THE UNITED REPUBLIC OF TANZANIA

MINISTRY OF HEALTH

GUIDELINES FOR HOME BASED CARE SERVICES

National AIDS Control Programme
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TABLE OF CONTENT

ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ART	Antiretroviral Treatment
ARV	Antiretroviral
BCC	Behavior Change Communication
CBO	Community Based Organisation
CHBC	Community Home Based Care
CHMT	Community Health Management Team
CHW	Community Health Worker
CoC	Continuum of Care
CTC	Care and Treatment Clinic
DHBCC	District Home Based Care Coordinator
DHMT	District Health Management Team
DOTS	Directly Observed Therapy, Short Course
ELISA	Enzyme Linked Immuno-absorbent Assay
FBO	Faith Based Organisation
HAART	Highly Active Antiretroviral Therapy
HBC	Home Based Care
HIV	Human Immunodeficiency Virus
HMIS	Health Management Information System
IEC	Information, Education, and Communication
INH	Isoniazid
M&E	Monitoring and Evaluation
MCC	Medicines Control Council
MCH	Maternal and Child Health
MTCT	Mother-to-Child Transmission
NGO	Non-governmental Organisation
NNRTI	Non-nucleoside Reverse Transcriptase Inhibitors
NRTI	Nucleoside Reverse Transcriptase Inhibitors
NSAID	Non-steroid Anti-inflammatory Drug
OI	Opportunistic Infection
OVC	Orphans and Vulnerable Children

PCP	Pneumonystic Carinii Pneumonia
PCR	Polymerase Chain Reaction
PEP	Post-exposure Prophylaxis
PI	Protease Inhibitors
PLWHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother-to-Child Transmission
PTB	Pulmonary Tuberculosis
RNA	Ribonucleic Acid
STI	Sexually Transmitted Infection
TB	Tuberculosis
THP	Traditional Health Practitioners
TLC	Total lymphocyte count
VCT	Voluntary Counseling and Testing
WDC	Ward Development Committee

Acknowledgement

This document is one of the various guidelines developed by the Ministry of Health (MoH) to support the effective implementation of the National Care & Treatment Plan for People Living with HIV/AIDS. This document serves as an important link in efforts to provide comprehensive care and support for people living with HIV/AIDS in a continuum that spans from the health care facilities, communities and households. Indeed, the document is a result of efforts of many individuals and organizations involved in the response to HIV/AIDS in the country.

This document is based on the earlier HBC Guidelines developed in 1999, and the members who developed it continued to provide technical advice during the development process. The Ministry of Health is grateful for their input. Special appreciation is also extended to the Technical Team consisting of managers and health care providers who reviewed the draft and gave very valuable inputs to concretize it.

The content of the document is based on available World Health Organization (WHO) guidelines and the organization provided a continued technical support towards the completion of the document. The Ministry of Health recognizes this important contribution.

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FOREWORD

Since the development of the "Guidelines for Home Based Care Services in Tanzania" in 1999 a number of very significant developments have happened which necessitate a revision of the document. Among the developments that have occurred are the endorsement of the National Policy on HIV/AIDS (2001), the Health Sector Strategy for HIV/AIDS (2003-2006), the National Care and Treatment Plan and the revision of the standards for care and treatment.

On this basis therefore, it is emphasized that this document should be read in reference to the following list of documents:

1. National Policy on HIV/AIDS, Prime Minister's Office, November 2001.
2. Guidelines for Clinical Management of HIV/AIDS for Frontline Workers, MOH 2002.
3. National Multi-sectoral Strategic lth Sector Strategy for HIV/AIDS (2003-2006), Ministry of Health, March 2003.
5. National HIV/AIDS Care and Treatment Plan 2003-2008, Ministry of Health, September 2003.
6. Guidelines for the Clinical Management of HIV/AIDS, Ministry of Health, (draft) June 2004.

This document has included additional sections on the following:

- Brief descriptions of the HIV/AIDS epidemic in Tanzania todate covering epidemiology, natural history, progression and stages of the disease etc
- The basic concepts of the "continuum of care" covering chronic disease management, palliative care and Antiretroviral Therapy (ART)
- In all previous sections reference has invariably been made to include issues around
  - Monitoring and support to adherence to ARV therapy
  - Reduction of stigma and discrimination in the households and communities
  - The need for adequate and balanced food for PLHAs.

Indeed, it is not the aim of these guidelines to replace the routine hospital services that are currently in use for managing patients with chronic illnesses. The intention continues to be to provide guidance on what to do at the district levels, especially the District Health Management Team (DHMT) taking into consideration the limited resource available at the level. Furthermore, the document is intended to inform senior and middle level managers of national and international organizations (NGOs, FBOs and CBOs) that are currently implementing HBC programmes or plan to do so in the future. The guidelines stress the importance of linking services within the continuum of care covering the patients' homes, the community and the healthcare facilities in both the public and the private sectors.

We believe this book supported by other policy guidelines on HIV/AIDS/STDs will make a valuable contribution to the fight against HIV/AIDS and other chronic

illnesses in our country.

The Ministry of Health would like to thank all those who participated in one way or another in preparing this document. Special thanks go to Family Health International for providing both technical and financial support that enabled the production of the guidelines document.

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SECTION ONE
BACKGROUND INFORMATION

1. Epidemiology of HIV

The impact of the HIV epidemic has been profound and has affected all sectors. Today, HIV/AIDS is recognized not only as a major public health concern but also a social, economic and developmental problem in the country.

Since 1983 when the first cases of AIDS were reported in Tanzania the HIV epidemic has spread to all districts and communities albeit at different rates. HIV infection has rapidly spread throughout the country, affecting all communities and sectors of the society. Over 1.8 million people were estimated to be living with HIV/AIDS and close to 800,000 cumulative AIDS cases by end of year 2002. Most infections (over 80%) are transmitted through sexual intercourse and hence the population groups most severely affected are the sexually active youth, men and women.

2. Health Impact

The HIV/AIDS epidemic poses one of the greatest challenges to public health. It is estimated that one in 12 adults in the country is currently infected with HIV. The latest data from the Adult Morbidity and Mortality Project (AMMP) shows that HIV/AIDS and TB were the leading causes of mortality in all the three districts where the study was conducted. The number of patients with HIV/AIDS related diseases has continued to increase steadily over the years. Between 50-60% of adult patients admitted in medical wards are believed to be due to HIV related causes.

The HIV/AIDS epidemic has interacted with other underlying public health problems, most notably tuberculosis. TB remains one of the principal causes of death in persons with HIV infection worldwide. National TB rates have escalated over the past decade in sub Saharan Africa. Since the mid-1980s, in many African countries with well-organized programs, annual TB notification rates have increased fourfold, reaching peaks of more than 400 cases per 100,000 population. Between 50-70% of TB

patients test positive for HIV in many countries including Tanzania. The HIV epidemic has reduced resources available for other health problems thus adversely affecting quality of health care services delivered in the country.

HIV related mortality has affected the health sector as well. Attrition rates due to HIV disease and mortality rates has seriously reduced the available human resources to provide medical care in general and HIV care in particular. Replacement has been very difficult. It is estimated that around one quarter of the health work force has been lost over the last 15 years (McKinsey report 2004).

3. Economic Impact

Increasingly, reports show that poverty is an important co-factor to the spread of HIV/AIDS. The economically and socially disadvantaged, women, youth and other marginalized groups in the society, are disproportionately affected by HIV/AIDS. Ill health and death due to AIDS are reported to have reduced agricultural labour force, productivity and disposable incomes in many families especially in rural communities.

Data from Kagera, one of the regions most severely affected by HIV/AIDS in Tanzania, indicate that the annual Gross Domestic Product (GPD) declined from USD 268 to USD 91 between 1983 and 1994. Indeed similar trends of declining GDP have been associated with reduced agricultural production and increase in the number of AIDS cases in Tanga region.

4. Social impact

Today, HIV/AIDS is recognized not only as a major public health concern but also a serious social, economic and development problem in the country. The loss of adolescents and adults has taken away an important resource for economic and social development. Average life expectancy has declined by 10–15 years. The World Bank Report (1991) states that the decline in health due to HIV/AIDS has four major effects: (i) reduction labor productivity, (ii) increase in health care expenditure, (iii) reduction savings, and (iv) reduction in human capital investment. It further states that demographic changes will alter the composition of the population and

work force. The work force will become younger (average age 29 years instead of 31 in 2010) and less experienced and will have less education and skills.

5. Nutrition Impacts

HIV/AIDS has significant impacts on nutrition at the level of the individual, household, and community. At the individual level, it accelerates the vicious cycle of inadequate dietary intake due to disease. HIV infection raises nutrient requirements and erodes the immune system, thus increasing vulnerability to other diseases. At the household level, HIV/AIDS is likely to diminish the capacity to care for young children or HIV infected members and/or the capacity to ensure food security, which, in turn, may lead to a worsening in nutritional status. At the community, HIV/AIDS derails community-based interventions aimed at improving the food, health, or care preconditions of nutritional well-being hence making it less able to promote sustainable agriculture, food security, and good nutrition.

The HIV/AIDS epidemic is occurring in populations where malnutrition is already endemic. As a priority, there should be renewed focus on and use of resources for nutrition as a fundamental part of the comprehensive packages of care. In addition, focused evidence-based nutrition interventions should be part of all national AIDS control and treatment programmes. Improving nutritional status is a critical challenge in the care and treatment plans.

6. HIV Transmission

HIV infection is acquired through sexual intercourse, exposure to infected blood and blood products, from mother to the unborn child in the uterus, during delivery and/or from breast milk. More than 80% of adults in Tanzania acquire HIV infection from unprotected sexual intercourse. Transmission of HIV through body fluids other than blood is certainly possible. Other means of transmission include through injecting drug use, contaminated needles, blood transfusion and mother to child transmission.

7. Natural history of HIV infection

Major advances have been made during the past few years in the understanding of the complex pathogenetic mechanisms leading to the propagation of HIV infection overtime and to the progression of HIV disease and AIDS. .

Initial infection with HIV is characterized by a relatively brief period of high level acute virus replication that is sometimes marked by the development of a flu like illness with fever, malaise, enlarged lymph nodes, sore throat, skin rash or joint pains. This acute febrile illness is accompanied by widespread dissemination of the virus to different tissues especially the lymphoid system that is extensively involved. HIV blood tests that are designed to detect presence of HIV antibodies (ELISA, Rapid immunoassays etc) are usually not yet positive at this point in time. However such patients are highly infectious although they test negative for HIV using the common tests that depend on detection of antibodies against HIV. The high level of viraemia present at the time of sero-conversion may persist for about three months but eventually stabilizes at an individual " set point'. Nevertheless most patients are clinically asymptomatic in spite of this ongoing extensive immunological battle.

During this asymptomatic phase of the infection levels of CD4+ lymphocytes, the prime target cell for HIV, gradually decline although the rate of decline varies substantially among patients. Major factors that are known to influence the rate of CD4+ T lymphocyte decline include:

- Patients genetic factors
- Viral load (number of HIV-RNA copies/unit volume) at the "set point".
- Viral characteristics
- Age

Studies of cohorts of patients over long periods both clinically and biologically have demonstrated the value of measuring viral load (expressed as number of copies/ml) as the most powerful predictive indicator of disease progression. Viral load and number of circulating CD4+ lymphocytes/mm_ are the two most important parameters to consider in deciding to start evaluating treatment. Viral load is the

measure of disease activity and can be used to evaluate the rate of the immune system deterioration before treatment and risk for development of resistance during treatment. The CD4 count can be used to evaluate the risk for complications.

High 'set point' has been shown to be associated with rapid disease progression than low "set point". Development of severe immuno-suppression could occur within 2-4 years but may be delayed for more than 15 years. In the "typical" HIV infected patient however it takes 8-10 years. Activation of the immune system for example by infections such as tuberculosis and worm infestation accelerates onset of immuno-suppression. Consequently, institution of preventive therapy to opportunistic infections, early detection and administration of effective and appropriate treatment of infective conditions in persons with HIV infection do minimize the risk of rapid onset of immuno-suppression. Preventive therapies currently used include those for TB, bacterial infections, Pneumocystis carinii pneumonia, (PCP) and cryptoccocal meningitis.

Comprehensive clinical care of persons with HIV disease therefore requires the heath care personnel to have appropriate clinical knowledge, experience and laboratory support to identify patients with subtle as well as those with gross features of HIV disease. Once diagnosis of HIV infection is made, the goal of any treatment aims at limiting or delaying progression and onset of AIDS for as long as possible to reduce morbidity and to increase survival.

In summary, delay of disease progression can be achieved through the following ways:

- Early and appropriate treatment of HIV related illnesses
- Preventive therapy for OIs particularly TB with INH and PCP with Cotrimoxazol
- Prevention of malaria (impregnated bed-nets and weekly prophylaxis)
- Clean environment and safe water supply
- Maintaining balanced nutritional intake
- Use of ARV therapy to lower viral load

8. Clinical Staging of HIV/AIDS (WHO Criteria)

1. Clinical Stage I
   - Asymptomatic
   - Persistent generalized lymphadenopathy (PGL)

2. Clinical Stage II
   - Weight loss <10% of body weight.
   - Minor mucocutaneous (seborrheic dermatitis, pruritis, fungal nail infections, and recurrent oral ulcerations, angular cheilitis)
   - Herpes Zoster, within the last 5 years.
   - Recurrent upper respiratory tract infection (i.e. bacterial sinusitis)

3. Clinical Stage III
   - Weight loss >10% of body weight.
   - Unexplained prolonged diarrhea > 1 month.
   - Unexplained prolonged fever (intermittent or constant) > 1 month.
   - Oral candidiasis (thrush).
   - Pulmonary tuberculosis within the past year.
   - Severe bacterial infections (i.e. pneumonia, pyomyositis).

