIV-infected people had been enrolled at 832 health facilities throughout the country. Scaling up ART remains a challenge. Out of the estimated 440,000 HIV-infected Tanzanians who are eligible, 335,292 are currently on ART (NACP, 2010).

More vigorous efforts are needed to promote HIV testing and counselling, reduce HIV stigma among the general population and health professionals, improve the quality and quantity of trained human resources, improve the management and supply of antiretroviral drugs (ARVs), and integrate HIV care with TB care, Reproductive and Child Health and other health services.

SECTION 2: HOME BASED CARE SERVICES

2.1 The minimum package for HBC services

When setting up a HBC programme, it is important to consider and include the following service components for the affected client and family or household members, a minimum package that may be provided either directly by the programme or indirectly, through effective linkages and referral systems:

- Medical and Nursing care
- Identification of infected family or household members through HIV counselling and testing and early infant diagnosis
- Adherence counselling and support
- Effective referral systems, including referrals to CTC, TB services, reproductive health and family planning services, and social and legal services
- Nutritional guidance and support and food security
- Emotional support
- Palliative care, including pain management
- Healthcare and emotional support to meet specific needs of children and adolescents
- Socioeconomic support
- Spiritual support
- PLHIV involvement and participation in programmes
- Male involvement and participation in programmes
- Care for carers
- A national recording and reporting system
- Positive Health Dignity and Prevention (PHDP) packages that foster prevention for positives, equal rights, and healthy living

2.2 Needs met by HBC programmes

HBC programmes will ensure that clients' physical, emotional, social, and spiritual needs are met, either by the HBC providers or through linkages with other services.

2.2.1 Physical needs

- Symptom management (including vomiting, breathlessness, nausea, and itching)
- Nursing care
- Treatment of opportunistic infections (OIs)
- Screening for TB for adults and children
- Adherence to treatment
- Provision of prophylaxis such as cotrimoxazole and INH
- Pain management
- Basic hygiene and sanitation
- Safe food and water
- Nutritional support, including infant feeding counselling
- Safe shelter
- Rehabilitation support (including physiotherapy, occupational therapy, and physical exercises to prevent bedsores and other problems)
- Wound care
- Mouth care
- Skin care
- End-of-life care
- Treatment of sexually transmitted infections (STIs)
- Demand assessment for family planning
- Screening for pregnancy and referrals for services that prevent mother-to-child transmission (PMTCT) of HIV where necessary
- Drugs, supplies, and equipment for home-based palliative care

2.2.2 Emotional needs

- Emotional support
- Assistance with problem-solving
- Disclosure support for adults, adolescents and children
- Treatment for depression or anxiety
- Mental health services
- Bereavement counselling
- Referrals to support groups
- Psychological support for infected and affected adults and children
- Facilitation of communication and improved relationships within families
- Substance-abuse counselling

2.2.3 Social needs

- Recreation
- Social support
- Legal support
- Future planning
- Income generation
- Reduction of stigma and discrimination
- Rights education
- Vocational education

2.2.4 Spiritual needs

- Spiritual counselling and support
- Religious services
- Rituals (as requested)
- Prayers (as requested)
- Funeral arrangements

- Life review
- Life-completion tasks

2.3 Factors for identifying patients eligible for HBC services

Community HBC service providers who are unable to conduct clinical diagnoses can use the following criteria to register clients in HBC programmes:

- Loss of more than 10% of body weight without intention within three months
- Failure to gain weight among children
- Recurrent fevers in a period of not less than one month
- Oral thrush
- Recurrent or chronic ulcers and sores in the mouth and throat
- Pulmonary TB in the past 12 months and children with TB household contacts
- Chronic cough
- Recurrent skin infections and boils
- Chronic genital ulcers
- History of herpes zoster
- On prophylaxis or treatment with ARVs
- Clients identified as HIV infected or HIV exposed infants through any testing site
- Suspected or known case of cancer
- Insulin-dependent diabetes
- Any chronically ill patient

After using these criteria to identify patients, HBC providers should refer them to CTCs for further evaluation.

2.4 Potential HBC services for PLHIV

With availability of ARVs, HIV has become a manageable chronic condition and the needs of PLHIV have changed. Table 1 outlines the type of services to be provided to PLHIV at three stages: pre-ART, during ART, and at end of life. The assumption is patients have reached these stages because they have been referred to a CTC and initial assessments are complete.

Table 1. Potential services for PLHIV during three stages

	Services during each stage		
Care component	**Pre-ART**	**ART**	**End of life**
Medical and nursing care	o Prepare clients and family for ART and manage expectations o Assist clients to identify treatment assistants o Prepare clients for adherence before ART initiation o Provide education on ARVs and drugs to treat OIs o Manage symptoms, including pain o Refer to CTCs for further management o Discuss drug-storage issues o Provide OI prophylaxis as per national guidelines o Provide health education on HIV prevention and behaviour-change messages o Provide positive health dignity and prevention services o Screen for TB and refer clients to TB clinics	o Continue providing information and training to clients and treatment assistants on care and support, including ART adherence o Recognize side effects (including pain) and take appropriate actions o Follow up clients who miss appointments and have been lost to follow-up and refer them back to CTCs o Provide positive health dignity and prevention services o Refer client to RCH clinics for IMCI, PMTCT, pregnancy, and family planning services o Provide health education on HIV prevention and behaviour-change messages o Monitor and ensure availability and safe	o Provide nursing care o Assess for mental illness interventions and refer when necessary o Assess, prevent, and treat pain and other symptoms o Assess and treat medicine side effects o Provide equipment and supplies that promote comfort and mobility o Educate family members on hygiene o Provide information about death and dying

	o Refer PLHIV to reproductive and child health (RCH) clinics for integrated management of childhood illnesses (IMCI), pregnancy care, PMTCT, and family planning services o Provide services in column 3 for patients in failing health	storage of ARVs, working with patients and treatment assistants	
Psychological support (includes emotional and spiritual support)	o Provide emotional and coping support o Promote disclosure of HIV status o Promote testinh for HH members including children o Support positive living o Sensitise on stigma and discrimination reduction o Provide spiritual and bereavement support o Refer to PLHIV support groups	o Provide supportive counselling o Assess all factors that hinder adherence to ART and provide support o Provide psychological and coping support o Promote disclosure of HIV status o Support positive living o Sensitise on the importance of reducing stigma and discrimination o Provide spiritual and bereavement support o Refer to PLHIV support groups	o Provide emotional and psychological care and support o Address spiritual needs o Provide bereavement counselling o Support family members to prepare for and cope with the dying process o Provide age-appropriate emotional support for children
Nutrition	o Assess and monitor nutritional status (body mass index, mid upper-arm circumference, weight for age and height if possible, and dietary history) o Provide nutritional counselling o Promote healthy eating and balanced meals o Promote planting of vegetable gardens o Provide and/or refer to	o Same as those provided during the pre-ART stage o Advise on dietary management of drug side effects o Advise on dietary management of non-communicable diseases affecting patients, such as diabetes and hypertension	o Same as those provided during pre-ART and ART stages o Provide therapeutic diet

	organizations that provide nutritional care and support services including food support o Provide any needed nutrient supplements o Assist with dietary management for HIV and AIDS-related conditions		
Socioeconomic support	o Link household members to microfinance credit services o Screen for social problems and link household members to relevant services o Link household members to education and vocational training o Screen for abuse and promote protection of the vulnerable o Mobilize and promote community awareness of HBC programmes o Assist with a hygienic and safe household environment o Promote efforts to reduce stigma and discrimination o Assist in accessing grants for children o Link households to safe water and sanitation systems and programmes o Provide social support to isolated clients o Provide services in line with cultural and social norms and values o Increase community awareness of the needs of PLHIV and the chronically ill	o Same as those provided during the pre-ART stage	o Same as those provided during pre-ART and ART stages o Leverage financial support for funeral costs

Legal support	o Link households to paralegal or traditional legal services, including planning support for surviving children and dependents, including information on will writing and inheritance rights o Monitor cases of abuse and discrimination and follow-up	o Same as those provided during the pre-ART stage	o Same as those provided during the pre-ART and ART stages o Assist with carrying out wishes expressed in wills, including property and guardianship provisions

2.5 Home based care kits

HBC providers at facility and community levels are required to manage common minor illness as well as distressing symptoms, including pain. It is important that these providers are supplied with HBC kits for use during home visits to their patients. The kits are of two types, and their drugs and related supplies differ. The first type is used by trained health workers who may be providing HBC services and may be also supervising community HBC providers. The second type is used by trained community HBC providers. HBC contact persons at healthcare facilities monitor the use of drugs supplied in these kits.

