HOME BASED CARE AND MANAGEMENT OF PEOPLE LIVING WITH HIV/ AIDS IN RUFIJI DISTRICT

BY

JOHN DISMAS

A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF ARTS IN RURAL DEVELOPMENT OF THE SOKOINE UNIVERSITY OF AGRICULTURE. MOROGORO, TANZANIA.

2008

ABSTRACT

HIV/AIDS has brought in new challenges of care and support to those who fall sick and the surviving family members. As the HIV/AIDS epidemic worsens, community home-based care services are critical in the continuum of care to mitigate the burden of the disease on health facilities and families. The Government of Tanzania has developed different programmes, strategies and models for HBC to PLWHA. However, there is inadequate knowledge about the effectiveness of HBC and management of PLWHA. The current study examines the determinants of effectiveness of HBC and management of PLWHA in Rufiji District. The study specifically determines the characteristics of PLWHA under HBC system, best or bad practices for PLWHA, the types of home based care offered and key stakeholders involved in the caring for PLWHA. Cross-sectional survey using quantitative data collected from a sample of 104 PLWHA and 3 focus group discussion and in-depth interviews were used for the study. The analysis has been done using the Statistical Package for Social Sciences (SPSS). The findings show that of all the households of PLWHA that were interviewed, majority were male headed household (MHHs), than female headed household (FHHs). The study has shown that the type of HBC offered is the one which emphasizes on psychosocial support to PLWHA and their families delivering their services primarily through volunteer networks in the community together with program staff, who are not necessarily health professionals. PLWHA do not have information on where to get legal aid an aspects such as inheritance, writing of wills and human rights or PLWHA support groups. The study recommends the introduction and or strengthening of programmes that promote legal aid awareness along side other services provided to PLWHA. Finally HBC programmes cannot be successful unless they are accorded active support and participation from government, NGO's and communities.

DECLARATION

I, John Dismas, do hereby declare to the Senate of Sokoine University of Agriculture that this dissertation is my own original work and has neither been submitted nor concurrently being submitted for a higher degree award in any other University.

19/11/2008

John Dismas
(MARD Student)

Date

The above declaration confirmed

19/11/08

Prof. Eleuther Mwageni
(Supervisor)

Date

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ACKNOWLEDGEMENTS

This work would not have reached this stage had it not efforts and contributions of many people who gave their time and hard work. I thank all of them for their assistance.

However, I wish to extend my heartfelt gratitude and appreciation to special individuals and institutions that significantly helped me in this work for without their particular support, guidance and encouragement the success of this study would have been very difficult if not impossible.

I would, therefore, first and foremost like to express my indebtedness to The Government of Belgium through its Belgium Technical Cooperation (BTC) for their finance assistance.

I thank very much my supervisor Prof. Eleuther Mwageni, the Deputy Vice Chancellor of the Ardhi University (Planning, Finance and Administration) for his tireless guidance and encouragement, critical and constructive comments, suggestions and advice, right from the development of the research proposal to the final stage of writing the dissertation.

This work would not have been possible without the foundation of my parents, Bibiana Peter and the late beloved father John Banzi Francis. I thank them for their foresight, sacrifice and commitment that have been my guiding beacon. Sincere appreciation also goes to my dear wife, Mwashamba, to my beloved sons Romanus and Daudi for their moral support, assistance, great patience and continuous encouragement throughout the study.

There are many individuals who in one way or another assisted me in completing this dissertation. Although their names are not mention here, I am greatly indebted to them.

Lastly, I would like to state that whatever errors in this work are solely mine and should not be attributed to anyone whether acknowledged or not.

DEDICATION

To my parents Bibiana Peter and my late beloved father John Banzi Francis, because all my success depended much on the foundation I got from them. I also dedicate this work to my dearest wife Mwashamba and my beloved sons Romanus and Daudi.