4. Clinical Stage IV
   - HIV wasting syndrome
   - Pneumocystic carinii pneumonia
   - Toxoplasmosis of the brain.
   - Cryptospodiosis with diarrhea > 1 month.
   - Cryptococcosis extra pulmonary.
   - Cytomegalovirus (CMV) disease of an organ other than liver, spleen or lymph nodes.
   - Herpes simplex virus (HSV) infection mucocutoneous >1 month or visceral any duration.
   - Non-typhoid salmonella septicaemia.
   - Extra-pulmonary tuberculosis
   - Lymphoma.

- Kaposi's Sarcoma
- Candidiasis of esophagus, trachea, bronchi or lungs.
- Atypical mycobacteriosis, dissemination.
- HIV encepalopathy.

9. Introduction of Highly Active Antiretroviral Therapy (HAART)

Combination therapy with at least 3 different antiretroviral drugs have been shown to reduce viral load and can be maintained as long as the patient/client fully adheres to daily intake, drugs are tolerated and are still effective. Treatment has been shown most effective if therapy is started when the immunosystem is already compromised and clinical features have appeared (Clinical staging III and IV and/or CD4 count below 200) Restoration of the immunesystem results in weight increase, reduction of HIV related illnesses, improvement of quality of life and ability to participate again in daily functioning and work. At a population level, the introduction and proper use of HAART has been shown to reduce the HIV specific mortality by half.

SECTION TWO
THE CONTINUUM OF CARE CONCEPT

1. Rationale for Comprehensive Care Across the Continuum

The continuum of care refers to linking of the elements of comprehensive care, from the relevant health and other sectors, social or support facility, institutions or programmes that will ensure that the needs of clients and their families are met through timely and effective interventions. Tanzania will provide comprehensive services to PLWHAs at three levels, namely: at facility, community and home levels. The patient receiving care must have access to all the three levels. A functional referral system must link all levels with each other.

People living with, and households affected by, HIV/AIDS have psychological, social, nutritional, legal, clinical and nursing care needs which change over time as infection progresses to illness and advanced disease. Care and support programs are developed as a response to these needs and demands. Both biological and environmental factors determine those needs. In resource rich and constrained settings alike, environmental factors include stigma, discrimination, fear, neglect, and impoverishment in the community, in the workplace, and in healthcare settings. HIV/AIDS care interventions can thus not operate in isolation but must be embedded into programs within a health facility, a community, a workplace, or within a household

From various experiences in Tanzania and other countries in sub-Saharan Africa it is evident that clinical and psychosocial interventions are more effective and more sustainable if built upon a foundation of mutual trust between programmes and facilities and followed up within community care programmes. The fulfillment of these conditions constitutes the continuum of care to PLWHAs.

2. The Purpose of HIV/AIDS Care and Support Services

HIV/AIDS care and support services have the purpose of improving the quality of life of people with chronic illnesses including HIV/AIDS. This can be achieved through:

- Assuring equitable access to a functional health system for diagnostic, medical care, pharmaceutical supplies and supportive services.
- Reduction of morbidity and mortality from HIV/AIDS and related complications
- Promotion of preventive measures within the care and support service delivery system
- Provision of effective palliative care across the continuum of care
- Enhancing partnership with people living with HIV/AIDS

3. The Role of Prevention in Comprehensive Care.

Prevention cannot be separated from care; prevention and care should always operate in synergy. Each care support intervention offers an ideal opportunity to discuss prevention approaches seen as appropriate for that particular care circumstance. Although this makes good sense from a public health perspective, experience during the last 20 years of HIV care provision particularly during the recent ART specific treatment opportunities in resource—rich countries has shown that these opportunities by care providers are usually not taken. 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/family group education or discussions, and still others are part and parcel of counseling.

4. Principles of Chronic Disease Management

To meet the challenges of a continuum of care approach for clinicians and managers of healthcare systems, a shift has to be made from acute care models of health service delivery to the organization of health services enabling chronic disease management. Health services are currently being organized in a reactive way to respond to managing episodes of

acute diseases. Managing diabetes or cardiovascular disorders, and now HIV disease, requires ongoing, proactive, and planned provider-patient relationships where time, privacy, trust, a team approach, and proper data/records management are of essence to ensuring adherence. It is now estimated that life-long HIV treatment and the management of other chronic illnesses, such as diabetes and cardiovascular disorders, will make up more than half of all health services required in developing countries. Lessons should be learned from diabetes management and TB control, which could be adapted to life-long management of HIV disease across the continuum between facilities, community services, and homes.

The following principles and measures need to be taken into consideration when planning HIV/AIDS comprehensive services at the different levels of healthcare provision.

- Active patient involvement is essential in disease management at all levels. The patient will develop knowledge and self-care and treatment skills that will optimize his/her role and benefit treatment outcomes over his/her lifespan.
- Involvement of one or more "significant others" (e.g., spouse, life partner, family member) to assist care providers and/or observe timely drug intake, maintain appointment schedules, and identify side effects early. Every patient should be encouraged to identify a "buddy" from within the household to whom he/she would disclose his/her HIV status. The care provider would then counsel the patient along with his/her "buddy" whom would serve as support for treatment adherence and/or monitor therapy.
- The patient and health providers must work as a team to foster the patient's development of self-management skills, and the individual provider's transfer of knowledge, skills, and assistance in counseling and social services. At a minimum this includes a physician/clinician who can prescribe, a nurse-counselor, a pharmacist, and a social/community worker.
- A functional referral system is important across a continuum between institutions and community organizations that provide the non-medical services involved in patient care, such as support groups for people

living with HIV/AIDS, home care and social support. Partnership through regular meetings between institutional and community care services will 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 visits on a predetermined schedule, within the clinical team to monitor disease status and treatment outcomes, and to 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 record keeping and facilitate data retrieval.
- Support for care team members is essential to provide quality care, avoid loss of morale, and prevent burnout.
- Home based care plays the central role in enabling the principles of chronic disease management to apply.

5. Treatment with HAART as Part of a Comprehensive Care Program.

Comprehensive HIV/AIDS care and support services are essential for enhancing access to ARV therapy (ART) and to ensure that patients eligible –as well as those ineligible, for whatever reason – can benefit from care and support systems. For example, patients who do not meet eligibility criteria for ART will all need HIV care and support. These patients may include those with concurrent OIs or co-infectious diseases who require treatment for their OIs prior to antiretroviral therapy, those who cannot tolerate or are unable to remain on ART, those with terminal illness, or those who no longer respond to the available antiretroviral regimen. Thus, ART can only complement ongoing HIV care and support services and will not replace the need to prevent and manage OIs or to provide home based care. Efforts are being made to affordably implement all elements of comprehensive care with ART in Tanzania. Nonetheless, there is still a long way to go to achieve equity and reach all of those in need.

6. The role of HBC Programme in ART

The introduction of large-scale treatment with ART will add to the roles

of HBC services currently in place. The person living with HIV/AIDS as a chronic illness while being closely monitored by clinic or hospital will naturally spend most of his or her time at home, at least during the initial stages of ART. For assisting ART delivery to be successful, an HBC program will need to insist in:

- Preparing clients, family and community on expectations of the treatment, issues of disclosure, recognizing clients who need referral and assisting the client to identify treatment assistant.
- Where ARVs are in use discuss on issues of storage and adherence to drugs, side effects identification and referral, and nutrition issues.

7. Nutrition Care and Support in HBC services

Nutrition Care and Support for chronically ill people including PLWHA is one of the crucial components of comprehensive care package of the home-based care program. HIV/AIDS affects nutrition by decreasing food consumption, impairing nutrient absorption, and causing changes in metabolism. Improving and maintaining good nutrition may prolong life and delay HIV disease progression. In order to improve nutrition for chronically ill patients including PLWHA, the Ministry of Health shall play a role in facilitating discussions with partners and other stakeholders at all levels for developing mechanisms to address issues of food security and food acquisition for the most needy.

The government and particularly Ministry of Health in collaboration with District Councils, partners and stakeholders at various levels have the responsibility of carrying out measures aimed at improving the nutritional wellbeing of PLWHA. These measures among other things include:

- Training of home based care workers and other care providers on nutritional issues related to HIV/AIDS. These include food, water safety and hygiene; dietary management of HIV/AIDS related complications, and food and drug interactions.
- Provision of nutrition education and counseling for PLWHA and families including nutrition for special groups such as children born to HIV positive mothers, orphans and vulnerable children.
- Monitoring of nutritional status of PLWHA and needs for the households

- Mobilization of communities and partners for food provision for the chronically ill patients and their families.
- Mobilization of resources for improving household food security for PLWHA.
- Integration of actions aimed at improving household food security into the development plans.
- Food should become an essential element in care and support, especially for patients on ART.

8. Programming a Continuum of HIV/AIDS Care Treatment and Support

The following interventions are considered essential elements of programming a continuum of HIV/AIDS care, treatment, and support at district level. VCT, including VCT for diagnostic purposes.

- Primary care and home care services with functional referral networks.
- Comprehensive HIV care, including OI management (prevention and treatment), TB-DOTS, and palliation and nursing care (e.g. nutrition, universal precautions, support).
- Capacity for ART management: Trained staff, drugs and commodity management, space, and appropriate laboratory support.
- Client follow-up and other adherence-enhancing measures (e.g. ongoing counseling, informed guardian(s) or family members(s)
- Community involvement and participation in the ART program

This does not mean that all of those interventions are prerequisites before one can initiate an ART program, as this would be both unrealistic and lead to unacceptable delays. It simply means that these interventions need to be strengthened or developed at the same time as one introduces ARV drugs. They can benefit from standardization in order to allow rapid continuum scale-up, as well as to ensure optimal benefits for patients in need of HIV care, including ART.

Planning steps at the implementation level

1. Situational analysis.
   - Assess infection and disease burden within communities
   - Assess community perceptions and preparedness
   - Assess stigma levels within facilities and communities
   - Assess recurrent capacities for healthcare provision (e.g. clinical units, labs, outreach)
   - Develop work plan to strengthen care provision and address destigmatization

2. Policy development.
   - Strategic planning meetings involving staff, community representatives, NGOs, support groups for people living with HIV/AIDS.
   - Develop criteria for treatment eligibility, if necessary, including social criteria, develop or strengthen standard operational procedures and protocols
   - Ensure links to national policy guidance.

3. National guidelines and standards.
   - Obtain, adapt, and disseminate national or international clinical management, VCT, and home care guidelines.

4. Establish/strengthen home based care services.
   - Strengthen the referral system and integrate into the existing health care system
   - Strengthen proactive, explicit referral system within the health facility, community, and household and between different care and support partners.
   - Coordinate and meet regularly with all relevant care and support organizations in catchment area.

- Allow for rapid internal and external programmatic assessment and evaluation, documenting "lessons learned" that can be used to adjust programs prior to service scale-up and/or as best practices

5. Human resources capacity building.
   - Identify home based care service providers at different levels
   - Training of health workers to conceptualize and operationalize the continuum of care concept
   - Train home based care service providers in all aspects of home based care including ART and nutrition
   - Organize supervision, mentoring, and support for caregivers within institutions and for community care
   - Regularly inform all health staff about access to care, management, and the role of community services in HBC

6. Drug management system.
   - Identify cost recovery and exemption policy.
   - Ensure early and regular procurement of essential HIV drugs, including nationally approved ARV regimens.
   - Ensure the safety of ART storage and distribution.
   - Extend the eligibility to PEP to cover all HBC providers.
   - Develop patient clinical monitoring system.
   - Liaise with Health Management Information System (HMIS) team(s) to develop HIV illnesses reporting system.

SECTION THREE
HOME BASED CARE SERVICES

1. Introduction

The Government of Tanzania has recently introduced reforms in the health sector that aims at empowering districts in decision making on all health issues with the objective of improving the quality of health care at all levels. Home Based Care (HBC) services aim at improving the quality of care for chronically ill patients within the health facilities and at their homes. However, for HBC services to have the intended outcome and impact, it is imperative that both the quality and standards of the service be clearly defined. These Guidelines aim at providing guidance to the planning, implementation and evaluation of Home based care in Tanzania.

Comprehensive care for PLWHA is an essential element of any care and treatment programme. The community, and its support for and enhancement of the clinical component of care, is the most important provider of non-clinical elements of the continuum of care.

Community programmes supporting PLWHAs need to be closely linked with HIV/AIDS Care and Treatment Clinics (CTC) at the facility level. Care and treatment plans should ensure that activities for primary attention by community based programmes are implemented and these include:

- Prevention programmes
- Access to VCT
- Basic support, such as food and housing
- Promotion of PLWHA support groups
- Psychosocial support.
- Community education in ART fundamentals.
- Secondary support for adherence.

- Home based care.
- Family planning.

It should be encouraged that each facility entering the programme has a plan in place to link with and support community organizations that support community based care.

2. Definition of Home Based Care

Community home-based care is defined as any form of care given to chronically ill people in their homes. Such care includes physical, psychological, social and spiritual activities (WHO/GPA, 1993). Home care draws on the strengths of families and communities. Families are the central focus of care and form the basis of CHBC. The goal of CHBC is to provide hope through good quality and appropriate care that helps patients and families maintain their livelihood and have the best possible quality of life (WHO, 1999). From various studies (WHO, 2000; E. Lindsey, 2002), it is clear that most people would rather be cared for at home and that effective home care improves the quality of life for chronically ill people and their family caregivers. A well-functioning CHBC program provides a continuum of care for persons with chronic illnesses from a health care facility to the home environment. It must be linked and integrated into the existing district health care delivery systems and plans. Inputs from families, communities and the health care systems are essential for any results-based CHBC program. Since most terminally ill patients prefer to die at home, there is need to bring hope to all of them in more friendly and familiar environments.