2.5.1 HBC kit for a health worker

Drugs and non-prescription items

1. Co-trimoxazole 400mg/80mg
2. Co-trimoxamozole 200mg+40mg/5ml, 100ml pwd for susp.
3. Paracetamol 500mg
4. Paracetamol syrup 120mg/5mls, 60ml
5. Miconazole oral gel
6. Clotrimazole cream
7. Amoxillin 250mg capsule

8. Amoxillin 125mg/5ml 100mls
9. Ferrous sulphate + folic acid tab 200+ 25mg
10. Acetylsalicylic acid (ASA) 500mg
11. Chlorpheniramine maleate 4mg
12. Oral rehydration salts
13. Artemether + lumefantrine
14. Vitamin B complex
15. Vitamin A 50000IU capsule
16. Albendazole 200mg
17. Metronidazole 200 mg
18. Metronidazole suspension
19. Promethazine
20. Diclophenac sodium 25 mg enteric coated
21. Hydrocortisone acetate 1% skin ointment 15 mg

Renewable supplies

1. Examination gloves latex disposable large
2. Examination gloves latex disposable medium
3. Toilet soap or antiseptic soap
4. Sodium hypochloride (Jik)
5. Cotton wool absorbent 500g
6. Cetrimide 15% + chlorhexidine gluconate 1.5% 5 litres
7. Hydrophylic gauze 90cm x 91m BP heavy (17g/m2)
8. Gauze absorbent BPC 90cm x
9. Adhesive wound plaster 5 cm x 5mt.
10. Condoms (male and female)
11. Packages of food by prescriptions
12. Micronutrient tablets
13. Wooden tongue depressor

Equipments

1. Standard scissors
2. Forceps artery Pean 18cm straight
3. Forceps dissecting, dressing spring type
4. Gallipots
5. Kidney dish stainless steel 24 cm
6. Thermometer auxiliary clinical flat type
7. Apron (plastic)
8. HBC bags
9. Umbrella (foldable) and gum boots
10. Blood pressure machine
11. Stethoscope
12. Penile model
13. Torch with battery
14. Rubber sheet

2.5.2 HBC kit for a trained community volunteer

Drugs and non-prescription items

1. Paracetamol 500mg
2. Paracetamol syrup 120mg/5mls, 60ml
3. Miconazole oral gel
4. Clotrimazole cream
5. Acetylsalicylic acid (ASA) 500mg
6. Oral rehydration salts
7. Vitamin B complex

Renewable supplies

1. Examination gloves latex large disposable large
2. Examination gloves latex large disposable medium
3. Toilet soap or antiseptic soap
4. Cotton wool absorbent 500g
5. Cetrimide 15% + chlorhexidine gluconate 1.5% 5litres

6. Hydrophylic gauze 90cm x 91m BP heavy (17g/m2)
7. Gauze absorbent BPC 90cm x
8. Adhesive wound plaster 5 cm x 5mt.
9. Sodium hypochloride (Jik)
10. Vaseline petroleum jelly
11. Condoms (male and female)

Equipments

1. Torch with battery
2. Rubber sheet
3. Standard scissors
4. Thermometer auxiliary clinical flat type
5. Apron (plastic)
6. HBC bags
7. Umbrella (foldable)
8. Penile model

2.5.3 Storage and provision of drugs and supplies for HBC kits

Drugs and supplies for HBC kits will be stored at the health centre or dispensary where the HBC provider is based. The health facility's pharmacy will be responsible for maintaining stock records and supply levels, including for buffer stock.

The designated HBC contact person at the health facility will be responsible for obtaining drugs and supplies from the pharmacy and for providing the drugs and supplies to HBC volunteers. Drugs and supplies will be maintained at a specific level, according to a developed imprest plan. On a weekly basis, HBC volunteers will replenish drugs and supplies up to imprest level, receiving them from the HBC contact person at the health facility.

SECTION 3: PALLIATIVE CARE AND CHRONIC DISEASE MANAGEMENT

3.1 Palliative Care

Palliative care is a holistic approach that improves the quality of life of patients and families facing problems associated with life-threatening illnesses. It is patient- and family-centred care, based on a partnership between care providers, patients, and their families. Delivery of services is organized from diagnosis through death and bereavement, and the preferences and values of individuals are respected to the maximum degree possible.

Palliative care affirms life and regards dying as a normal process, while enabling accurate assessment and appropriate treatment of pain and other problems, including physical, psychological, social, nutritional, or spiritual difficulties. Many aspects of palliative care are applicable early in the course of a serious illness.

There are many reasons why palliative care is relevant to the management of chronic disease and to HIV. Despite advances made in ART, mortality remains high, and quality palliative care is required for those without access to ART. Side effects related to ART can be managed through palliative care, and palliative care can help support adherence to ARVs and increase quality of life. The experience of distressing pain and symptoms occur throughout the chronic-disease trajectory, and simple palliative care strategies to prevent and manage these problems significantly improve people’s lives.

3.1.1 *Palliative care and its role in HBC*

The main aim of palliative care through home-based care provision should be to improve quality of life. They remove or alleviate unpleasant symptoms and help to protect patients from experiencing physical, spiritual, social, and emotional pain, including suffering caused by fears, loneliness, unrelieved physical symptoms, and difficulties in communicating concerns. Palliative care should neither hasten nor postpone death. A team approach is used to address the needs of patients and their families, including bereavement counselling.

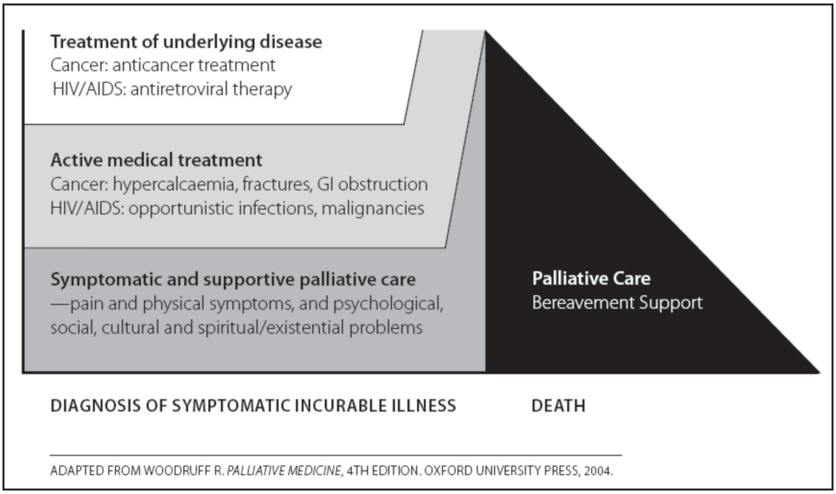
Palliative care should aim to

- Enable good communication within families
- Provide relief from pain and other distressing symptoms
- Integrate the psychological and spiritual aspects of patient care
- Offer a support system to help patients live as actively as possible until death
- Offer a support system to help families including children cope during patients' illnesses and during bereavement

The HBC provider applies palliative care principles in the home, with the support of health professionals at health facilities. Training is required to enable HBC providers to deliver effective palliative care that is patient-focused as well as family-focused. Working as part of a multidisciplinary team, providers of home-based palliative care

- Conduct holistic assessments and develop comprehensive care plans
- Support and provide pain management and symptom management
- Offer counselling and problem solving
- Refer where appropriate
- Administer drugs for symptom relief and monitor side effects

Fig. 1. The integrated continuum of treatment and palliative care



ADAPTED FROM WOODRUFF R. *PALLIATIVE MEDICINE*, 4TH EDITION. OXFORD UNIVERSITY PRESS, 2004.

3.1.2 Paediatric palliative care

Often the palliative-care needs of children are ignored, primarily due to lack of training for care providers. However, palliative care for children is just as important as palliative care for adults. The same holistic and multidisciplinary approach is required, but it must be appropriate to a child's stage of development and illness. In addition, the palliative care team must include members who are knowledgeable about paediatric medicine and the social, emotional, and spiritual needs of children.