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LIST OF ABBREVIATIONS AND SYMBOLS

ACT	Aids Campaign Team
AIDS	Acquired Immuno-Deficiency Sydrome
AMREF	African Medical and Research Foundation
BOD	Burden of Disease
BTC	Belgium Technical Cooperation
CARE	Cooperation Assistance Relief Everywhere
CCBRT	Comprehensive Community based Rehabilitation and Treatment in Tanzania
CHBC	Community Home Based Care
CHH	Child Headed Household
DCC	Dar es Salaam City Council
DHMTS	District Health Management Teams
DSI	Development Studies Institute
DSS	Demographic Surveillance Survey
FAO	Food and Agriculture Organization
FGDs	Focus Group Discussion
FHHS	Female Headed Household
FHI	Family Health International
GTZ	German Agency for International Development
HBC	Home Based Care
HIV	Human Immunodeficiency Virus
ICASA	International Conference on AIDS and STIs in Africa
ICHC	Integrated Community based Home Care
IDC	Infectious Disease Centre
MDGs	Millennium Development Goals

MHHs	Male Headed Household
MoH	Ministry of Health
MTP	Medium Term Plan
MUHAS	Muhimbili University of Health and Allied Sciences
NACP	National AIDS Control Programme
NGO's	Non-Governmental Organization
PI	Pathfinder International
PLWHA	People Living With HIV/AIDS
SANDoH	South African National Department of Health
SPSS	Statistical Packages for social Sciences
STI	Sexual Transmitted Infections
SUA	Sokoine University of Agriculture
TACAIDS	Tanzania Commission for AIDS
TANESCO	Tanzania National Electricity Supply Company
TBS	Tanzania Bureau of Statistics
TEHIP	Tanzania Essential Health Interventions Project
THIS	Tanzania HIV AIDS Indicator Survey
UN	United Nations
UNAIDS	Joint United Programme on HIV and AIDS
UNDP	United Nations Development Programme
URT	United Republic of Tanzania
VCT	Voluntary Counselling and testing
WAMATA	Walio Katika Mapambano na Ukimwi Tanzania
WB	World Bank
WHO	World Health Organization

CHAPTER ONE

1.0 INTRODUCTION

1.1 Background Information

Acquired Immunodeficiency Syndrome (AIDS) is a name given to fatal clinical conditions that result from long-term infection with human immunodeficiency virus (HIV). HIV progressively damages the body immune defense system, preventing the body protecting itself against opportunistic diseases that that would otherwise have been rendered harmless (Dossier, 1992). Over time the virus weakens the immune system to the extent that several opportunistic diseases attack the body simultaneously. HIV does not cause death directly but one or more of these diseases can lead to death (Dossier, 1992). Appropriate care during different stages of HIV is an integral component of the continuum of care for maintaining the health and nutritional status and the general wellbeing of PLWHA (WHO, 2003).

As a consequence HIV/AIDS has also brought in new challenges of care and support unique to the PLWHA and the family members. As they require special type of care apart from medical care. Such care includes psychosocial, socio – economical and human right and legal support. HIV/AIDS has also added a great burden to the grossly under funded and already over stretched health sector, therefore, affecting the quality of health care provision (MoH, 2006).

Care and support regarding HIV/AIDS cases is not just health care, it encompasses a wide range of services and support for people infected with or affected by HIV/AIDS and their families. Care and support is intended to provide relief from physical pain as well as social and psychological stress (URT, 2006).

Apart from the medical care provided through health facilities, people also need care and support in the home environment, communities, and in their places of worship. In other words, social, psychological, emotional and spiritual care is just as important as is medical care. The type of emotional care persons get often reflects in their medical care when they need it, and feel more comfortable doing so (URT, 2006).

Many countries have started to outline a care agenda that includes providing psycho-social care, reducing stigmatization towards PLWHA, and ensuring that such people have access to essential AIDS medicines, including antiretroviral drugs and treatment for opportunistic infections (WHO, 2003). Proper caring for PLWHA involves meeting food security, health, health environment services, appropriate treatment of opportunistic infections, stress management and physical exercises together with emotional, psychological and spiritual counseling and support and balancing these with the needs of other members of the families (WHO, 2003).