Other Definitions for Quality of Home Based Care Services

In order to be able to measure the quality of HBC, it is important to define clearly the quality and standards to be expected.

Quality: Quality is a measure of how good something is, or the degree of excellence or superiority that a thing possesses. A service is said to be of quality if it meets or exceeds the expectations of the user. Quality HBC is defined as delivery of care for patients at home following the standards, which have been set.

Quality at the Health Facility Level
For a health facility to have the potential to provide quality services there should be adequate and conducive space; equipment, supplies and drugs adequate for the provision of quality care; and acceptable number of competent personnel to provide the minimum intervention package of HBC services.

Quality During the Process of Care Provision: Includes the service or the performance of procedure with available resources, the knowledge and skills that a health worker should have in order to perform a specific function to improve the quality of care.

Quality at the output/ outcome level: Level at which the expected results of the care, such as reduction in dissatisfaction, discomfort, disability, morbidity and mortality have been achieved.

Standards
Are the minimum accepted levels of practices on performance, based on environmental situation, knowledge, resources and statements of expected quality. Standards assist in guiding the development, implementation, monitoring and evaluation of services.

Chronically ill patients
A patient is defined as having chronic illness if she/ he continues to be ill for more than one month. Such patients include those with diseases that take long to be cured e.g. leprosy, or those known to be life long e.g. HIV/AIDS and sickle cell disease. Adults and children with the following chronic diseases/ illnesses should be considered for HBC

HIV/AIDS	Asthma	
Tuberculosis		
Leprosy	Cancers	Epilepsy
Stroke	Diabetes	Cerebral Palsy
Sickle Cell Disease		

3. Benefits of Home Based Care:
   To Patients
   - Permits them to receive care and treatment in a familiar, supportive environment

- Allows them to continue participating in family matters
- Maintains the sense of belonging in social groups
- Maximizes their emotional health
- Makes it easier for them to accept their condition
- Reduces medical and other related costs
- Death occurs at home amongst loved ones

To the family

- Strengthens family ties/attachment
- Helps the family to accept the patient's condition
- Provides opportunity to learn about chronic illnesses
- Can reduce medical and other care related costs
- Makes it easier for family members who provide care to PLHAs to attend to other responsibilities.
- Involvement of the family in care enables the grieving process to be easier

To the community

- Promotes awareness about prevention of the infection, care and support of chronic illnesses
- Promotes awareness about prevention of chronic illnesses
- Helps the community understand the disease and to correct myths and misconceptions about chronic illnesses and therefore reducing stigma
- Encourages sustainability of care services
- Makes easier for the community to provide support

4. Guiding Principles for Successful HBC Services:

The international debate on home based care in the last few years has reached consensus on several key principles for home-based care:

- Care should be comprehensive (holistic), including medical and nursing care, counseling and psychosocial support, spiritual care, material and social support (welfare, legal advice and care for survivors), and referral.
- Care should be along a continuum. Home care is an essential

component in a continuum of care for people with chronic illnesses including PLHAs, but at certain stages, cannot substitute the role of other health institutions such as hospitals and clinics. Referral systems and links between services along a continuum are necessary.

- Care and prevention may be most effective if fully integrated.
- Home care should target all people that are chronically ill to avoid stigmatization of people with chronic illnesses including PLHAs and discrimination of patient categories (equity). Resources permitting, home care should also provide support not only to the patient but also to the entire affected family.
- Home care should be pursued, not as a way to divert the burden of chronically ill including AIDS patients on hospitals to the community, but to provide the same kind of care in a different environment.
- Home care programs are more sustainable and feasible if they are community initiated and fully owned.

5. The Scope of HBC Services

Home Based Care Services aim at providing a continuity of care for persons with chronic conditions from any level of health care facility to the home environment. HBC services shall be linked and integrated in the existing district health care delivery services. It is important to realize that inputs from the family, community and the health care system will be necessary in the provision of high quality HBC services.

a) The family shall be the main actors of implementing HBC

b) The community will play a supportive role in all aspect of care, treatment and support for the chronically ill, AIDS patients and their families

c) The home based care provider could be a public servant, private person, volunteer from the community or NGO whose duties are described in section four of this document.

d) The health facility will have at any one time at least two members of its staff trained in HBC services. These people will be the “CONTACT

PERSONS" and their functions are provided in detail in section four of this document.

e) The District Health Management Teams (DHMT) will be responsible for the integration of HBC services in their health care delivery systems, monitoring and evaluating implementation as stipulated in section four of this document.

As the number of chronically ill patients is increasing fast both in the institutions and the community, HBC services are recommended to all chronic illnesses. A well integrated, planned and implemented HBC service will serve to bring hope to all people with chronic illnesses as they get assistance both at health care facilities and at homes.

6. The Minimum Package of a Home Based Care Program

When setting up a home base care program it is important to ensure the following which constitutes the minimum package for HBC are in place or linked to:

- Access to counseling and testing
- All elements of palliative care including pain management
- Medication adherence
- Functional referral system
- Psychological support
- Nutrition guidance and food support
- Participation of PLWHA
- Male involvement
- Care for the Carers
- Health Care for children, orphans and vulnerable children including sick children (OVC)
- Record and reporting system
- Prevention interventions (e.g. PMTCT, condom programming)

7. Essential Intervention Package for Quality HBC

The minimum intervention package is the essential set of activities and resources (equipment, drugs, supplies and personnel) required for providing the expected HBC services to all of the chronically ill patients at the set level of quality and standards. The basic aim of the minimum

intervention package for HBC is to provide a continuum of care for chronically ill patients, from health facilities to their homes and vise versa, using existing resources within the current delivery system and communities.

Home based care includes the following components:

Physical

Care providers should always ensure that a patient receives adequate attention on the following:

- Treatment of opportunistic infections and appropriate nursing care at all times
- ART- identification of patients, monitoring for side effects and adherence
- Pain relief with use of NSAIDs and Morphine
- Nutritional care and support: provision of balanced diet to ensure adequate nutrients. The Care- takers should be educated on the importance of appropriate food intake and guided on feeding patterns and preparation of the food to suit the condition of the patient, and those on ART
- Hygiene – the patient and family members should be educated on the practice of basic hygiene e.g. oral, skin, hair and environmental care
- Exercises – patients need to exercise regularly and if they are too weak the family members should assist the patient in doing passive exercises for body movement and to enhance blood circulation thus reducing the risks of complications such as bedsores and pulmonary problems.

Emotional support

Patients suffering from chronic or terminal illness usually have a lot of fear and worries. Care givers should therefore provide emotional support and help them to ventilate and deal with the conditions.

Social support

Patients suffering from chronic or terminal illness usually suffer from loneliness and neglect. It is therefore important for care givers to interact

with the patient and to include him/her in decisions regarding his/her care. The patient should also be involved in recreational activities as appropriate and support or self-help groups in the community should be identified for the patient to interact with.

Spiritual support
Addressing spiritual needs is an important aspect in any type of care. Chronically ill patients often loose hope, and reason to continue to live which is often relieved through reassurance and spiritual care. Spiritual needs of the patient must be determined and attended to appropriately.

Legal support
Patients should be informed about how to get legal aid that they need especially in areas such as inheritance and human rights issues.

Economic support
When a person is diagnosed with HIV/AIDS, this increases the financial burden to the family, as the family has to incur extra expenses for medical care. The infected bread earner may loose his/her job, while other issues such as children's education, rent and others require money. Therefore it is necessary for home based care givers to be aware of the support networks where such issues are addressed.

Other services/activities include the following:

a) Reducing stigma and discrimination at household and community level
b) Rehabilitation support e.g. physiotherapy and occupational therapy
c) Training and providing appropriate information concerning specific conditions/ illnesses
d) Continuity of treatment for the specific diseases as per diagnosis and prescription
e) Referral and networking among the care providers.
f) Supervision and Monitoring
g) Evaluation and re- planning.

8. Palliative Care

Palliative care is an approach that improves the quality of life of patients

and their families facing the problem associated with life-threatening illness. Many aspects of palliative care are applicable early in the course of illness. It affirms life and regards dying as a normal process. This can be done through the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other problems, be it physical, psychological or spiritual.

The main aim of those providing palliative care should be to improve the quality of life by removing or alleviating unpleasant symptoms and helping to prevent the patient from suffering, fear or loneliness. The palliative care must be provided wherever the patient is at home or in the hospital. It should aim at:

- Providing relief from pain and other distressing symptoms.
- Neither hastening nor postponing death.
- Integrating the psychological and spiritual aspects of patient care.
- Offering support system to help patients live as actively as possible until death.
- Offering a support system to help the family cope during the patient's illness and in their own bereavement.
- Using a team approach to address the needs of patients and their families, including bereavement counseling, if indicated.
- Enhancing quality of life, and may also positively influence the course of the illness.

The role of HBC in palliative care

The HBC provider can apply principles of palliative care in the home. Effective palliative care requires access to a range of drugs including opioids and extended training. The HBC provider will be responsible for:

- Identifying the pain and symptom needs of the patients including the need for strong analgesics e.g. morphine which will be available on prescription at the health facility
- Educate on the administration of drugs for symptom relief and monitor the side effects
- Refer where appropriate

9. Symptom management

Pain

Determine the site and asses the severity of the pain, then treat according to the analgesic ladder.

Figure 4: WHO analgesic ladder

<table>
<tr><th>Step1</th><th>Step 2</th><th>Step 3</th></tr>
<tr><td rowspan="2">moderate</td><td></td><td>Opioid for to severe pain – morphine, PLUS Non-opioids</td></tr>
<tr><td rowspan="2">Add opioids codeine for mild to moderate pain</td><td rowspan="2"></td></tr>
<tr><td>Non-opioids or NSAID e.g. aspirin, paracetamol and ibuprofen</td></tr>
</table>

Breathlessness

Patients with AIDS often develop severe breathlessness terminally. This may be the result of a severe non-responding lung infection or cancer such as Kaposi's sarcoma or lymphoma affecting the lungs and pleura. In such patients alleviate dyspnoea by propping up the patient and then refer for further management.

Vomiting

Vomiting may lead to poor fluid intake and hence dehydration and therefore it is necessary to correct dehydration. Encourage the patient to take small amounts of fluids frequently. Vomiting may be relieved by administering antiemetics on prescription. Where there is no improvement refer for further management.

Mouth care

Good mouth care should always be practiced. This includes brushing the teeth with a soft toothbrush two times a day and gargling after food. In persons with mouth sores oral care helps. If the sores are painful patients will not be able to eat or swallow and should be given soft foods and liquid diets. If a specific cause for the ulcers is found these should be treated as described.

Itching

For pruritus bath oils or other emollients such as emulsifying ointment may be useful. If a rash is present then antifungal creams will help if the rash is due to a fungal infection or topical steroids will relieve inflamed areas of the skin if a bacterial or viral infection is not present. Orally administered antihistamines, such as, diphenhydramine or hydroxyzine 25mg PO given at night may reduce the pruritus and allow a relatively more comfortable sleep.

Skin care

Prevent the development of bedsores by changing the position of the patient every 4 hours and arrange for the patient to lie on an extra soft material. Avoid pressure on any one part of the body for prolonged periods of time. Protect areas that have become inflamed because of pressure by avoiding any pressure at all on the area and by applying soothing lotions. Change soiled bed sheets immediately. Massage pressure points such as the heels, elbows, ankles, back and hips frequently. Cover all open sores with a gauze bandage after applying an antiseptic cream.

Terminal care

All persons with terminal illnesses need end of life care. Towards the end of life it is essential that the patient and the family have social, emotional and spiritual support. In palliation in terminal illness one attempts to allow the patient to die with dignity and relieve him/her of distressing symptoms. Palliation also offers support to help the patient live as actively as possible until death and enables the family to cope with their loved-one's illness and with their own bereavement. The carer needs to listen with empathy and should encourage communication within the family. Issues such as family and child support, schooling and welfare should be discussed. The

patient should be told that he/she is loved and will be missed by family members. Spiritual support and discussion with the relevant religious leader may relieve feelings of guilt. The carer should be available and should visit regularly.

10. Care of the Dead Body

Care after death is one of the most important aspects of HIV/AIDS care. Universal precautions stipulate that all people, no matter what they have died from, should be treated the same. These precautions should be applied also to people who have died of HIV/AIDS. People preparing the bodies should be instructed to wear gloves, and follow the hand washing procedure. Bleach powder should be used if the body is seeping out fluids, the bleach will kill the virus. However, it is not necessary to cover the body with plastic unless there is need for that. Disposal and care of linen, instruments, and other materials should follow the same procedures normally used for disinfection, sterilization and disposal of contaminated materials.