There are other important differences between adults and children that affect providers' decisions related to palliative care:

- Children need special attention since they depend on adults for care. The adults they depend on need to be identified, counselled, oriented, and educated on HIV prevention, and on care-giving and support for treatment adherence.
- Children's best interests and protection need to be considered, especially where there may be an abusive home environment.

- Special attention needs to be paid to how children communicate, especially when they are very young. Especially for pain management, it is vital to become familiar with patterns and indications in non-verbal children. Often, communicating with children requires the use of stories, drawings, dancing, and drama.
- Emotional, social and spiritual support to children is very important. Bereavement counselling and succession planning should be an intrinsic part of psychosocial support for children living with HIV and their families.
- Disclosure of HIV status to children should be handled with care. It has to be a gradual process, tailored to the child's understanding and with parental consent. The disclosure should preferably be communicated by parents.
- Children need care and treatment as much as adults. Often the pain they experience is under-diagnosed.
- Children need to be encouraged to participate in decisions affecting their care, according to their age and levels of understanding.
- Specific needs of adolescents and young people should be planned for and addressed.
- Every child or young person should be given support to access education and opportunities to play and interact with siblings and friends. This applies to children who are palliative-care clients as well as child carers who are looking after an ill family member in the home.

3.2 Chronic disease management

HBC supports and applies the principles of chronic disease management: self-care by the patient and ongoing, proactive, and planned lifelong management of the disease across the continuum of care. In the case of HIV/AIDS it may result with the support of ART in manageable lifelong infection and restoring productivity and health. Chronic disease management and palliative care work hand–in-hand to support the patient whose life could be limited by disease but in the case of HIV/AIDS becomes more hopeful with the availability of anti retroviral therapy. HBC plays the central role in applying the principles of chronic disease management.

At different care levels, the following should be taken into consideration when planning and implementing services relating to chronic disease management:

- Active patient involvement is essential. Patients with chronic diseases must develop knowledge on self-care and treatment skills that optimize their roles and benefit treatment outcomes. Children on ART can become productive adults given support and education.
- The involvement of one or more "significant others" (such as a spouse, life partner, or family member) is also essential to assist care providers, observe timely drug intake, maintain appointment schedules, and identify side effects early. All patients should be encouraged to identify a "buddy" in each household to whom they would disclose their HIV status. The care provider counsels these buddies to equip them to support treatment adherence and monitor therapy. Infected children need someone to administer treatment who also needs support. The "significant others" will help to reduce stigma. For orphans, a family care provider need to be identified and referral made to orphan support programs.
- A team approach is needed to foster the development of patient's self-management skills and promote openness and reduce stigma. A team could include HBC team members including a clinician who can prescribe, a nurse-counsellor, PHLA volunteer and community or social workers together with the home care providers.
- A functional referral system is important across a continuum between institutions and community organizations providing non-medical services, such as PLHIV support groups,

home care, and social support. Regular meetings between these actors build partnerships and allow multidisciplinary teams to discuss organizational issues, review treatment and adherence to protocols, provide care and support to care providers, and address stigma-related issues.

- Ongoing chronic-care management involves regular home visits from HBC support team members, who monitor disease status and treatment outcomes and provide ready responses to emerging health and psychosocial issues.
- Ongoing, easily retrievable documentation and records of patient visits should be maintained. Standardized clinical monitoring of records and flow charts will streamline recordkeeping and facilitate data retrieval.
- Support for care-team members is essential to provide quality care, maintain morale, and prevent burnout.

SECTION 4: HOME BASED CARE AND THE CONTINUUM OF CARE

4.1 Definition and rationale of the continuum of care

The continuum of care is a set of comprehensive and linked care, treatment, and support services provided at all levels: from health facility to community to home. Services are provided by the government, NGOs, community-based organizations (CBOs), faith-based organisations (FBOs), community members and by PLHIV and their family members.

The needs of PLHIV and households affected by HIV and AIDS change over time, as infection might progress to illness and advanced disease. Care and support programmes are developed as a response to these psychological, social, nutritional, legal, clinical, and nursing-care needs and demands. Needs are determined by both biological and environmental factors. In resource-rich and resource-constrained settings alike, environmental factors include stigma, discrimination, fear, neglect, and impoverishment, within communities, workplaces, and healthcare settings. Thus HIV and AIDS care interventions cannot operate in isolation; they must be embedded into programmes within health facilities, communities, workplaces, and households.

In Tanzania and other countries in sub-Saharan Africa, clinical and psychosocial interventions have been shown to be more effective and sustainable if they are built upon a foundation of mutual trust between programmes and facilities and then followed up by community care programmes. The fulfilment of these conditions constitutes the continuum of care for PLHIV.

Fig. 2. Holistic needs of PLHIV

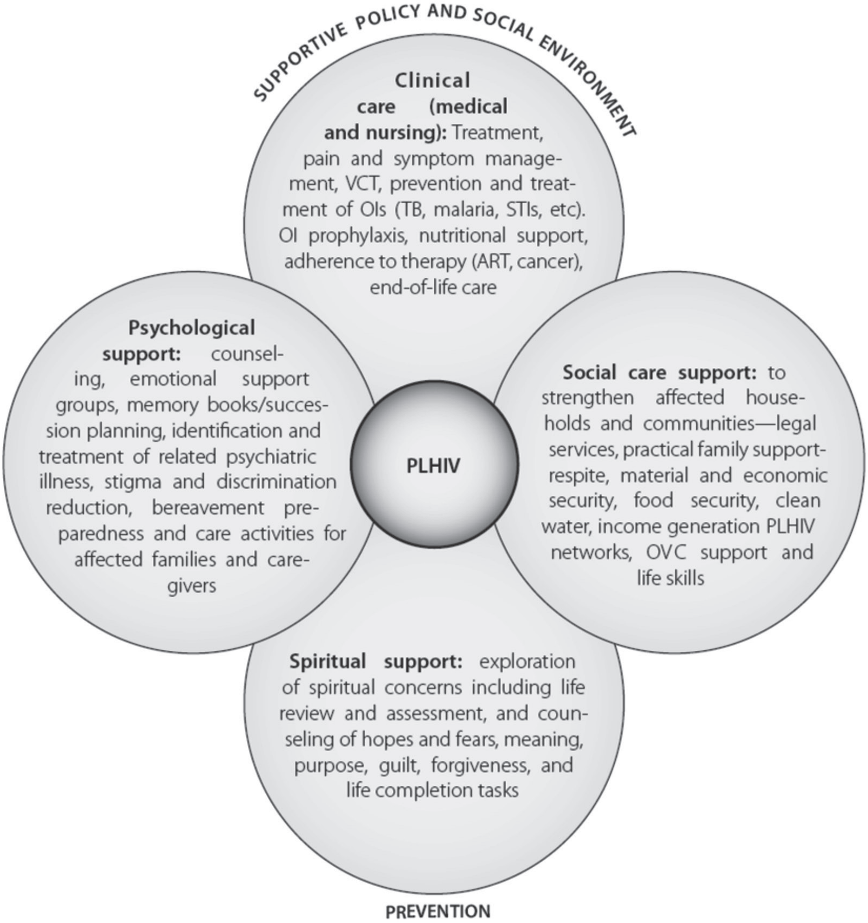


Fig. 3. The continuum of care

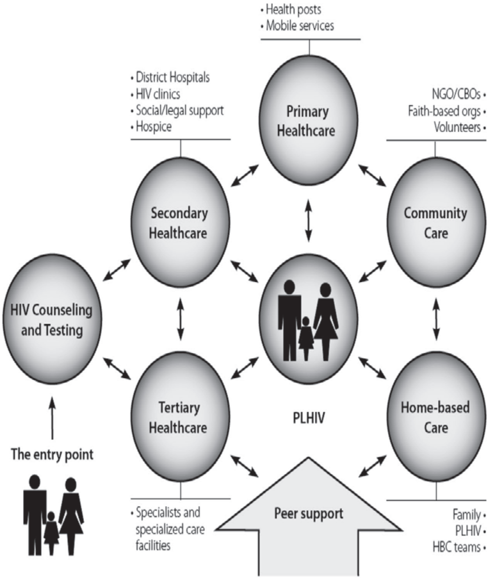


FIGURE 1. THE CONTINUUM OF CARE is a set of comprehensive and linked care, treatment, and support services provided at all levels, from health facility to community to home. Services are provided by government, NGOs, community and faith-based organizations, PLHIV, and family members. Palliative care is offered throughout the entire continuum.