11. Drugs, Supplies and Equipment Required for HBC

List of drugs, equipment and supplies for home based care services at different levels of health facilities

S/N	ITEM
1.	Co-trimoxamozole 400mg/80mg
2.	Co-trimoxamozole 200mg +40mg/5ml, 100ml pwd for susp.
3.	Cloxacillin caps 250mg
4.	Cloxacillin syrup 125mg/5ml 100ml
5.	Paracetamol 500mg
6.	Paracetamol syrup 120mg/5mls, 60ml
7.	Miconazole 10mg muco adhesive
8.	Miconazole 2% cream
9.	Loperamide
10.	Amoxillin 250mg capsule
11.	Amoxillin 125 mg/5ml 100mls
12.	Ferrous sulphate + Folic Acidtab 200+. 25mg
13.	Acetyl Salicylic Acid (ASA) 500mg
14.	Cholopheramine maleate 4mg

15.	Oral rehydration salts (ORS)
16.	Sulphadoxin 500mg + Pyrethamine 25mg
17.	Vitamin B Compound
18.	Vitamin. A 50,000IU Capsule
19.	Amodiaquine 500mg/25mg tabs
20.	Albendazole 200mg
21.	Metronidazole 250 mg
22.	Metronidazole suspension
23.	Promethazine
24.	Diclophenac sodium 25 mg enteric coated
25.	Hydrocortisone acetate 1% skin ointment 15 mg
26.	Benzoic Acid Ointment (Whitfield)
27.	Griseofluvin Tabs
28.	Examination gloves latex large disposable Large
29.	Examination gloves latex large disposable medium
30.	Toile soap wrapper 100g
31.	Cotton wool absorbent 500g
32.	Cetrimide 15% + chlorhexidine gluconate 1.5% 5litres
33.	Hydrophylic gauze 90cm x 91m BP heavy (17g/m2)
34.	Torch with battery
35.	Mackintosh sheet rubber
36.	Gauze absorbent BPC 90cm x
37.	Adhesive wound plaster 5 cm x 5mt.
38.	Scissors surgical sharp straight 18 cm
39.	Forceps artery Pean 18cm straight
40.	Forceps dissecting- dressing spring type
41.	Gallipots
42.	Kidney dish stainless still 24 cm
43.	Thermometer auxiliary clinical flat type
44.	Apron (plastic)
45.	HBC bags
46.	Umbrella (foldable)
47.	Wooden tongue depressor
48.	Blood pressure machine
49.	Stethoscope

Drugs and supplies under shaded rows are recommended for HBC kits

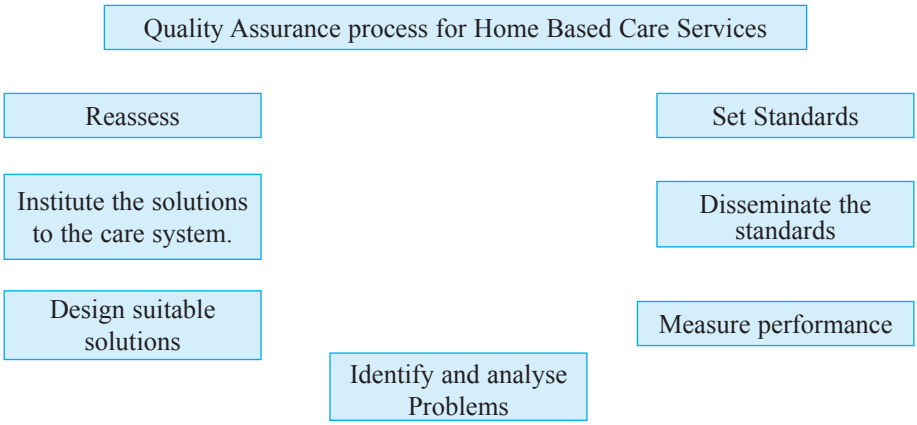
for the community home based care service providers. The HBC contact person at the health care facility will monitor the proper use of drugs.

Mechanism for provision of drugs and supplies at household level:

- Drugs and supplies for HBC kits will be stored at the health care facility at which the HBC provider is based (i.e. dispensary, health centre)
- The health facility pharmacy in-charge will be responsible for maintaining stock records and supply levels (including 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 drugs and supplies to HBC volunteers
- Volunteers' drugs and supplies will be maintained at a specific level according to a developed imprest plan
- Volunteers will obtain replenishment of drugs and supplies up to imprest level on a weekly basis from the HBC contact person at the health facility.

THE QUALITY ASSURANCE CYCLE FOR HOME BASED CARE SERVICES

The aim of the proposed cycle is to ensure that the services have a process for continuously improving the quality. The cycle should be reviewed annually, especially at the beginning of the HBC strategy for care of the chronically ill patients by the relevant DHMT and each health facility.



SECTION

FOUR

ROLES AND RESPONSIBILITIES IN HBC AT DIFFERENT LEVELS

1. Introduction

The HBC roles and responsibilities are located at different levels: from the central level, health facilities and community level. This section intends to address the roles and responsibilities at each level. Standardization of roles and responsibilities is mandatory to ensure the delivery of highest possible quality of HBC services.

2. Administrative levels

The Central level – Ministry of Health

i. Develop policies to ensure good quality care
ii. Develop the HBC policy guidelines and standards which will enhance the implementation, quality assurance and monitoring of the services.
iii. Develop and regularly review service guidelines for HBC services.
iv. Develop and frequently review training guidelines and manuals.
v. Develop mechanisms for effective linkages and referrals to enhance a continuum of care
vi. Evaluate reports on HBC service provision aiming at its improvement from time to time
vii. Develop mechanisms for dissemination and feedback of new policy guidelines and standards
viii. Develop mechanisms for coordinating HBC implementing organizations and donors at central level
ix. Advocate for improving food availability as an essential component of comprehensive care and support
x. Develop mechanism to address nutrition care and support for chronically ill including HIV/AIDS patients.

xi. Ensure pre-service training in HBC. The training on HBC should be incorporated/included in the training curriculum in medical, paramedical and nursing.
xii. Integrating the Home Based Care into District Health Care System. This implies that these services should be part and parcel of the district health care delivery system.

Requirements.

- At least two experts of HBC at the NACP
- A Multidisciplinary Technical Advisory Team
- Monitoring and evaluation tools, protocols and plans
- Resources.

The Regional Level.

The responsibility of the Regional Health Management Team (RHMT) will be to:

i. Interpret the HBC Guidelines and standards and ensure their implementation
ii. Co ordinate:
    - The link between the districts, Ministry of Health and Development Partners
    - Monitor and evaluate HBC plans and budget in all the districts.
    - Assess training needs for HBC contact persons in the districts.
    - Ensure and maintain effective linkages and referrals for continuum of care
iii. Supervise data collation, processing, analysis and utilization in all districts
iv. Maintain quality assurance of HBC
v. Prove HBC technical of support to districts
vi. Carry out operational research to improve on HBC services
vii. Compile HBC data, quarterly/annually and submit reports to the MOH and give feedback to districts
viii. Oversee the implementation of HBC guidelines in districts.
ix. Facilitate efforts for improving nutrition care and support for chronically ill including HIV/AIDS patients.

Requirements

- At least one HBC contact persons at the RHMT level (preferably, a medical officer or a nursing officer).
- HBC guidelines for service provision, training and supervision
- HBC sensitization campaigns
- Relevant monitoring and evaluation tools

The District Level

Within the health sector reform policy, HBC services are planned to be integrated in the Primary Health Care programme. Therefore, the District Health Management Team will be responsible to:

i. Implement the HBC policy guidelines.
ii. Integrate HBC activities in the council comprehensive health plans
iii. Create awareness of the community on the need and importance of HBC aiming at their involvement.
iv. Conduct a needs assessment and plan for HBC to be integrated in their health care delivery system.
v. Establish an effective networking and referral system for the patients to benefit from a functional continuum of care at facility, community and household level.
vi. Conduct the required training for personnel to ensure provision of effective HBC services in the district.
vii. Support and ensure community involvement and participation.
viii. Regularly monitor and supervise the services.
ix. Provide the necessary equipment, supplies, drugs and transport for HBC
x. Identify the health center/dispensary contact persons for HBC and monitor/ supervise their work.
xi. Evaluate the service every two years aiming at its improvements.
xii. Allocate resources needed for HBC in the district.
xiii. Compile and analyze HBC data quarterly and annually and submit reports to the region and give feed back to the health centers and dispensaries.
xiv. Support activities directed at improving nutrition care and support of chronically ill including HIV/AIDS patients through:
    - Mobilization of community and partners for food provision.
    - Mobilization of resources for improving household food security

for PLWHA.

- Provision of nutrition educate and counseling for families and the chronically ill including HIV/AIDS patients.
- Coordination and support of extension staff rendering support to households with PLWHA for improved household food security.
- Insuring that food security for households with PLWHA and their family is a permanent agenda for the Ward Development Committee (WDC) meeting.

Requirements

- The HBC guidelines for:
  - Service provision.
  - Training of trainers and community HBC providers.
  - Resources for supportive supervision.
- Drugs and equipments for HBC services as per suggested list.
- Transport for supervision.
- HBC sensitization campaigns.
- Resource allocation for HBC
- Competent HBC personnel at least two for each health facility.

3. Health Care Facilities.

For HBC to be functional, it is vital that good lines of communication be developed and maintained between the different levels of patient care. Health care facilities will be required to make proper diagnosis, initiate the right treatment and provide appropriate counseling services. At the time of leaving the health facility, patients should be given adequate discharge summary information to enable the next care provider to take over efficiently. Patients would take such information to a health facility nearest to their place of domicile or to the community HBC provider. This will ensure the continuum of quality health care from the health care facility to the household.

Consultant Hospitals.

Patients with difficult and/ or complicated problems would be attended at this level. Once the clinical problems have been sorted out, patients may be referred back to the respective regional or districts hospital for further management.

Consultant hospitals are therefore responsible for:

i. Providing specialized diagnostic services e.g. viral load assessments, PCR, viral and microorganism resistances and initiating treatment until the patient is stable.
ii. Providing counseling.
iii. Referring patients in stable conditions to their respective districts where they will be channeled in the home based care system.
iv. Teaching students about HBC
v. Providing technical support for district/ regional hospitals in their zones
vi. Keeping liaison with other hospitals through HBC contact persons.

Requirements

- Hospitals should have at least two people trained in HBC within the CTC team. These will be responsible for channeling patients in need of HBC services back to their respective districts and receive them when they are referred from a lower lever. (A Medical Officer and Nurse are recommended).
- Guidelines for discharge, record keeping and referral.

Regional Hospitals

The responsibilities of the regional hospitals will include:

- Providing technical support to the districts.
- Compiling records from all the district hospitals ready for reporting to the Ministry of Health.
- Providing supportive supervision to the district health services
- Refer patients to HBC and feed back

Requirements

- Supervision guidelines.
- Drugs and equipment for discharged patients.
- Discharging system.
- Two people at the regional hospital as HBC contact persons linked to CTC teams.

District Hospital

The district hospitals should be able to make diagnosis for most patients

suffering from chronic illnesses referred from the lower levels. Once diagnosis has been made and appropriate management has been initiated/ instituted patients with chronic illnesses would be discharged from hospital through the HBC system.

The tasks of the district hospital will include the following:

i. Implementing the HBC policy guidelines:
ii. Training the trainers for HBC personnel at the health centres and dispensaries.
iii. Regularly (at least monthly) supervise and monitor HBC staff at lower health facilities
iv. Keeping records of the patients under care as per available guidelines
v. Mobilizing and allocating resources as per DHMT guidelines
vi. Evaluating HBC services in each health facility.

Requirements

- Trainers guidelines, course plans and training materials.
- Supervision guidelines and tools.
- Two persons trained in HBC per hospital (preferably a Clinical Officer and a Nursing and a Officer) attached to the CTC.
- Drugs and equipment as per recommended list.
- Resources mobilization and allocation.

Health Centres

The responsibilities of the health centres will be to:

i. Implement the HBC policy guidelines.
ii. Train the community HBC providers in their catchment areas.
iii. Follow up patients discharged from the health centres or from other hospitals residing in their catchment areas.
iv. Supervise the Community HBC providers, at least on one home-visit per week.
v. Raise community awareness among leaders on HBC and mobilize the same to get involved in provision of quality HBC in their community and stigma reduction.
vi. Provide horizontal supervision for the dispensary contact persons.
vii. Mobilize resources for HBC

viii. Keep records for HBC

Requirements

- Trainers guidelines, course plans and training materials.
- Supervision tools and guidelines.
- Drugs, supplies, equipment and resources as per recommended list.
- Trained HBC contact persons.

Dispensaries

i. Should implement the HBC policy guideline.
ii. Should have trained HBC contact person(s). At least one-trained staff (preferably Public Health Nurse).
iii. Should monitor HBC services as per guidelines and report to the district contact person monthly.
iv. Should have the required supplies, drugs and equipments as per recommended list.
v. Should supervise the Community HBC Providers with at least one visit per week.
vi. Support the community care givers to enhance drug adherence especially for those on ART.

Requirements

- Trainers guidelines, course plans and training materials
- Supervision instruments and guidelines.
- Drugs, supplies equipment and other resources as per recommended list.
- Trained HBC contact person.

4. The Community.

It is the responsibility of the DHMT and relevant health facility leadership to introduce the concept of HBC to communities, after which each community should identify their HBC needs and develop appropriate plans to address them. However, communities should be guided in the planning by DHMT members or relevant personnel from nearby health care facilities. All along due emphasis should be made to enhance community ownership and effective support for HBC services.

For performance-based implementation of HBC services, communities

should be assisted to:

i. Identify specific needs for HBC services.
ii. Identify resource for HBC services.
iii. Make appropriate decisions on health issues.
iv. Look for local solutions for the prevailing health problems.
v. Identify the community HBC provider(s) to be trained by the contact persons at the health center or dispensary. The number of HBC provides trained will vary from community to community, depending on the needs and available resources.
vi. Determine sustainable and appropriate modalities of motivating the community HBC providers.
vii. Play a role in the identification of patients with chronic illnesses to be reached by the service and a system of registering new ones.
viii. Plan for home visits, community awareness meetings and support for referrals (e.g. transport)
ix. Plan for on-going community involvement in the improvement and sustainability of the service.
x. Work towards the reduction and/or elimination of stigma and discrimination at the community level.