ADAPTED FROM FHI PUBLICATION, HIV/AIDS AND SEXUAL TRANSMITTED DISEASES, WHO

ADAPTED FROM FHI PUBLICATION, HIV/AIDS AND SEXUALLY TRANSMITTED DISEASES, WHO, 2007.

4.2 Referral and networking systems

HBC services are to be perceived as part and parcel of the continuum of care and the provision of support at different levels. An effective continuum of care requires that a functional network and referral system is in place to improve access to appropriate services for chronically ill patients at all times. Through an effective and functioning referral system, these patients will continue to receive relevant services within their respective communities and homes after being discharged from healthcare facilities, and they can revert back to facility care as and when needed.

To enhance this system, service providers must ensure that the national HBC referral forms are used in all referrals. The provider receiving the referral form must also ensure that the feedback portion is filled in and returned to the referring provider.

The health referral system in districts has four levels: (1) the community (2) the dispensary, (3) the health centre, and (4) the district hospital. Patients are referred up as well as down through these levels, though lower levels can be bypassed for higher levels in the event of emergencies and accidents.

Referrals of HBC clients will depend on what their needs are and what is available to them in their communities by way of spiritual, legal, income, nutrition and food, and socioeconomic support. These support services should be known at all levels and form part of a networking mechanism. A service directory and referral network must be developed by service providers to enhance this referral system.

4.2.1 Referral systems in districts

Tanzania's *Health Sector HIV/AIDS Strategy II (2008–2012)* requires that the following linkages and referrals between healthcare facility services and community services are established to provide care, treatment, and support for PLHIV:

- From district hospitals, PLHIV and chronically ill patients will be discharged directly to the nearest catchment health facility where a HBC service contact person is located. In most cases, this will be a dispensary.
- All relevant information, including diagnosis and instructions on the current management and treatment of the condition, should be summarized on the referral forms and handed over to the receiving service provider or contact person.

- In turn, the contact person at the health facility will introduce the patient to the respective community HBC provider for follow-up, care, and support at the household level.
- If the patient requires a referral to a higher level of healthcare, the community HBC provider will supply it.
- All four levels in the network should ensure that referrals are properly reported and feedback is provided promptly to referring sites.

SECTION 5: ROLES AND RESPONSIBILITIES

Important HBC roles and responsibilities reside at the central level, health-facility levels, and community levels, as well as at patient and household levels. Standardization is mandatory to ensure the continuum of quality healthcare from health facility levels to household levels.

The provision of care and the quality of care are affected by many factors, including those related to the client, the family, the community HBC provider, the health facility, the HBC contact person, and the organization or group involved in home-based care, whether a CBO, NGO, or FBO. To get optimum benefits from HBC services, each of these actors at different administrative levels is required to perform the respective roles and responsibilities outlined in this section.

5.1 Family teams

The family team is a key actor implementing HBC services. Teams comprise patients and their family members, and each includes an adherence assistant. Family team members respect patients' rights and seek informed consent whenever appropriate.

5.1.1 Cients

Clients receiving HBC services will be expected to

- Take their medicines accordingly
- Keep to required schedules for CTC visits
- Report any complications and side effects
- Appoint adherence assistants and keep in regular contact with them
- Cope with their illness and maintain healthy practices appropriate to their conditions

- Prevent transmission of HIV infection to others
- Reveal their serostatus to close family members
- Prepare any last wills and testamentary documents that may be required

5.1.2 Adherence assistants

Adherence assistants are selected by patients or in case of children by the care provider, to assist them in ensuring that they follow their prescribed drug regimens. They may or may not be family members. Adherence assistants must

- Accept this responsibility and be on hand at the times when the patient needs to take drugs
- Discuss the drug regime with the HBC provider and the client and set up a routine that can be followed
- Assist in making the drugs available to patients, along with the water they need for taking the drugs
- Be knowledgable about drug administration to infected infants and children

5.1.3 Family members

Family members are seen as the main actors providing high-quality HBC services for patients at home. They choose from among themselves at least one person who will be mentored or coached on specific elements of care. However, it is essential that more than one family member is informed about how to care for chronically ill patients and PLHIV to assure continuity if the chosen care-provider is absent.

Family members need to

- Be counselled about the patient's illness being it adult, adolescent or child and informed about infection: the cause, signs and symptoms, treatment adherence, possible side effects, special needs for infected children and counselled about prevention of transmission

- Ensure that men are actively and directly involved in the care and nursing of chronically ill family members and do not leave all the chores to women in the household
- Provide patients with adequate, balanced diets
- Nurse and comfort patients according to their conditions
- prevent complications and potential OIs such as TB
- Link with community HBC providers for support and referrals
- Alleviate pains and discomfort as much as possible
- Inform and involve children appropriately

5.2 Community HBC providers

Community HBC providers shall provide health care support to families with chronically ill patients and train families on how to care for them. Community HBC providers shall also engage in awareness-raising and mobilisation to encourage stigma reduction, as well as community involvement and participation in the provision of quality HBC services. The providers shall also ensure that food security for HIV-affected households is a permanent agenda item in meetings of ward development committees and village governments.

Community HBC providers shall provide patients with the following services, including those listed in the HBC minimum package:

- Nursing care
- Feeding
- Nutritional care and support (education, counselling, nutritional assessments, and attention to household food security)
- Alleviation of pain and other distressing symptoms
- Spiritual and emotional support
- Prevention of OIs
- Detection of complications and danger signs

- Linkages to healthcare facilities and other relevant services in the community
- Support for adherence to medication and clinic visit schedules

To deliver these services, community HBC providers require the following tools and supplies:

- Appropriate reading materials and job aids
- HBC notebooks for recording patients receiving services
- Monthly summary and report forms
- Required stationery
- Drugs and supplies, as per the HBC kit

5.2.1 Selection criteria for community HBC providers

Community HBC providers work under difficult conditions and for long hours, and they have access to sensitive and confidential information while performing their duties. Consequently, only persons of sound integrity who can maintain confidentiality should be considered for the task. They should also know how to read and write.

To be entrusted with HBC tasks, communities shall be directed to consider persons who are

- Based in the communities they are going to serve
- Accepted and trusted by community members
- Capable of building good interpersonal relationships
- Interested in caring for sick people
- Willing to volunteer
- Reliable
- Possess coping skills

5.3 Communities

A community is a group of people living in the same geographical area and under the same administrative system who share (more or less) common social and economic conditions. A community is known as a village in rural areas and as a hamlet *(kitongoji)* in urban settings. In a community, most members know one another and have close or wide interaction. They are expected to act together in their common interests. Because HBC services take place in a community, the community must support them with engagement and participation.

Community involvement is a process by which partnerships are established between the public sector and local communities that plan, implement, monitor, and evaluate development projects and activities executed within communities. Genuine community involvement is an essential prerequisite for successful implementation of HBC activities. To be genuine, the involvement must be on voluntary base. There should also be a real devolution of authority, power, and responsibility. Involvement must be also generated and maintained from the village to the national level. Community participation in HBC is the involvement of the community in taking care of PHLIV and chronically ill patients and providing physical, emotional, spiritual, social, and material support for them and their families in their homes.

It is the responsibility of council health management teams (CHMTs) and relevant health facility leadership to introduce the concept of HBC to communities. After this, each community shall identify their HBC needs and develop appropriate plans to address them, guided by CHMT members or relevant personnel from nearby healthcare facilities. Throughout, emphasis is on enhancing community ownership and effective community support for HBC services.

For performance-based implementation of HBC services, assistance shall be provided to communities so they can

- Identify specific needs and resources for HBC services
- Make appropriate decisions on health issues
- Look for local solutions for prevailing health problems
- Identify HBC providers to be trained (in numbers corresponding to community needs and resources) by contact persons at health centres or dispensaries
- Determine appropriate and sustainable ways of motivating and supporting community HBC providers
- Play a role in identifying patients with chronic illnesses who need HBC services and in establishing a system for registering patients
- Plan for home visits, community awareness meetings, and support for referrals (such as transport support)
- Plan for ongoing community involvement and participation to improve and sustain HBC services
- Work towards the reduction of stigma and discrimination at community levels

5.4 Contact persons in healthcare facilities

There should be at least two trained HBC contact persons stationed in each health facility who provide services for HBC providers, patients and families receiving HBC, and communities within the facility's catchment area. They shall be expected to perform the following tasks:

- Train and mentor community HBC providers within the facility's catchment area.
- Supervise community HBC providers, making at least one visit per week to them.
- Compile and use HBC summaries and reports and submit them to district HBC coordinators.
- Join HBC staff where possible to follow up patients discharged from facilities to care at home.
- Counsel patients and families.

- Provide nutrition education to PLHIV and their families.
- Mentor or coach families to provide care and support for patients and children.
- Raise community awareness and mobilize involvement and participation in the provision of quality HBC services and stigma reduction.
- Plan and participate in HIV-prevention activities (Positive prevention for adults and adolescents).
- Ensure that food security for households affected by HIV is addressed at every meeting of village governments and ward development committees.

Where the health facility is providing CTC services, the HBC contact person is required to

- Receive referred clients from the CTC
- Channel received patients to HBC providers or implementing partners in the catchment areas where each patient lives
- Facilitate follow-up of defaulters and missed appointments including mother- exposed child follow up
- Refer clients from CTCs , RCH- and TB clinics to the community and HBC programs
- Keep a directory of care and community services and an up-to-date inventory of all HBC Providers in the various catchments areas
- work within the CTC care and treatment team

Facility-based HBC contact persons require the following tools and supplies to perform these tasks:

- Drugs and supplies, as per the HBC kit
- Appropriate reading materials and job aids, including HBC guidelines
- Supervision checklists and related items
- Monthly summary and report forms
- Stationery

5.5 District HBC coordinators

District HBC coordinators should be stationed at district hospitals, and they shall be expected to perform the following tasks:

- With support from CHMTs, implement district HBC plans, as per policy guidelines.
- Advocate for the integration of HBC activities into comprehensive council health plans.
- Facilitate the establishment of effective district networking and referral systems so patients benefit from a functional continuum of care at facility, community, and household levels.
- With support from CHMTs, organize, coordinate, and conduct required training for personnel to ensure provision of effective HBC services in districts.
- Promote community involvement and participation in HBC activities.
- Regularly conduct supportive supervision and monitor district implementation of HBC services, using supervision checklists.
- With support from CHMTs, ensure the availability of equipment, supplies, drugs, and transport for HBC services.
- Collaborate with CHMTs and health facilities in charge to identify contact persons for HBC at health centres and dispensaries.
- In collaboration with the District AIDS Control Coordinator, compile, analyze, use, and give feedback to health facilities and stakeholders.
- Integrate HBC activities into ongoing programmes being implemented in districts.
- Promote the initiation of community food banks and food baskets.

The following are required by district HBC coordinators to perform these tasks:

- HBC policy guidelines for service provision
- Materials for training facility and community HBC providers
- Resources for supportive supervision, such as transport support and checklists
- Drugs and supplies, as per the HBC kit
- Resources allocated for HBC services, including for training, supervision, coordination meetings, and data management
- Monthly summary and report forms and referral forms
- stationery
- A district service directory and a list of HBC providers at facility and community levels

5.6 Regional HBC Coordinator

Regional HBC coordinator should be stationed at regional Hospitals, and they shall be expected to perform the following tasks:

- Interpret HBC guidelines and ensuring their implementation
- Collaborate with RHMT to coordinate linkages between the districts, the Ministry of Health and Social welfare and development partners.
- Advocate for incorporation of HBC activities into the regional plans
- Collaborate with RHMT to monitor and evaluate HBC plan and budgets in all districts
- Assess training needs for district HBC coordinators
- Ensure and maintain effective linkages and referrals for a continuum of care

- Regularly conduct supportive supervision and monitor implementation of HBC services in all districts in the region
- In collaboration with the Regional AIDS Control Coordinator, compile, analyze, use, and give feedback to districts and stakeholders
- Maintain quality assurance of HBC services
- Provide technical support in HBC to Regions and districts
- Carry out operational research to improve HBC services
- Facilitate efforts to improve nutritional care and support for chronically ill patients including PLHIV
- Planning and implementing HBC sensitization campaigns
- Advocate for community involvement and participation of HBC activities in the districts

The following are required by regional HBC coordinator to perform these tasks:

- HBC policy guidelines for service provision
- Resources for supportive supervision, such as transport and supervision manual
- Monthly summary and report forms and referral forms
- Regional service directory
- Stationeries and computer for data entry

5.7 HBC service organizations

All organizations (including FBOs, NGOs and CBOs) that have an interest in or are providing in-home care for PLHIV and chronically ill patients should be encouraged to perform in the following tasks:

- Provide HBC to PLHIV and chronically ill patients according to the national HBC guidelines.
- Establish effective links with HBC contact persons in health facilities for referrals and supervision.

- Educate communities on the need for HBC services and facilitate the selection of community HBC providers by community members.
- Support and train community HBC providers and facility-based HBC providers to provide quality HBC services according to national guidelines.
- Initiate and support efforts to reduce stigma and discrimination in communities and within families.
- Support the establishment of effective functional linkages and referral systems within districts.

5.8 Religious leaders

Religious leaders are often called upon to provide guidance, counselling, and spiritual support for patients and their families. Where appropriate, religious leaders should be encouraged to

- Continue giving spiritual and emotional support and counselling to patients
- Sensitize communities on health issues and HIV and AIDS
- Sensitize communities about caring for patients at home
- Provide appropriate and correct information to communities about chronic illness and HIV and AIDS
- Strive to reduce stigma and discrimination in communities and within families

5.9 Central, regional, and district administrative levels

5.9.1 Central level

The MOH&SW and the NACP shall be responsible for developing and frequently reviewing

- National HBC service delivery policies to enhance quality of care

- National HBC service delivery and training standards that enhance implementation and monitoring of the services and quality assurance
- Training guidelines and manuals
- Mechanisms for effective linkages and referrals to enhance a continuum of care
- Mechanisms for disseminating and receiving feedback on new policy guidelines and standards
- Mechanisms for coordinating the work of HBC implementing organizations and development partners at the national level
- Mechanisms that are feasible and sustainable to address nutrition care and support for chronically ill patients, including PLHIV

In addition, the central level has responsibility for the following activities:

- Advocating for improved food and nutritional supplement availability as an essential component of comprehensive care and support
- Continuously evaluating reports on HBC service provision to inform future improvements
- Ensuring pre-service training in HBC
- Working towards the incorporation of HBC training in medical, paramedical, and nursing curricula
- Advocating for and driving the integration of HBC services within district healthcare systems and making them part and parcel of comprehensive council health plans
- Carrying out operational research to improve HBC services
- Conducting regular capacity-building initiatives to maintain high staff competence levels

- Conducting regular supportive supervision in regions and districts
- Providing technical support in HBC to regions

The following are required at the central level to fulfil these responsibilities:

- At least four HBC experts and two M&E experts at the NACP
- A multidisciplinary, technical advisory team that has a subcommittee on care and support
- M&E tools, protocols, plans, and guidelines
- Resources

5.9.2 Regional levels

Regional health management teams (RHMTs) have the following responsibilities:

- Interpreting HBC guidelines and ensuring their Implementation
- Coordinating linkages between the districts, the MoH&SW, and development partners
- Incorporating HBC activities into regional plans
- Monitoring and evaluating HBC plans and budgets in all districts
- Assessing training needs for district HBC coordinators
- Ensuring and maintaining effective linkages and referrals for a continuum of care
- Supervising data collection, processing, analyses, and utilization in all districts
- Maintaining quality assurance of HBC services
- Providing technical support in HBC to districts
- Carrying out operational research to improve HBC services

- Compiling and using monthly and annual HBC summaries and reports, submitting them to the MoH&SW, and providing feedback to districts
- Facilitating efforts to improve nutrition care and support for chronically ill patients, including PLHIV
- Conducting regular capacity-building initiatives to maintain staff competences
- Planning and implementing HBC sensitization campaigns

The following are required to fulfil these responsibilities at regional levels

- At least one HBC coordinator at the RHMT level who are preferably trained as medical officers or nursing officers
- HBC guidelines for service provision, training, and supervision
- National recording and reporting tools
- Resources