SECTION FIVE

ROLES AND RESPONSIBILITIES OF KEY ACTORS IN HBC SERVICES

1. Introduction

Several factors are likely to affect the provision and quality of HBC services. Such factors may be related to the patient, the family, the community HBC provider, the health facility HBC contact person or the organization or group (CBO, NGO, FBO) involved in home patient care. In order to get optimum benefits from HBC services each of the players will be required to perform their respective roles and responsibilities as indicated hereunder:

2. The Family Team

2.1. The Patient

A patient receiving HBC services will be expected to:

i. Take his/her medicines accordingly.
ii. Keep to the required visit schedules to the care and treatment clinics
iii. Report any complications and side effects
iv. Appoint an adherence assistant and keep in regular contact
v. Cope with the illness.
vi. Prevent transmission of their infections to others.
vii. Provide care and support for orphans and vulnerable children of the patient and families for HBC

The adherence assistant is a person selected by the patient who assists the patient in ensuring that he/she follows the drug regimen as prescribed.

The adherence assistant will discuss the needs of the drug regime with the HBC provider and the client and set up a routine that they can follow through.
It is essential that the adherence assistant accept this task and be available and on hand at the required drug taking times. He/she may even assist in providing the drugs and water for the drug taking.

2.2. The Family

Patients with chronic illnesses will to a large extent be cared for in their homes. Since hospital based staff will not be available to provide care to such patients on a full-time basis, family members are expected to take over the responsibility of providing care at home. Indeed it is envisaged that family members will be the main actors in providing high quality HBC services.

a) The family will be required to choose among themselves at least one person who will be trained on specific elements of care for their patient. However, it is essential that more than one family member knows about the general care of the patient so as to support each other and assure continuity of care in case the primary care provider is absent.

b) With the patient's consent the family should be counseled about their patient's illness and informed about the cause, signs and symptoms, treatment, possible complications and prevention. This should be done at the health facility where the diagnosis is made before referral for HBC

It is recommended that men in the households should be actively and directly involved in the care and nursing of the chronically ill and not to leave all the chores to women only.
The family needs to:

i. Provide the patient with adequate balanced diet
ii. Nurse the patient according to her/his prevailing condition.
iii. Prevent complications.
iv. Prevent transmission of infections e.g. HIV, PTB
v. Link with the community HBC provider for support and referrals.

vi. Alleviate pains as much as possible
vii. Provide comfort to the patient.
viii. Make sure that the patient takes his/her medicines according to doctor's instructions.
ix. Make sure that the patient keeps his/her clinic appointments and observes medical advice appropriate for his/her disease.
x. Support the patient in order to avoid risk situations for infections and complications
xi. Provide emotional support and spiritual care to the patient.
xii. Provide care and support for orphans and vulnerable children

Requirements at the family/ household level.

- Patients take drugs according to prescription.
- Equipment (locally available) for avoiding infection.
- Disinfectant at the household (hypochlorite solution for households with AIDS patients).
- Food and other basic need of the patients.
- Physical exercises, fresh air and ambulation

2.3. The adherence assistant

Chronically sick people who are on life-long medication need support in ensuring that they abide with drug schedules and clinic appointments. A close family member will be required to know the patient's prescriptions and clinic visit schedules and constantly remind him/her to adhere to the same. The adherence assistant should also know and be known by members of the clinical care team and the home based care service provider.

3. Responsibilities of the Community HBC provider.

The principal responsibility of the community HBC provider is to implement the HBC policy guidelines by:

(a) Providing health care support to families with chronically ill patients.

(b) Training families on how to care for the chronically ill patients including

- Nursing care
- Feeding
- Providing comfort.
- Alleviating pain
- Preventing infections.
- Detecting complications and danger signs.

(c) Linking the family with the health facility and other relevant services in the community by reporting and referring patients.

(d) Reporting on the state of his/ her patients to the health facility contact monthly

(e) Raising the community awareness on new developments concerning the chronic illnesses and prevention of infectious ones including HIV/ AIDS and PTB

(f) Support the patient adherence to medication and clinic visit schedules

Requirements for community HBC provider

The community HBC provider should be provided with a First Aid kit containing the following items:

- Simple reading materials on different diseases.
- Register for recording patients receiving HBC services.
- Stationery.
- Drugs and supplies as per HBC kit

Qualification

Community HBC providers will have access to sensitive and confidential information while performing their duties. In addition they will be expected to work under difficult conditions and for long hours. Consequently, only persons of sound integrity should be considered for the task. Communities are therefore advised to consider person with the qualities listed below:

- Should be based in the community she/he is going to serve.
- Should know how to read and write.
- Should be able to build good interpersonal relationships
- Should be interested in caring for sick people.
- Should be willing to volunteer.

- Should be accepted by the community he/she is going to serve.
- Should be reliable and does not easily despair.
- Someone who can maintain confidentiality.

4. HBC Contact persons in health care facilities

The facility based contact person for community HBC service providers should be stationed at the nearest health facility and would be expected to:

i. Educate and provide support to the family to implement the policy guidelines.
ii. Train the community HBC providers in their catchment areas.
iii. Follow up patients discharged from their health facilities and those from higher-level hospitals.
iv. Supervise patient's adherence to ARTs
v. Supervise the Community HBC providers in their catchment areas.
vi. Raise awareness of the community and mobilize them for involvement in the provision of quality HBC services and stigma reduction
vii. Provide nutrition education to PLWHAs and their families
viii. Network with other health care providers in her/ his community.
ix. Keep patients records and report to the district contact person.
x. Participate in HIV prevention activities.
xi. Provide counseling services to the patients/ families.
xii. Train families to provide care and support to orphans and vulnerable children

Requirements

- Drugs as per recommended list.
- HBC guidelines.
- Supervision guidelines and tools.
- Training manual.

5. HBC service organizations (FBO, NGO, CBO)

Faith Based Organizations, Non Governmental Organizations and Community Based Organizations that have interest in providing care to chronically ill patients in the home environment should be encouraged to:

a) Provide HBC to chronically ill patients according to the national

guidelines for HBC.

b) Link with the health care facility HBC contact persons for referrals and supervision.

c) Provide counseling and spiritual support to patients/ families and communities.

d) Raise community awareness on various health issues and educate them accordingly, aiming at prevention of communicable disease including HIV/AIDS, STDs tuberculosis, leprosy etc.

e) Initiate and support efforts to reduce stigma and discrimination in the communities and families.

f) Establish effective functional linkages and referral systems with other relevant institutions to create a conducive environment for a good continuum of care for patients.

6. Religious Leaders.

Religious leaders are often called upon to provide guidance, counseling and spiritual support to patients and families. Where appropriate such persons should be encouraged to:

a) Continue giving spiritual and emotional support and counseling to patients.

b) Continue sensitizing the community on health issues to keep them health and

c) Sensitize the community on the importance of supporting the sick through HBC services.

d) Refrain from claiming to cure AIDS through prayers.

e) Encourage patients to obtain medical care.

f) Continue providing social support.

g) Strive to reduce stigma and discrimination in the communities and the families

SECTION SIX
REFERRAL SYSTEM

1. Introduction

Home based care services are to be perceived as part and parcel of the continuum of care, which involves the provision of support at different levels. An effective continuum of care requires that a functional network, linkage and referral system is in place to improve access of appropriate services for the chronic patient at all times. Through an effective and functioning referral system, chronically ill patients will continue to receive appropriate services after discharge from health care facilities within their respective communities and homes and revert back to facility care as and when needed.

The proposed referral mechanism for chronically ill patients will be developed and implemented within the district health care referral system. The health referral system in districts has four levels that can fully utilized. These include (i) the Community (ii) the Dispensary, (iii) the Health Center, and (iv) the District hospital levels. Patients are referred through these levels in an ascending order and vice versa. However, the referral system provides for a by- pass of these levels to higher levels in emergency conditions and accidents. The aim of this document is to assist the districts to set up a functional cost-effective referral flow within the exiting health care delivery system for the chronically ill patients.

Referral of HBC clients/patients will depend on her/his needs and the support system existing in a particular community. Therefore all those other support services should be known at all levels and be part of referral system. These may include spiritual, legal, income generating activities, nutritional and food, and social economic support.

2. Referral System in the District

2.1. Current referral system

Under normal circumstances a patient from a household will refer him/herself or be sent by relatives to a nearby dispensary or health center (if a dispensary is far away). From these two levels if the condition is not manageable, the patient will be given a letter of referral to the next higher level describing the condition and the treatment given so far. Therefore the order of referral is from household (or community) to dispensary, then to health center and lastly to the district hospital. For a proper working referral system, a critically ill patient at the health center would expect to be transported to the district hospital by a service vehicle or ambulance of the health center, but this system is not working in most districts because most of the motor vehicles have broken down.

In the current system a provision is in place for emergency conditions requiring surgery, deliveries etc. to be sent directly to the district hospital. On being discharged from district hospitals, patients have to go home and start afresh if the condition or other disease occurs again.

2.2. Proposed integrated referral system for chronically ill patients

In tandem with the Health Sector HIV/AIDS Strategy (2003-2006) care, treatment and support for PLHAs which requires that linkages and referrals between hospital/health care facility services and community services are established, the Ministry of Health proposes the following:-

i. From the district hospital a chronically ill patient will be discharged directly to the nearest catchment health facility, in most cases a dispensary, where a HBC service contact person is situated. Records should be kept at the district hospital Care and Treatment Clinic (CTC) by a HBC contact person.

ii. All the relevant information, including diagnosis and instructions on the current management and treatment of the condition should be provided to this contact person and kept at the catchment dispensary.

iii. The contact person at the dispensary will in turn introduce this patient to the respective community HBC provider for follow up and supervision at the level of household.

iv. In the case of a situation that requires referral to the higher level, the community HBC provider will refer the patient to the dispensary. At the dispensary if they are not able to provide needed care the patient will be referred to a health center. Similarly at the health center, if they are not able to provide the needed care the patient will be referred to a district hospital. At the district hospital the HBC contact person will facilitate the management of this patient through the CTC in the case of HIV/AIDS. In the event that the district hospital is not able provide the needed assistance the patient will be referred to higher levels of health care.

v. Like in a normal referral system, in case of emergency the chronically ill patient may be referred straight to the district hospital with a note to the contact person at the district to facilitate easy management.

3. Requirement for a functional referral system.

i. Finance.

Districts and respective local communities should be sensitised and mobilised to set up funds to meet referral costs.

ii. Training

- Health care providers in all facilities should be trained on how to properly implement integrated referral systems
- The subject of referral in the medical and allied health training curricula should be emphasised.
- Communities and their leaders should be sensitised on how the referral system functions and need for compliance.
- Periodic in-service training should be organised to enable health care providers to provide quality care.

iii. Record keeping and data collection

It is recommended that:

- Client registers should be kept at all levels
- The HMIS should incorporate and capture information on HBC services.
- The information collected in the HMIS should be analysed at all levels of health care system to enable evidence based planning.
- Actors at all levels should be able to make the necessary analysis

relevant to their level of health care provision

iv Reporting

- The District Health Management Team (DHMT) will manage the referral system.
- There are four levels in a district that are, community, dispensary, health centre and district at the top. Districts are to report to higher levels and give feedback to lower levels.
- A feedback referral register should be established at the district hospital, the health center and the dispensary. The register will keep record of all those who have been discharged or referred back. This register will contain information on demographic characteristics of the chronically ill patient, diagnosis, and place of back referral in case of a district hospital or discharging hospital, if it is a health center or a dispensary. The register will also contain information on recommended management while in the care of community HBC provider.
- A copy of discharge summary to be made available to the HBC provider and the discharging facility.

v. Monitoring, supervision and evaluation

- Every level should supervise the immediate lower level.
- Supervision of HBC should be integrated within the district supervision activities.
- Supervision checklist should be developed and revised regularly.
- The referral system should be evaluated regularly and the information gathered be utilized to improve the referral system.

vi. Personnel management and administration

- Where the number of staff in a health facility are adequate, there will be no need of employing new staff. Two of the dispensary key staff (Clinical officer or Public Nurse B) will be trained on how to provide HBC services.
- DHMT members will be responsible for the planning, implementation, monitoring and reporting of HBC services in the district.

vii. District strategies to sustain HBC services

- Staff at peripheral health facility should be trained.
- The quality of facilities should be improved so that they are able to offer quality services.
- Out reach consultative clinics should be organised within the supervisory schedule.

viii. Coordination and supervision

- Communities should be encouraged and mobilised to share the costs of communication including transport.
- Communication between the public and private sectors should be enhanced by sharing information through seminars, dialogue, workshops and meetings.
- Where geographical inaccessibility exists, local arrangements may be made with the private sector to offer the required services or else alternative means should be sought by the district.

4. District Planning for HBC Services

i District Health Boards and DHMT should be sensitised on the following:

-

- Conducting assessments for the need of establishing HBC services for the district.
- Establishing a cost- effective functional referral system of the chronically ill patients within the prevailing social economic environment.
- Integrate referral for chronically ill patients within the district health care delivery system.

ii Planning context

Planning for referral of chronically ill patients should be an integral part of district health plans. The aim is to have a functional cost effective system for chronically ill patients.

iii. Sources of information/data for planning

- Community HBC providers.
- Health facilities.
- Community and service surveys including patients.