5.9.3 District levels

HBC services are planned to be integrated in district healthcare systems as part of comprehensive council health plans. Therefore, CHMTs shall be responsible for the following activities:

- Implementing and supervising HBC policy guidelines
- Integrating HBC activities in comprehensive council health plans
- Creating community awareness on the need for and importance of HBC
- Supporting and ensuring community involvement and participation
- Conducting needs assessments to identify gaps and planning for district-responsive HBC services to be integrated into district healthcare delivery systems

- Establishing an effective networking and referral system so patients benefit from a functional continuum of care
- Conducting training for personnel to ensure provision of quality HBC services
- Regularly monitoring and supervising HBC services, especially that occurring in health centres and dispensaries
- Managing regular stocks of essential HBC equipment, supplies, drugs, and transport
- Identifying and training HBC contact persons at health centres and dispensaries and monitoring and supervising their work
- Evaluating HBC services on a regular basis to inform future improvements
- Allocating resources needed for HBC services
- Compiling and using HBC monthly and annual reports, submitting them to regional authorities, and giving feedback to health centres and dispensaries
- Supporting activities directed at improving nutrition care and support of chronically ill patients, including PLHIV, through community mobilization and advocacy
- Building the capacity of technical and management staff
- Ensuring that food security for households affected by HIV is a permanent agenda item during ward development committee meetings
- Conducting periodic mapping of HBC activities
- Developing and updating the district services directory
- Planning and implementing HBC sensitization campaigns

To perform these tasks, CHMTs require the following:

- HBC policy guidelines for service provision, training materials, and manuals

- Items and supplies provided in HBC kits
- Resources such as transport for supportive supervision
- At least two trained HBC providers in each health facility

5.9.4 Health facilities

Health facilities at different levels will have responsibilities related to HBC services, PLHIV, and patients with chronic diseases.

5.7.4.1 Consultant hospitals

Patients with difficult or complicated problems are attended at consultant hospitals and referred back to regional or districts hospital for further management once their clinical conditions have been stabilized.

The responsibilities of consultant hospitals relating to HBC services include

- Providing specialized diagnostic services, such as on viral loads, PCR (polymerase chain reaction), and viral and microorganism resistance
- Initiating treatment until patients are stable
- Providing counselling and discharge planning for patients and skills transfer in these areas for staff of lower-level healthcare facilities
- Referring patients who are in stable condition to their respective districts for further referral to HBC services
- Teaching medical and nursing students about HBC
- Providing technical support for district and regional hospitals within their zones
- Facilitating linkages within and outside the hospital

To perform these services, consultant hospitals should have

- At least two people trained in HBC on staff—preferably a medical officer and a nurse—who will be responsible for linking patients in need of HBC services back to their respective districts and for receiving patients referred from lower levels

- HBC policy guidelines for service provision, recording and reporting tools, referral tools, and service directory

5.9.4.2 Regional hospitals

Regional hospitals will have the following responsibilities:

- Management of complicated referrals
- Specialized diagnostic services, such as CT scans and CD4 counts
- Counselling and testing services
- Technical support for districts
- Supportive supervision for districts
- Referrals of patients in stable condition to their respective districts for further referral to HBC services.
- Linkage facilitation, within and outside the hospital

To discharge these responsibilities, regional hospitals require

- Supervision checklists and HBC service guidelines
- Drugs, supplies, and equipment for discharged patients
- Two people on staff who are HBC contact persons and linked to CTC teams
- HBC guidelines, recording and reporting tools, referral tools, and service directory

5.9.4.3 District hospitals

District hospitals should be able to make diagnosis for most patients referred from the lower levels who are suffering from chronic illnesses. Once diagnosis is made and appropriate management initiated or instituted, patients with chronic illnesses would be discharged from hospital through the HBC system. The tasks of the district hospital will include:

- Implementing and supervising HBC services
- Providing HIV testing and counselling
- Keeping records of patients under care, as per available guidelines
- Mobilizing and allocating resources for HBC services
- Providing specialized diagnostic services
- Facilitating linkages within and outside the hospital

For district hospitals to discharge these tasks, they require

- HBC policy guidelines, supervision checklists, recording and reporting tools, referral tools, and service directory
- At least two trained HBC persons attached to the CTC, preferably a clinical officer and a nursing officer
- Drugs, supplies, and equipment for discharged patients
- Resources
- Stationery

597.4.4 Health centres

Health centres shall implement HBC services, as per policy guidelines. They have the following responsibilities:

- Following up patients discharged from health centres or other hospitals who reside in their catchment areas
- Raising awareness among communities and community leaders and mobilizing them to get involved and participate in provision of quality HBC services and stigma reduction
- Providing horizontal supervision for dispensary contact persons
- Compiling, using, and keeping HBC data

To discharge these responsibilities, health centres require

- HBC policy guidelines, supervision checklists, recording and reporting tools, referral tools, and service directory

- At least two trained HBC persons, preferably a clinical officer and a nursing officer
- Drugs, supplies, and equipment, as per the HBC kit
- Resources
- Stationery

5.9.4.5 Dispensaries

Dispensaries shall implement HBC services as per policy guidelines. They should

- Monitor HBC services, as per guidelines, and report to the district contact person monthly
- Support community HBC providers to enhance drug adherence, especially for patients on ART

To discharge these responsibilities, dispensaries need the following:

- HBC policy guidelines, supervision checklists, recording and reporting tools, referral tools, and service directory
- At least two trained HBC persons
- Drugs, supplies, and equipment, as per the HBC kit.
- Resources
- Stationery

SECTION 6: SPECIAL ISSUES

6.1 Integration

HBC is integrated into the public health system and other services of prevention, care, treatment, and support for families, including those for orphans and vulnerable children. Services provided to families, especially those infected and affected by HIV, need to be linked and provide access to related services.

Where there is counselling and testing for HIV, there must be links with support from within the community. That support is usually provided by HBC programmes. Patients who require interventions at health facilities and other services are often first identified by HBC providers. Among services that should be well integrated within HBC are care and treatment, TB treatment, counselling and testing for HIV, prevention, family planning, and programmes for orphans and vulnerable children. These services are integral to bringing care and support to those in need at the community level.

6.2 Prevention

Prevention approaches and practices are incorporated into HBC services. Prevention cannot be separated from care; they should always operate in synergy. Each care and support intervention offers an ideal opportunity to discuss the prevention approaches that are seen as appropriate for the particular circumstance. Implementing agencies should design a set of practical examples of the type of prevention interventions to be considered during the different phases of care provision.

Some interventions can easily be included in the clinical dialogue; others can be included in ongoing patient and family group education or discussions; and still others are part and parcel of counselling. Support of prevention of ongoing infection is very appropriate for HBC service providers.

6.3 Positive Health, Dignity and Prevention services

For PLHIV, care and support programmes provide essential services and opportunities for achieving optimal health and quality of life. However, HBC programmes should recognize the changing needs of PLHIV.

For example, with improved health on ART, individuals may become more sexually active, and they may have spouses or sexual partners who are HIV-negative. The fact of discordant couples makes addressing the issue of preventing ongoing HIV transmission urgent, along with preventing unwanted pregnancy and STIs. With ART, the potential for HIV to become a chronic condition also impacts care and support services, increasing need to educate and motivate PLHIV to take care of themselves and assume responsibility for managing their own health, including preventing illnesses and ongoing HIV transmission.

A key focus of existing programmes has been to educate, support, and motivate PLHIV to adopt basic lifestyle practices, such as observing good hygiene and eating nutritious food. As ART is initiated and health is restored, these concerns remain vital to the maintenance of good health. Basic prevention services are currently included in the HBC package. Community HBC providers convey safer-sex messages and distribute condoms; they educate on hygiene and sanitation, discuss good nutrition and safe drinking water, and they refer clients to health facilities when needed.

Community HBC providers also have regular contact with their clients; they usually see them more frequently than facility-based providers do. Community HBC providers are known to their clients and their households, and they are trusted members of the same community. Carrying kits with medical supplies and drugs, they are often viewed as the more trusted “extension” of facility-based providers, and the education and advice they convey are considered to have some degree of authority.

Home-based, comprehensive, prevention programming that incorporates PHDP shall strive to reach PLHIV and members of their households, including children. The PHDP approach encompasses three interrelated components:

(1) Preventing the onward transmission of HIV infection

(2) Preventing illnesses, including OIs, malaria, and other diseases

(3) Practicing healthy living

HBC and local PLHIV support groups provide community-based care and support services and offer valuable opportunities to integrate this approach within existing programmes. Community-based PLHIV support groups, many linked with HBC, also provide a broad range of care and support services. Their members serve as role models and supportive peers who advance the benefits of disclosing HIV status. Those well informed about HIV can perform the important role of an “expert patient,” who assumes responsibility for managing his or her own care. When positive prevention is an essential aspect of their lives, members of PLHIV support groups are important resources for their peers on preventing ongoing HIV transmission .

It is essential that HBC programmes for PLHIV fully integrate services that enhance community-based PHDP, building upon, expanding, and systematizing current support for PLHIV through community HBC services and local PLHIV support groups. The aim should be to establish comprehensive PHDP as a standard of the community-based care delivered routinely by these groups. Intended beneficiaries shall be all HIV-infected individuals reached through these services and members of their households. In addition, activities conducted shall focus on HIV-positive youth to ensure that PHDP reaches a population most likely to engage in sexual activity and who can be expected to live for many years after observing PHDP and adhering to ART.

For PLHIV, prevention, care, support and treatment are optimized when service delivery approaches are complementary and mutually reinforcing across a continuum of care. The proposal to integrate PHDP within community-based services aims to promote consistency with facility-based approaches, and thereby continuity between community-based and facility-based PHDP.

6.4 Gender equity

The HBC model requires fair distribution of gender roles and responsibilities. HBC for chronically ill patients, including PLHIV, is a responsibility of the household and/or family, as well as a community responsibility.

However, in current practice, women and girls have heavier workloads in the household, including in patient care, and they provide most of the patient-care services that occur at home. Families and communities should address the gender issues in HBC to ensure that females are relieved of some of their routine activities and that males participate fully in HBC activities, as appropriate and culturally sensitive.

Decisions on the gender-division of labour in HBC should be made by families and communities with due regard to their local conditions and environments.

6.5 Code of ethics

HBC service providers are required to perform their activities in accordance with the ethical requirements of health professionals, within a community context. Ethics are associated with morality and professional conduct with respect to HBC activities in communities.

In providing services to chronically ill patients including PLHIV, it is absolutely necessary that HBC providers work within existing legal frameworks and abide by the following ethical requirements:

- Confidentiality
- Respect for other people
- Commitment to HBC work
- Reliability
- Ability to recognize limitations and seek support where necessary
- Respect for and cooperation with professional staff

HBC clients and their relatives must provide personal information about themselves and their home conditions so their problems and needs can be assessed. Such information should be provided voluntarily, and it should not be used in any way that may inflict harm, injury, or embarrassment to the patients and their families.

At all times, the patient has the right to privacy. Information about patients and their families should not be disseminated without their permission or given to people who are not directly involved in their care or concerned with their welfare. HBC providers should maintain confidentiality and the anonymity of patients' identities and all other information.

The following are important standards:

- HBC services are voluntary and should not be imposed on anyone.
- HBC providers must be reliable people who respect and cooperate with professional orders and work well with other actors in HBC and care and support activities.
- HBC should be pursued so as to provide required care in a home environment, not just as a way to divert the burden of chronically ill patients from hospitals to communities.

- Community HBC providers should not in any way engage in deceitful behaviour. It is completely unacceptable to lie or give wrong information about patient care. In monitoring, supervision, and evaluation, the reporter must be faithful and honest about the information reported.
- A patient's rights, values, and culture should be respected at all times.

6.5 Carers or care-givers

A carer or care-giver is defined as a person with a responsibility for someone whose disability or lack of competence makes him or her dependent on another to accomplish the tasks of daily living. Care-giving in a home environment is a demanding job and requires special skills and support from the formal health sector.

Carers in HBC include healthcare professionals; family members; informal volunteers (family or neighbours); and formal volunteers who are recruited, trained, and supervised by an NGO, CBO, or FBO to provide care services in communities. In HBC programmes, carers are categorized as formal, informal, and family, and as primary or secondary carers. The primary carer is the one responsible for around-the-clock care of the patient, while the secondary carer provides support. Family carers tend to be the primary carers.

6.5.1 Formal carers

In hospital-driven HBC, the health worker is a formal caregiver who provides home care and functions within a formal structure. Usually, the health worker supervises other carers and is responsible for their training (WHO, 2003). The time allocated for home visits and the care process is defined by predetermined terms of reference.

Formal carers can also be volunteers, as long as they have the required training, registration and certification, and supervision.

Formal carers can be physicians, nurses, social workers, or trained community-based health workers.

6.5.2 Informal carers and family carers

In HBC, there are varied definitions of informal carers, including one that centres on whether carers are trained. Carers who are not trained are considered to be informal carers. This definition includes family carers who care for family members in home settings.

However, family carers differ from volunteer carers in that they tend to provide care whether or not they are linked to primary or secondary carers. A primary carer is responsible for around-the-clock care, while a secondary carer provides support. Family carers tend to be primary carers. Some do not make the decision to become a carer, and many cannot conceive of not providing care for a terminally ill or chronically ill family member. When access to healthcare is limited, some family carers provide the only care available for patients with long-term illnesses, especially for PLHIV.

6.5.3 Unlinked carers

A UNAIDS review found that large numbers of community HBC carers are not linked to any programmes. In this scenario (described as unlinked care), carers do not receive training from a formal programme or any material inputs such as gloves or medication. Their related needs go unaddressed, creating undesirable conditions for both the carer and the care recipient.

6.5.4 Gender of carers

For the most part, women and girls are the primary carers in community HBC. In Africa, the evidence shows that it is mostly women who are family carers for PLHIV. It is high time that male involvement in community HBC is given special emphasis.

6.6 Training and skills of carers

The World Health Organization recommends that HBC training include management of common symptoms, supervision and guidance for community workers, palliative care and moral support, support for families to maintain hygiene and nutrition, and linkages to the social welfare system.

Training of family members and volunteers is being precipitated by the increasing reliance of governments on lay people as primary carers of PLHIV in community settings, a phenomenon associated with the loss of human capital in formal health sectors as well as the sheer volume of healthcare needs in HIV-affected communities.

HBC providers should be trained as per national guidelines, and they should be provided with the support they need to have confidence in their abilities to work with the community. Close monitoring and supervision is mandatory.

6.6.2 Informal training of carers

It is recognized that not every carer enters HBC through a formal training process. For some, observation of the care processes and skills used during a family-member's hospitalization offer opportunities for learning (Sankar 1999). In other cases, carers are thrust into the role by circumstances and have no prior training. These carers learn on the job, as do child carers and other unlinked carers.

6.6.3 Support and supervision of carers

Caring for PLHIV at home is a challenging and stressful job, and carers require ongoing support (UNAIDS 2000b). Provision of this support in community HBC is regarded as training for carers and as a way to retain them and a strategy to prevent burnout.

The formal health system and the agencies recruiting and deploying informal carers are seen to be responsible for supporting them. Carers need the following:

- Good training, supervision, and support, as per national and international guidelines
- Ongoing training and new information and skills
- Recognition for their skills and hard work
- Time to meet with other carers and with health professionals (doctors and nurses) in the community
- Job aids and handbooks that help them to do their work well
- Access to trained counsellors for support and help with problem-solving
- Supplies for HBC kits, along with materials such as nutritional supplements (if possible)
- Transportation allowances and/or other ways to reach clients' homes

Community HBC is hard work, and providers usually have other responsibilities—to themselves and to their families. Sometimes community HBC providers feel tired, stressed, and "burned out" from the work they do. Those who feel they cannot meet the needs of their own families and keep up with all their HBC work may come to feel that they cannot continue to provide HBC services. To avoid this situation, carers should learn to take care of themselves and each other.

6.6.4 Carer burnout

One of the major problems faced by all carers is burnout, which occurs when carers feel so weighed down by stress and pressure that they are mentally or physically tired. Carers may be burned out when they

- Feel excessively stressed
- Experience headaches or body aches with regularity
- Feel that no one appreciates their hard work
- Do not sleep or eat well

- Have low energy and feel unhappy or hopeless
- Feel helpless because they cannot meet all the needs of PLHIV and their families
- Feel anger toward PLHIV and their families because of their needs and demands
- Need special support

Local NGO partners and supervisors of community HBC providers should learn to recognize the signs of burnout. Carers should also look for these signs in each other and offer to step in with help.