- Experience from other districts with well functioning referral systems
- Review of documents
- Others.

iv. Assessment of health Service Inputs

The District Health Boards and DHMT need to answer the following questions in detail so that the resulting information can be used for better panning and identification of appropriate cost- effective interventions:

- What is the quality of current referral services for the chronically ill patients in the district?
- What are the weaknesses and strengths of the current referral service of chronically ill patients?
- Are there possibilities to have contractual understanding with the private providers?
- Are the referral services reaching all who need it?
- Are the referral services being delivered in line with given standards?
- What efforts are being made to involve the community?
- How much are the communities willing to contribute to running of the HBC services?
- Are the communities participating in decision making?
- Is the referral system acceptable by the community?
- What resources available? (human, equipment, drugs and other supplies)
- Which other support systems exist in the district for referral?

v. Developing interventions

- Identify additional components and activities that are required to strengthen the referral system for chronically ill patients.
- Plan solutions to identified constraints and limitations to the system for chronically ill patients.

vi. Resources

- Proper deployment and development of existing staff.
- Drugs, equipment and food to be procured and distributed through established procedures.

- Other materials such as sundries, stationery, postage and transport to be purchased according to laid down procedures.

vii. Plan of operation

- At each level of health care, a list of all available services for referral will be prepared.
- All activities will be assigned to various members in each facility.
- DHMT should participate in the allocation of tasks and timing.

viii. Monitoring of activities through:

- Regular supportive supervisory visits.
- Periodic check on the transport availability.
- Periodic assessing and evaluating staff performance.
- Regular checks on the community HBC providers and assessing their performance.
- A supervisory schedule of the DHMT members (and District HBC Coordinator) should include supervision of HBC services.
- The peripheral health facility contact person for HBC should have a supervisory schedule for HBC services.

5. Criteria for Discharging of admitted patients

The general guiding criteria of discharging patients shall be based on the following factors.

- Improvement of the patient's general conditions judged by its own merits.
- Ethical consideration and professional discretion of the discharging officer.
- When laboratory and radiological investigations or examinations have revealed significant improvement compared to the initial findings that warranted the admission.
- The family should be involved when planning for discharge of the patient. This will make family members participate adequately in the care of the chronically ill patient at home, thus ensuring continuity of patients care.
- The patient's willingness to comply with subsequent clinic consultation schedules
- Patient's wishes to be discharged should be considered on its own merit.

Issue to consider during discharge

- Discharge card should be issued to all discharged patients. The discharge should contain necessary and adequate information that is understandable to those who will be caring for the patient without violating the patient's confidentiality.
- The patient's discharge should be documented in the discharge register and should contain the date of discharge, condition on discharge, where discharged to and name of discharging officer.
- The patient should be referral back to his/ her home catchment health facility as well as to the community HBC provider.

6. Criteria for referring patients to a higher level

i. Within the district health care delivery system one should make sure that referral for chronically ill patients fulfils the followings:-

- Referring facility is unable to provide required care
- There is an agreed system of referral within a district.
- The referred individual is treated preferentially.

ii. General criteria for referral to higher level

- Patient whose condition is deteriorating.
- Patient's condition does not improve despite treatment.
- Emergency conditions which need surgery or specialist attention.
- If the diagnosis cannot be established.

iii. Private referral

- Nearly all referrals to private health facilities are self referrals
- Private hospitals should be encouraged to discharge their patients to HBC services. Referral from HBC to a private health facility will depend on the patient's request. For those who cannot pay for their back referral to a private facility should be referred to the nearest public health facility. If any of the criteria in the right hand column occur, the chronically ill patient under care of the HBC provider should be referred to the higher level.

7. The table below shows the criteria to guide the HBC provider to refer patients under their care to higher level.

CONDITION	CRITERIA
Fever	Persistent cough Persistent fever >38 C. Sharp chest pain Difficult in breathing Neck stiffness and severe headache Mental confusion Fits/ convulsions. Loss of consciousness Diarrhoea and vomiting
Mental confusion	Mental confusion of any degree.
Chest pain/ difficulty	Fever > 38C Sharp pain Blood stained / rusty sputum Greenish / yellowish sputum
Oral / throat sores	Difficult swallowing Bleeding
Oral thrush	Difficult swallowing Bleeding No response to treatment Hard swelling in the mouth or on the skin and cause is unknown.
Nausea and vomiting	Fever > 38 C Severe nausea and vomiting
Diarrhoea	Severe diarrhoea Unable to drink oral fluids Frequent/ severe vomiting Severe body weakness/ severe dehydration Fever > 38 C
Boils	Fever > 38 C Big boils

Allergy	Cause unknown
Vaginal /penile discharge	Pus discharging ulcer Enlarging ulcer
Bed ridden	Fever > 38 C Diarrhoea Vomiting Difficulty in swallowing
Tuberculosis (TB)	Oral lesions/ body itching Worsening body condition
Other conditions	Worsening patient's condition.

8. Strategies to comply with referral.
   - Improve the physical and service quality of health facilities.
   - Empower DHMT to implement own evidence based plans.
   - Educate both the public and health care providers, on the importance of a cost effective functional referral system.
   - Introduce referral guidelines for peripheral health workers.
   - Facilitate proper documentation of back referrals.
   - Establish community fund that could also be used to meet the cost of referral.
   - Encourage private health facilities to refer back patients to HBC services.
   - Initiate dialogue with private health care providers on how that can fit in the district health care referral system.

SECTION

SEVEN

COMMUNITY INVOLVEMENT AND PARTICIPATION AND THE ROLE OF TRADITIONAL HEALERS IN HBC SERVICES

1. Introduction:

The National Health Policy clearly stipulates the need and role of community based health care in the overall improvement of the peoples' well being. Indeed the main objectives of the policy are to improve the health and well being of the people. The specific aims of the health policy are to:

i. Make health services more accessible to all people in Tanzania
ii. Increase community participation and involvement in promoting healthy life styles.
iii. Promote multisectoral action in health care.
iv. Support and promote family health.
v. Reduce mortality and morbidity by providing preventive and promotive health care services.
vi. Train human resources from village level to the national level.

The health services policy accommodates HBC for chronically ill patients because the service improves access of health services to the very sick individuals within the confines of their homes. However, for the HBC to be successful it is vital that there be active community involvement and participation in the promotion of the service. These guidelines have been prepared to assist stakeholders (planners, policy makers, partners) in implementation; and communities in establishing and strengthening their involvement and participation in HBC services.

2. Community Involvement and Participation in HBC for Chronically Ill Patients

2.1. Definition of concepts

(a) A community is defined as a group of people living together in the same geographical area and under the same administrative system sharing more or less common social and economic conditions. In a community, the majority of members know one another, have close or wide interaction and they are expected to act together in their common interests. A community is known as a village in rural areas and a hamlet (kitongoji) in urban setting.

(b) Community involvement is defined as a process by which partnership is established between the public sector and local communities in the planning, implementation., monitoring and evaluation of development projects and activities that are executed in the community. Genuine community involvement is an essential prerequisite for successful implementation of community based HBC activities. To be genuine, the involvement must be on voluntary basis and there should be a real devolution of authority and power as well as responsibility. Involvement must be generated and maintained from village to national level.

(c) Community participation in HBC is the involvement of the community in taking care of chronically ill patients providing social and material support to the patients and their families in homes.

2.2. Objectives of Community Involvement and Participation in HBC Services

(a) To assist communities to identify their health and development problems through understanding of HBC as an essential part of the health care system.

(b) To assist communities to plan and mobilize resources available locally and elsewhere for sustainable HBC services for chronically ill patients.

(c) To assist communities to plan and implement HBC activities aimed at supporting chronically ill patients receive quality continuum of

care in the communities.

(d) To assist communities asses and address stigma and discrimination against HIV/AIDS related illnesses.

2.3. Strategies For community Involvement and Participation in HBC Services

(a) Provision of community education and sensitization to raise awareness in order to mobilize communities for action to solve their identified problems

(b) Identification and training of community HBC providers and patient care providers on the home based care mode and its operation.

(c) Finding ways and means to be used by the community to motivate HBC providers.

(d) Strengthening home based care management information systems that is appropriate and efficient.

(e) Coordinating a focused inter-sectoral response with all stakeholders from village level to district level.

(f) Identification and supporting of economic groups conducting income generating activities.

(g) Identification and utilization of resources available locally as well as resources from else where.

(h) Strengthen community health care service delivery system and integration of vertical programmes in the districts.

(i) Identification and utilization of community based organizations and structures.

(j) Ensuring regular availability of essential and appropriate medicines and supplies.

(k) Conducting operational research on HBC and using the findings for re-planning and implementing HBC activities.

2.4. Strategies for implementation of Home Based Care Services in the Community.

Patient's care takes place both in the community and in established health and related institutions. Indeed, HBC is an integral part of Community Based Primary Health Care. Ideally it should be initiated and implemented in the community by the community.

Essential/Basic elements of Home Based Care Implementation in the community.

Element of HBC	Activities in the Community.
The Concept of Home Based Care and Basic education of HIV/AIDS	• Provision of Community education on Home Based Care • IEC on effective measures for prevention; • Reduction of stigma and discrimination • Basic information on ART
Promotion of appropriate food production, storage and use	• Food production, processing, distribution, storage and preparation • Adequate and balanced food preparation and use • Community, education on good methods of food production processing, distribution, preparation and utilization.
Adequate supply of safe water and basic sanitation	• Identification and protection of water source • Fetching, storage and utilization safe water • Proper utilization of sanitary facilities (latrines etc) • Community education on safe water and proper sanitation.
Prevention and control of endemic diseases	• Community education on prevention and control of endemic diseases. • Personal and household hygiene. • Utilization of safe water and food hygiene.
Adequate treatment of common diseases and injuries.	• Community education on recognition of common diseases and injuries and on First Aid. • Community education on prevention of common diseases and injuries and early and complete treatment.
Provision of essential medicines and supplies.	• Community education on proper use of drugs and medicines • Basics of adherence to long-term treatment requirements • Acquisition and use medicines and supplies.

Community Understanding of Home Based Care (HBC)
The community is the key stakeholder in HBC activities. It is therefore important for community members and leaders to have a clear understanding of the nature and functions of HBC The community needs to fully conceptualize their roles and responsibilities in the planning, implementation and monitoring of successful and sustainable HBC services.

In order to fully sensitize the communities and get them to understand the HBC concept and internalize it, strategies should be developed to create proper awareness among key stakeholders in the communities and these should include health workers, religious leaders, civic leaders, government workers and professionals e.g. teachers and media people, NGOs, CBOs, and other influential members and groups such as PLHAs.

Key strategies for effective sensitization will include:
(i) Conducting regular meetings in the community
(ii) Using religious sermons and sessions
(ii) Conducting specific seminars for strategic groups and players.
(iv) Effective use of newspapers, the radio, TV, leaflets, brochures, posters.
(v) Conducting culturally appropriate plays, and events with youth and women groups.

Roles and Responsibilities of the Community in HBC Services.
A community has a variety of roles and responsibilities in the provision of HBC services. Effective implementation of HBC activities rest on the community's understanding that chronic illness among community members is not a problem of one individual but rather a problem of the whole community. On this basis, the community has to undertake broad and specific actions to address the need of providing care to chronically ill patients.

The major roles and responsibilities of the community on the HBC services

Roles	Responsibilities
Conducting Situation Analysis	• Collection of data or information on chronically ill patients in the community. • Assessment of needs and problems of chronically ill patients in the community. • Review what is being done about the situation of chronically ill persons. • Determination of the number of orphans in the community and their problems. • Make strategic decisions on what should be done to redress the situation.
Development of a Community HBC Program	• Identification of planning team. • Setting achievable objectives for HBC • Identify target groups and criteria for their selection • Design strategies i.e. the approach to be taken • Set out activities to be implemented • Identify resources that will be required • Set out time frame for monitoring and evaluation. - Identify collaborators and resources available in the community.
Development of Plan of action	• Decide on major activities to be undertaken • Determine who should do what, how, when and where. • Plan for resources needed. • Do training needs assessment • Agree on how to fill gaps of the required resources.
Implementation of Planned Activities	• Determine management and organization i.e. how the programme will be managed and administered • Make decision on supervision of HBC activities: Follow up and reporting • Supply requirements, storage and utilization.
Monitoring and Evaluation	• Make assessment of programme performance and trends; Resource utilization and community involvement and participation.
Re – Planning Activities.	• Set new objectives and targets based on evaluation of programme performance and results achieved.

Roles and Responsibilities of Community actors in HBC

Community actors are the people and other structures and institutions that play essential roles and have responsibilities in the implementation of HBC. The reduction of stigma and discrimination is a cross cutting issue which is the responsibility of all members of the community.

Roles and Responsibilities of the Community Actors

Actors	**Roles**	**Responsibilities**
Family/Household	Provision of love, care and support	• Provide adequate and balanced food • Ensure adherence to treatment • Provide clean shelter, clothing. bath and dressing. • Administer medicines • Pay costs of drugs and supplies.
Community HBC provider	Provision of basic services to the chronic-ally ill in their homes including HBC services in the community	• Monitoring patients' medication and adherence to treatment • Regularly visit chronically ill patients/ families. • Provide basic health education to patients and families • Make referral to dispensary and health centre • Prepare and submit reports to village government • Prepare and submit reports to health facility.
Village government	• Community organizer • Management, supervision and evaluation of HBC • Reduction of stigma and discrimination	• Mobilization of the Community on HBC. • Resource allocation. • Implementation of HBC Services • Monitoring and Evaluation of HBC Services, • Continuously assess and address stigma and discrimination
Dispensary	• Provide technical support, coordination and supervision. • Train community HBC providers.	• Treatment of diseases • Counseling patients and their families. • Referral and discharge of patients • Follow –up HBC activities • Supervision of Community HBC providers. • Prepare and submit reports to higher level. • Provide education on locally available food for better nutrition • Re-enforce adherence to treatment

Ward Development Committee	• Advocacy on HBC services • Coordination of social and economic development including HBC activities in the ward. • Reduction of stigma and discrimination	• Mobilization of Communities on HBC • Allocate resources. • Submit report. • Continuously assess and address stigma and discrimination
Health Center	• Plan for HBC services. • Provide health services • Provide technical support to community HBC	• Provider technical support to communities for HBC activities. • Diagnosis and treatment • Counseling patients and families • Referral and discharge of patients • Monitoring and Supervision of HBC • Activities. • Provide education on locally available food for better nutrition • Re-enforce adherence to treatment
District leadership	• Advocacy on HBC services. • Coordination of social and economic development including HBC activities. • Plan for HBC services. • Reduction of stigma and discrimination	• Mobilization of communities on HBC activities. • Policy matters on the HBC • Resource mobilization and allocation. • Administrative maters on health including HBC • Continuously assess and address stigma and discrimination
District hospital	• Advocacy, management and coordination of HBC services • Provision of technical support.	• Implement policy issues on HBC mobilization on HBC • Resource allocation • Design, implement, monitor and evaluate HBC district plans • Administrative matters on heath including HBC • Diagnose, organize treatment and counseling. • Training and supervision of HBC service providers. • Preparation and submission of reports. • Coordination the provision of effective continuum of care • Ensure proper chronic disease management including treatment adherence

		• Provide education on locally available food for better nutrition
Non-governmental and Faith Based Organizations including Community Based Organizations (where available)	• Community empowering for social and economic development • Support for HBC services	• Support to communities on • Mobilization for HBC • Training needs • Basic supplies. • Income generating activities • Stigma reduction
Traditional healers and Traditional birth attendants	• Healing practices • Ensure safe baby delivery	• Emotional and spiritual support i. Assist deliveries ii. Treatment of illnesses iii. Counseling patients and families • Referral to health facilities.

Financing and Sustaining HBC services.

Sustainability of an activity is the ability of that activity to remain functioning after withdrawal of external funding. In order to bring this about, it is necessary to establish sustainable funding mechanisms right from the initial stages of designing HBC activities in the community.

Models of financing and sustaining HBC

(i) The Household/ Family is responsible for the financial costs of patient care. This is in line with the cost sharing policy of the Government.

(ii) The community should support/families that are unable to pay for the costs and expenses of their patients care.

Possible options for the community support of HBC services

- Establishment of community health fund, that is owned, managed and controlled by the community.
- Contributions by community members in form of cash, material and in-kind in order to address specific problems of patients
- Faith Based organizations, Non – government organizations/ community based organizations can support communities to establish income generating activities which will enable them pay for the financial requirements for HBC activities and services.
- District support in terms of funds, medicines and other necessary resources.

- Contributions from individuals on voluntary basis and other financial resources identified by the community.

People to be involved in HBC at Community level include.

(a) Community volunteers
(b) First Aiders
(c) Traditional birth attendants
(d) Traditional healers
(e) Religious leaders
(f) Other relevant people selected by the community
(g) Village health worker

Criteria for Selection of HBC Providers.

The community should consider the following criteria when selecting candidates for HBC

(a) Literate person.
(b) A person who is willing to volunteer to do the work
(c) Someone the community really wants because he/she has shown interest in caring for the sick or people in trouble.
(d) A person who has good interpersonal relationship.
(e) One who maintains confidentiality.
(f) A reliable person.
(g) Preferably active middle aged men and women

Training.

Communities must be educated on HBC operations and services. HBC providers and patient care providers must be trained on how to administer HBC services to chronically ill patients.

Where possible, the communities should use their own resource persons. The communities should select community members to be trained by selected trainers and HBC providers. These people after their successful training should work as community resource people. The communities should decide on how to motivate them, in kind or in cash, based on the abilities of the communities themselves.

Extension workers and other professional employees in the communities should also be educated, sensitized and eventually mobilized to support HBC in the communities.

The management and administrative staff at the District, Regional and National levels (Ministry of Health) will be required to facilitate the training of HBC providers identified by the communities.

Training Needs for Actors in HBC

Actors	Roles	Training needs.
Community Resource People • Community leaders • HBC providers. • Traditional healers. • Traditional birth attendants • Any other person selected by the community	• Education and sensitize on nutrition, and HBC • Mobilize community to implement HBC • Provide HBC services of treatment, counseling and basic human needs.	• HBC model and its operation. • Community modalities of involvement and participation • Basic first aid and management of common illness • Methods of collecting reporting and utilizing information.
Community Extension • Workers and Health facility contact persons.	• Technical support to the community to improve health and development activities. • Train community resource people. • Community change agents.	• HBC model and its operations • Community modalities of involvement and participation • Functional duties for development. • Collection, reporting and use of information.
Facilitators/Supporters at district, regional and National levels.	• Policy formulation • Coordinate planning of community projects • Training and supervision.	• HBC model and its operation • Community involvement and participation • Management and supervision.

Monitoring and Evaluation of Community Involvement and Participation.

People Responsible

i. At village level.

- The Community HBC provider will monitor and report to the village government and to the contact person at dispensary level.
- The village Health Committee will also monitor and report to the village council.

ii. The Dispensary will report to the health centre.

iii. Health centre will report to district level.

Hence the reporting chain should be from Village, Dispensary, Health Center and District level. In addition the reports should be sent through people in charge of those units. Supervision, monitoring and evaluation of HBC activities should be participatory. To facilitate supervision, monitoring, evaluation and control, there be regular collection and analysis of relevant service management information. The communities should be given feedback so that they can re-plan their activities on HBC

Appropriate and adequate organizational support should be set up at all levels from the community to the national levels with responsibilities and logistic support for HBC

HBC should be part and parcel of the existing health systems. The District has the responsibility of ensuring that the appropriate committees are enlightened of the services and accommodate them during the regular meetings. It should be understood that HBC is not a different /parallel service, but a means to cater for the increasing burden of long-term illnesses to the existing health care services.

Check list for Monitoring and Evaluation of Community Involvement and Participation.

a) Education on HBC
b) Promotion of food production, use and nutritional practices.
c) Supply of safe water and basic sanitation.

d) Prevent and control of endemic disease.
e) Treatment of common disease and injuries.
f) Provision of essential medicines and supplies.
g) Prevention and control of deformities related to bed- ridden patients.
h) Mechanisms to ensure a well coordinated continuum of care spectrum
i) Principle of chronic disease management
j) Ensuring of adherence to treatment

9. Special Issues.

9.1 Code of Ethics for HBC providers.

Ethics is associated with morality and professional conduct. Professional ethics in the health sector in the context of home based care activities require the actors to perform their activities in accordance with health professional requirements in a community context. The ethics deal with the methods employed in the process of executing activities in the communities. In doing HBC services to chronically ill patients, it is absolutely necessary to abide with following ethical requirements:

(a) Confidentiality.
(b) Respect of other people.
(c) Commitment to work on HBC
(d) Reliable person.
(e) Ability to recognize ones limitations and seek support where necessary.
(f) Respect and cooperate with professional orders.
(g) Should work within the existing legal framework

- HBC services require patients and their relatives to reveal personal information about the patient and home conditions in order to be able to assess the problem and the needs required. Such information should be provided voluntarily and the information should not be used in any way that may inflict harm, injury or embarrassment to the patients and the family.
- HBC providers must be reliable people who respect and cooperate with professional orders as well as work well with other actors in home based care activities. Information on patient's problems should not be revealed to people who are not concerned with

the HBC activities. Thus the HBC providers should maintain anonymity and confidentiality on the patient identity and the problems involved. The patient has the right to privacy.

- HBC providers have confidence and willingness to work with the community.
- They must at the same time be able to recognize their limitations on their ability to provide services to patients.
- In monitoring, supervision and evaluation the reporter must be faithful and honest to the information that is reported. It is absolutely not acceptable to lie or give wrong information about the patient care activities. The HBC provider should not in any way engage in deceitful behavior in working for the community.
- Ethical issues in the health sector can become political when for example infringements on the rights of individuals, communities or even countries become a source of controversy or demand for regulations. Both ethics and politics hinge on ideological points of view. What is acceptable from one point of view might be unacceptable from another. Watch and take precaution when political issues are involved.

9.2 Gender issue on Home HBC services.

HBC for chronically ill patients is a responsibility of the household/ family as well as a responsibility of the community. The current practice shows that the females have bigger workload of the production and household activities and even in patient care at the household the females provide most of the patient care services. The HBC model requires fair distribution of gender roles and responsibilities. The families/ communities should address the gender issues in HBC to ensure that:

- Females are relieved of some of their routine activities.
- Males participate fully in HBC activities.

However, decisions on the gender division of labor in HBC activities should be made by the families and communities with due regard to their local conditions and environment.

9.3 Traditional healers in HBC

Definition of Traditional healers

Traditional health practices are characterized with conflicting terminologies. Terms such as traditional health practitioners, herbalists, spiritualists, bonesetters, medicine sellers, faith healers, magicians, traditional birth attendants and traditional medicine man/women have been used to identify categories/ type of traditional health practices. Even people who study traditional medicine mix terms, confusing practitioners with malpractitioners, the trained with the untrained, established healers with non- healers.

The Regional (Africa) Expert Committee of the World Health Organization (WHO) on traditional African medicine defined traditional medicine as: "the sum total of all knowledge and practices, whether explicable or not used in diagnosis, prevention and elimination of physical, mental or social imbalance and relying exclusively on practical experience and observation handed down from generation to generation, whether verbally or in writing.

On traditional African medicine, the committee observed that it involved the sum total of practices, measures, ingredients and procedures of all kinds, whether materials or not, which from time immemorial had enabled the African to guard against disease, to alleviate his suffering and to cure himself. According to the same source (WHO) a traditional indigenous healer is a person recognized by the community one lives in, to provide health using plant, animal and mineral substance and other methods based on social, cultural and religious backgrounds as well on the knowledge, attitudes and beliefs that are prevalent in the community regarding physical, mental and well- being and the causation of diseases and disability.

The term traditional medicine does not denote a uniform or clearly identifiable medical practice nor is it used in the sense of being backward, unscientific and static. Traditional healers can be classified on the way they were trained, their methods of healing or the disease they treat.

Focusing on the role of traditional healers in patient treatment and care

in the communities, these are people who use their own environment and knowledge of diagnosing diseases and treating them using plants, minerals, insects and animal products. In this context traditional healers include herbalists, bonesetters and traditional birth attendants.

Areas of Concern on the Role of Traditional Healers
Existence of Traditional healers.

(i) Traditional healers have practiced in most African communities since time immemorial and may continue to do for a long time to come.

(ii) Need for traditional healers.
   a) People seek traditional treatment.
   b) Communities accept traditional healers and their practices.
   c) Traditional healers have high credibility in the community because they manage some illnesses.
   d) Traditional healers have legal recognition and some are members of registered associations of traditional health practitioners

(iii) Involvement of traditional healer in patient care
   Traditional healers give treatment and counseling to patients on illness which patient considers respond well to traditional healing. The service is given at the home of a traditional healer or at the house of a patient. Traditional healers lack scientific explanation of their treatment, nevertheless, they enjoy wide acceptance by the community.

iv) Relationship of Traditional healers and medical personnel.
   The role of traditional healers in the existing health care system is yet to be defined. However there is need to explore the possibility of working with them to care for patients in the communities. This can be done by doing the following:
   (a) Medical practitioners should educate traditional healers on basic health education to enable them handle patients safely.
   (b) Medical personnel should sensitize traditional healers on the importance of referring patients to health facilities as early as possible if the condition of patient does not respond to traditional

therapies.

(v) Relationship between traditional healers and home based care services

- HBC service providers should be oriented on tradition healers and their roles in HBC.
- Traditional healers should be sensitized about the home based care services in their environment and be encouraged to establish linkages
- Where appropriate communities should work out modalities of getting cooperation of traditional health practitioners with the main objective of providing effective and safe health services to the individual person and community in general. Traditional health practitioners should therefore be asked to do the following while performing their practices:

  a) Not to do activities which enhance transmission of infections.
  b) Refer patients through a Home Based Care referral system.
  c) Give correct information to patients and refrain from claiming to cure AIDS
  d) Encourage patients to obtain modern medical care, i.e. ARVs.

Requirements

- Advocacy and mobilization strategies to enhance their positive involvement.
- Appropriate information and education materials
- Community information and awareness of proper treatment of common diseases.
- An efficient and functional referral system to support patients get appropriate care

SECTION EIGHT

SUPERVISION GUIDELINES AND MONITORING TOOLS

1. Introduction.

Extensive Home Based Care services are relatively new in Tanzania but due to the on-going HIV/AIDS epidemic, the services are expanding at a fast rate. Indeed the need for proper monitoring, evaluation, supervision and reporting cannot be over-emphasized. Through proper monitoring and evaluation lessons learnt and best practices will be identified to inform programme expansion and continuation. The supervision guidelines have to be prepared in order to:

- Have a standard supervision tool to assess quality of HBC services.
- Have standard supervision strategies for HBC services to ensure that the national objectives are accomplished.

Definition of Supervision.

Supervision in the context of HBC services is a management function planned and carried out in order to guide, support and assist HBC providers in carrying out their tasks. It involves on job transfer of knowledge and skill between the supervisor and the one being supervised through opening of administrative and technical communication channels:

The objectives of the supervisory guidelines are to:

- Provide guidance to supervisors on how to carry out supervision of HBC activities more effectively and efficiently at all levels of the health care delivery system.
- Make supervision an effective tool for on the job learning and professional updating of HBC providers' skills at all levels of health care.

- Promote objectivity, consistency and impact of supervision on quality of HBC service delivery in the country.
- Determine the performance of HBC providers in relation to quality and standard in implementing HBC activities.