SECTION 7: RECORDING, REPORTING, AND REFERRAL SYSTEMS

The national HBC recording and reporting system aims to provide information needed for monitoring implementation and making informed decisions on various aspects of service provision for managers, programmers, and HBC stakeholders, including the general public.

The MoH&SW coordinated the development of an M&E system by HBC partners. Ten indicators were selected and agreed upon by all stakeholders. These serve the needs of programme management as well as the reporting needs of national, international, and implementing partners. Recording and reporting tools were designed to be user-friendly and capture only information needed to respond to the indicators.

All levels of the health system are assigned information-handling responsibilities to facilitate ownership and use. The system emphasises dissemination of information and discussions of findings at every level so that implementation constraints are identified in a timely fashion and dealt with at local levels.

7.1 Ten monitoring indicators for HBC services

Implementation and scale-up of HBC services will be monitored using ten indicators in three categories:

7.1.1 Indicators on clients

1. Number of new clients enrolled in HBC services during the reporting period, disaggregated by sex and age group
2. Number of new and old clients receiving HBC service during the reporting period, disaggregated by age group; sex; HIV status (positive, negative, and unknown); and care and treatment status

3. Number of clients ever enrolled in HBC service during the reporting period, disaggregated by sex.
4. Number of clients receiving HBC services in this month e.g medical care, nursing care
5. Number of clients who were enrolled but are no longer receiving services during the reporting period, disaggregated by reason for discontinuing services: died; lost (did not attend clinic for three consecutive months with no explanation); transferred to other HBC service; no longer in need of HBC service; opted out; migrated
6. Number of clients referred to other services during the reporting period, disaggregated by type of referral
7. Number of clients who reported that they received the referred service during the reporting period, disaggregated by type of referral

Indicators on service providers

8 a). Number of individuals providing services during the reporting period, disaggregated by sex; provider type (healthcare worker, volunteer, HBC coordinator); who trained according to national guidelines

8 b). Number of individuals providing services during the reporting period, disaggregated by sex: provider type (Healthcare worker, volunteer, HBC coordinator) who didn't trained according to national guidelines.

Coverage indicators

9 a). Total number of health facilities in the district

9 b). Total number of health facilities which provide HBC services

9 c). Total number of wards which provide HBC services in the district

9 d). Total number of wards in the district

10 a). Total number of districts which provide HBC services

10 b). Total number of districts in the region.

7.2 Recording, reporting, information flow, and use

For the M&E system, there is a recording tool, an HBC-provider notebook, two summarization or reporting forms, a report form and community-level HBC monthly summary, and a health-facility level report form and monthly summarization form.

The notebook is used by the HBC provider to record the condition of clients and the services provided. Each provider routinely fills in client information while providing services. At the beginning of each month, each HBC provider will refer to these records to summarize information for the month just ended. To create community-level HBC monthly summaries, the provider uses a report form that contains indicators.

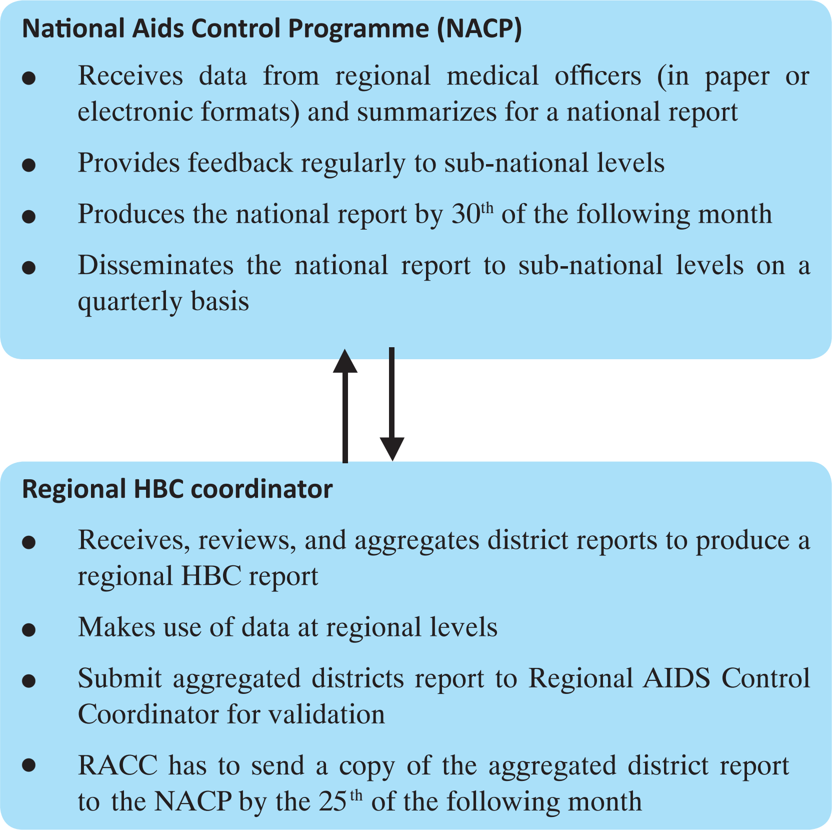
Once the community-level monthly record is generated, the service provider shares it with members of ward health committees and other community leaders, informing them on progress in implementing HBC services and identifying strengths and weaknesses for improvement. By third (3rd) day of the following month, the service provider will also send a copy of the monthly summary or report to the health-facility HBC contact person.

The health-facility HBC contact person will aggregate reports from all service providers in the catchment area, using the health facility-level report form to generate a monthly summarization on indicators in wards or divisions. This report will be shared and discussed by the management team of the health facility and committees responsible for HBC services to identify strengths and weaknesses and improve implementation. The HBC contact person will send a copy of this report to the district HBC coordinator by 10th day of the following month.

The district HBC coordinator will aggregate reports from all facilities in the district to generate a district report. This district report will be sent to the CHMT for discussion and a copy sent to the regional HBC coordinator by the 20th day of the following month.

The regional HBC coordinator will aggregate reports from all districts in the region to generate a regional report, which will be disseminated to the RHMT for discussion and a copy sent to the NACP by the 25th day of the following month.

Fig 4. Information flow for HBC reporting



National Aids Control Programme (NACP)

- Receives data from regional medical officers (in paper or electronic formats) and summarizes for a national report
- Provides feedback regularly to sub-national levels
- Produces the national report by 30th of the following month
- Disseminates the national report to sub-national levels on a quarterly basis

Regional HBC coordinator

- Receives, reviews, and aggregates district reports to produce a regional HBC report
- Makes use of data at regional levels
- Submit aggregated districts report to Regional AIDS Control Coordinator for validation
- RACC has to send a copy of the aggregated district report to the NACP by the 25th of the following month

District HBC Coordinator (under District Medical Officer)

- Verifies monthly summary reports submitted by HBC contact persons and aggregates their information to produce a district report
- Enters patient monthly summary data into computerized systems, if available, for additional analysis and verification
- Submit the aggregated health facilities report to District AIDS Control Coordinator for validation.
- DACC has to send a copy of aggregated districts report to the region by the 20th of the following month

HBC Contact Persons (at Dispensary and Health-centre Levels)

- Receives and reviews monthly patient summary forms and compiles a report
- Uses the information for program me management and planning
- Sends compiled report and monthly patient summaries to the district by the 10th of the following month

Community Home-based Care Provider (Volunteer or Healthcare Provider)

- Enters information on patients in a notebook at each visit
- Completes a patient summary form each month and sends it to the HBC contact person by the 3rd of the following month

7.3 Referral form

The referral form is designed to provide client information, the reason for referral, and the facility or services to which the client is referred. The form can also record information on the person referring the client. A section of the form will be filled in by the recipient and returned to the referring organization as evidence that the client followed up with the referral.

7.4 Training guide

The M&E package consists of a training guide for HBC recording and reporting and referral tools. This guide provides a detailed description of monitoring indicators and tools and guidance on how to fill in each item and generate monthly summaries. The training guide also describes information flow and recording and reporting responsibilities at community, facility, district, regional, and national levels. It shall be used to train HBC providers and coordinators at each level.