Supervisory visits aim at:

- Assisting the HBC providers to improve their performance.
- Ensuring uniformity to set performance standards.
- Identification of problems and solving them at appropriate time.
- Maintaining and reinforcing the administrative and technical link between higher and lower levels.
- Follow up decisions reached during previous supervision visits.
- Identification of the HBC provider's needs.

2. Levels and scope of supervision.

Supervision roles will be undertaken at five levels: National, Regional, District, Health Centre/ Dispensary and at community.

Level of service delivery	Activities	How to carry out the activities	Time frame	Responsible person	Feedback
Central level (Ministry of Health)	Develop, review and disseminate HBC supervision guidelines and monitoring tools. Monitor and evaluate HBC services rendered countrywide Coordinate supervision activities at national Document and disseminate lessons learnt/best practice experiences on Home based care	Organize HBC program guideline review Analysis of reports from supervisory visits. Receiving service reports from regions and use to assess program performance Evaluation of the HBC services using developed tools for data collection. Collect and analyses monitoring, supervision and evaluation reports	Biannually Annually Quarterly Mid term/ end of program evaluation	Technical officers/ professionals will be identified and trained in HBC services and supervision. NACP in collaboration with department of hospital services and PORALG	Give and receive feedback to and from RHMT and other development partners.
Regional	Co-ordinate and support the district in planning, implementation, supervision, monitoring and evaluation of HBC services.	Support DHMT's data collection, processing, analysis and utilisation in all the districts. Receive monitoring and evaluation reports from districts and use to assess program performance Compile and forward reports to MOH.	Quarterly Annually Routine Quarterly	RHMT to appoint a home based care focal person RHMT	Give and receive feed back to and from DHMT central level

District level	Monitoring and evaluating HBC services rendered within the district. Supervise the work of the partners and supervisors in delivering of HBC services in the district Coordinate supervisors to effectively supervise Share lessons learnt and experience among partners	Evaluation of services using HBC monitoring tools. Use monitoring information and supervision report to compare service achievements against set standards and targets. Supervision of HBC services in the district. Supervisory visits plans, logistical support and feedback Assess competence of HBC providers Compile M & E reports of RHMT. Organize experience sharing workshop among partners in HBC	Annually Quarterly Routine Annually	DHMT (to support the District HBC Coordinators)	Give and receive feed back to and from Health Centres Dispensary, RHMT and MOH
Health Centre/ Dispensary	Supervise and monitor HBC activities in their catchment areas.	- Supervisory visits to all community HBC providers in their catchment areas. - Monitor adherence to services standards and policies. -Compile monitoring and evaluation reports to DHMT.	-Supervising community HBC providers weekly -Compiling reports monthly. Six monthly	Contact person at Health Centre/ Dispensary.	Give feed back to community HBC providers and community leaders
Community level (CBO, FBO, NGO)	Share experience among partners Supervision of families/ care givers. Monitor support to	Supervisory visits families/ care providers in their homes. Keeping registers for all the patients. Filling monitoring and evaluation forms Compiling reports for Health	Weekly and according to need Every visit Monthly Monthly	Community HBC provider.	Give feed back village leadership, and givers. Care providers and supervisors (contact person)

3. Planning for Supervision.

Supervision must be included in the annual health plans at each health facility level. These include routine and focus supervision. Routine supervision is carried out to check daily activities performed. Focus supervision addresses specific areas that need more time and thorough examination. Emergency supervision is carried out in the event of changes or divergence from performance and ethical standards in health care delivery.

3.1 Areas to be supervised in HBC services include.

1. Planning, monitoring and evaluation:
   - Routine recording and reporting.
   - Evaluation procedures.

2. Materials management
   - Established procurement system and adequacy.
   - Maintenance of supplies records.

3. Facilities and equipment management.
   - Adequacy of equipment and supplies.
   - Condition of equipment and supplies.

4. Human Resources management.
   - Placement of staff according to qualification.
   - Norms, ethics and standards of performance.

5. Clinical package.
   - Clinical management of patients and nursing care.
   - Referral support.

6. Support
   - Material support.
   - Nutritional support
   - Legal support
   - Psychosocial support

3.2 How to supervise.

Before the supervision team conducts supervision it should familiarise itself with:

- The understanding of HBC services.
- The understanding of HBC services supervision and monitoring through training.
- Main objectives of supervision.
- The meaning of quality health care.
- The roles and responsibilities of staff to be supervised.

The process of supervision can be divided into 3 stages: preparatory, actual supervision and immediate feedback.

In the preparatory stage – the necessary tools for supervision are assembled, the problems at the level identified and objectives for supervision set. Transport, schedule of supervision arranged.

Actual supervision stage – the supervisor study the performance of HBC providers at work place and identify support need.
Immediate feedback the supervisors meet with the management teams to discuss findings from the respective areas.

3.3 Supervision report (district – regional -national levels).

The purpose of making supervision reports is to inform the supervised HBC providers and those who have authority to make decisions.

Composition of the supervision reports.
Supervision reports may be structured as follows:

- Title page.
- Acknowledgement.
- Acronyms.
- Executive summary.
- Background.
- Main report – Analysis of findings/ observation/ situation analysis, need, service and systems.
- Conclusion and recommendation. (Lessons learned, challenges and way forward)
- Appendices.

Explanation of the above report contents.

Acknowledgement:
Word of appreciation to individuals and organizations participated in the supervision.

Acronyms:
Elaborate meaning of short forms.

Executive Summary (if required):
This section may be important if someone have little time to read the whole report. The Executive summary is not supposed to be more than one page. It needs to disclose to the most essential points of the whole report. Most of the essential points are Aims of the supervision, objectives of the supervision, how supervision was conducted, what were the constraints, what are the lessons learned, challenges and way forward. In the report, the summary comes first, but it is written after all the sections of the report have been completed.

Introduction:
Describes the objectives of the supervision, places visited and people met. A brief description of the methods used to do the supervision should be included in this section.

Main report:
Analysis of findings/ observations/ situation analysis: this section describes strengths, weaknesses and constraints observed during supervision

Conclusions and recommendations:
Recommendations include action taken on the spot and action to be implemented based on conclusions. There will be action taken on the spot and action to be implemented by the supervised health workers and those that will need in puts from the higher level.

Lessons learned, Challenges and Way forward
Lessons learned include all findings that can be shared among stakeholders. Challenges are issues encountered during implementations that need

immediate action and replaning for improved performance.

Appendices.
This section may be included in very report. It will include all the references, which are not reflected in the main text.

4. Supervisory Checklist

The purpose of a checklist is to guide the supervisor on areas to be addressed during supervision. It also services as a reminder to the supervisors on areas that would otherwise be overlooked. A well – filled checklist will act as a good reference in the future for the supervisor and the health staff who are supervised in the subsequent visits.

4.1 Checklist of issues for HBC supervision.

Questions.

1. Are the HBC reporting forms filled in correctly?

a. Does the HBC provider enter all the necessary information in the HBC form
b. Are the HBC forms not in use kept in appropriate place?
c. Are the quarterly summaries up to date?

Equipment, drugs and supplies.

2. Is there a record of drugs and medical supplies?

a. Are the equipment maintained in good condition? Check the standard list.
b. Are drugs/ supplies ordered in time according to needs and resources?
c. Are there adequate supplies of drugs?
d. If no then specify

Performance assessment

3. Is there a qualified HBC provider?

a. Does he/ she has job description?
b. Check – Is the HBC provider patient relationship good?
c. Is history taking adequate?
d. Is the patient given correct treatment?

e. Is the patient give correct treatment?
f. Is the patient counseled properly?

4.2 Monitoring and Evaluation.

Does the RHMT/DHMT assess the performance/ check progress reports and action plans to determine the degree of implementation vis – a – vis planned level?

a. Are there any operational research carried out? Check if the district used the results and how?
b. Does the RHMT/DHMT evaluate their performance?

4.3 Scoring system.

There are several methods that can be used in assigning a score on the performance of various activities observed during supervision. Numerical scoring method was chosen as a standard scoring method for HBC service as this scoring method allows calculating average score through time and across facilities.

In this method each performance category is assigned a subjective number as shown in the example below:-

- Excellent
- Very good
- Good
- Satisfactory
- Poor

At the end of this exercise average score for a health facility or district can be calculated using an acceptable numeral scoring chart.

FRAMEWORK FOR MONITORING AND EVALUATION OF HOME BASED CARE PROGRAMME

Organisation of Monitoring and Evaluation of HBC:

NATIONAL LEVEL
NACP, MOH
(A national coordinator for HBC;
National HBC Management Committee for quarterly assessment
Of HBC programme implementation)

↑ ↓

REGIONAL LEVEL
RHMT
(Regional HBC Coordinator for coordination of
activities in the region and to link with national level.
The RHMT will use M&E information quarterly to assess progress in
the implementation of HBC in the region and advice on how to proceed).

↑ ↓

DISTRICT
DHMT
District HBC coordinator
The DHMT will use M&E information quarterly to assess progress in
the implementation of HBC in the district and advice on how to proceed).

↑ ↓

HEALTH FACILITIES
(HBC Contact person)
Collects filled M&E data forms from the providers
forwards copies to the district level as required
carries out simple analysis of data and use
for improving implementation

↑ ↓

COMMUNITY HBC PROVIDERS
CHBCP, NGO, CBO, FBO etc
Fills M&E data forms as required
Forwards filled data forms to the facility level

MONITORING AREAS, INDICATORS AND INDICATOR DEFINITIONS

SN	AREA	INDICATOR	INDICATOR DEFINITIONS
1	Coverage	1. Number of new patients visited at home in the last three months (by age, sex, cause of illness/ diagnosis, condition of patient/severity of illness).	All patients who were provided care at their homes for the first time in the last three months. This indicator should be analysed by age, sex, cause of illness/diagnosis, and whether the patients were bed-ridden or mobile.
		2. Percentage of districts that have established and are actively providing HBC	Percentage of districts with at least one functioning home based care service. Numerator – Number of districts with at least one functioning home based care service. Denominator – Number of districts in Tanzania mainland.
2	Quality of services	3. Number of HBC providers who are trained using National HBC training tools. (a proxy indicator for quality of services)	Number of HBC providers who are trained using National HBC guidelines and training curriculum. This is a proxy indicator for quality of HBC services.
3	Linkages between HBC and other HIV/ AIDS care services, (VCT, ART, TB etc.).	4. Percent of new patients visited at home who are on ART	Percent of HBC patient provided care in their homes for the first time during a specified period that were found to be on antiretroviral therapy (ART). Numerator: Number of patients visited for the first time during a specified period that were on ART. Denominator: Total number of patients visited for the first time during the same period.
		5. Percent of patients visited at home who were referred for any service.	Proportion of patients who were provided care in their homes and referred by the HBC provider during a specified period. Numerator: Number of patients (new + revisits) who were referred during a specified period. Denominator: Total patients (new + revisits) who were visited during the same period.

PATIENTS' RECORD KEEPING AT THE SERVICE LEVEL

Every HBC provider should establish a register book for keeping records on daily service provision. Key information to be recorded in the register shall include date, name and home address/locality of patients, name of the head of the household, type of services provided and remarks. Any other information which HBC providers think will be helpful to remind them on the patient during the next visit may also be added.

DATA COLLECTION

Data collection forms that are printed in triplicate will be used to collect data for the above monitoring indicators. Care providers will use one data collection form per patient to collect information. S/he will forward filled forms to health facility HBC contact person at least weekly. Facility HBC contact person will collate the information on the forms to analyse the indicators every month for programme monitoring. At the end of the month, facility HBC contact person will send first and second copies of the filled forms to the District HBC Coordinator while retaining a third copy in the health facility.

At the district level, the District HBC Coordinator (DHBCC) will forward first copies of the filled forms to NACP and retain the second copy at the district level. DHBCC will coordinate collating and analysis of the data to compute for the indicators as required. The analysed information will be used by the District Health Management Team in monitoring HBC implementation in the district.

A copy of the district monitoring information will be forwarded to the Regional HBC Coordinator (RHBCC) who will in turn compile information from various districts to generate one regional report that will be used by the RHMT in assessing progress in the implementation of HBC in the region.

At the national level, data will be entered into a computer routinely. Data analysis will be carried out to generate monitoring information that will be assessed quarterly by the National HBC Management Committee. A copy of the quarterly monitoring information will be made available to RHMTs.

NATIONAL HOME BASED CARE PROGRAMME MONITORING AND EVALUATION

DATA COLLECTION FORM

Date: ____/_____/_____ Month:_____

Year: 200 __

Patients' village:_____ Ward: _____

District:_____Region:_____

1. Name of HBC provider: _____

2. Has the HBC provider being trained? (Circle)
    1. Yes
    2. No

3. If yes, how long was the training?
    1. 2 weeks
    2. 4 weeks
    3. Over 4 weeks

4. Coded name of the patient:_____

5. Date of birth (day/month/year):_____/_____/_____

6. Sex:(circle)
    1. Male
    2. Female

7. Occupation :(circle)
    1. Employed
    2. Business
    3. Farming
    4. Student / pupil

5. Child
6. Others (specify)

_____

8. Marital status: (circle)
1. Married,
2. Single, other

9. Type of visit:(circle)
1. New
2. Revisit

10. Cause of illness/Patients' diagnosis:_____

11. Patients' condition:
1. Mobile
2. Bed ridden

12. Is the patient on any of the following medications?
1. ARV
2. TB drugs
3. Other (specify)

_____

13. Was the patient referred?
1. Yes
3. No

14. If yes, referred to:
1. VCT site
2. Health facility
3. Support groups

4. Other (specify) _____