Like most countries in Sub-Saharan Africa, Tanzania is facing a challenge in providing care and support services for PLWHA, their families and to patients with other chronic conditions. As the epidemic continues to escalate, the number of patients with AIDS related conditions has dramatically increased leading to an overwhelming rise in hospital admissions which are beyond the coping capacity of the health institutions. For example, reports from urban hospitals have shown that patients with AIDS or HIV/AIDS related conditions occupy approximately 50 – 60% of hospital beds (MoH, 2006).

Despite all these efforts made by a strong network of HBC across all levels, many PLWHA lack the care they need, both at home and at the health facility. Where a strong care support network is available to such people often it is either not sustainable or not of high quality or both. This is why the need for quality care and support for PLWHA and those affected by the epidemic in various ways cannot be overemphasized (URT, 2006).

HBC is a holistic, collaborative effort by the hospital, the family of the clients, and the community to enhance the quality of care for PLWHA and those with other chronic diseases (clients), and their families. Furthermore, home-based care is comprehensive care across the continuum of care from the health facility through to the community and home level. It encompasses clinical care, nursing care; counseling and psycho-spiritual social support care. These are complementary and the actors in each should understand the role of the others in the team (AMREF, 2005).

HBC cannot be accomplished by only one sector or one type of services. There are many actors in the fight against HIV/AIDS and other ailments. Health, education, social development, local government, traditional healers and leaders, churches, NGOs and communities have a vital role to play in the whole process and successes of HBC (MoH, 2005).

It is now commonly understood that it takes quite a long period from the time of HIV infection to the time of developing AIDS disease. Therefore, throughout this period individuals undergo a series of life long psychosocial episodes before the attack of serious opportunistic infections (URT, 2006).

Receiving appropriate care and support at home and in the community can reduce such episodes. Because of its chronic nature, AIDS care sources and providers do change in number and in structure over the years. Care providers come and go, as families change and communities evolve. New family members join the existing families by birth, marriage or getting extended families. Members also exit their families through death or through establishing new families. Entire communities may change because of migration (intended or unintended), employment or education opportunities, displacement, e.g. refugees, or many other eventualities. Under such circumstances, the need for sustainable and reliable care and support for PLWHA is very important in order to enable them to live a quality life (URT, 2006).

1.2 Problem Statement

Tanzania, like other countries in Sub-Saharan Africa, is facing serious health, social, and economic problems of unprecedented nature as a result of AIDS epidemic (NACP, 1998). The current trend of the spread of the epidemic will make it a pervasive disease for a long time in the country (Kapinga *et al.*, 1993). The AIDS epidemic has been a huge burden to health care system in Tanzania. Currently, people suffering from HIV/AIDS related conditions occupy about 50% of the hospital beds in urban areas (MoH, 2003). As the result, the burden of care has fallen individuals, households, and communities (Campbell and Foulis, 2004). PLWHA often become frustrated with the disease. Many of these people are ready to do anything in the hope of staying healthy and live longer (FAO/WHO, 2002). Families, households, and the community have often been identified as having a crucial role in examining the limits of the support role rendered in the HIV/AIDS related care in developing countries. Yet few studies have sought to examine the limits of the support that caregivers provide (Singhatera, 2001). Most caregivers perform their arduous role in adverse condition. Little is known about how to facilitate the context that maximizes the effectiveness of caregivers (Campbell and Foulis, 2004). Much remains to be uncovered about the challenges of promoting community and social context that enable home-based caregivers to effectively care for their patients (Campbell and Foulis, 2004). Moreover, the Tanzania AIDS policy has declared HIV/AIDS as a national crisis and is now one of the top priority development agenda of the government along with poverty alleviation (URT, 2001).

1.3 Justification of the Problem

The increase of PLWHA in Tanzania has been accompanied with a rapidly increase of patients population while current health institutions cannot adequately provide quality health care. In addition to medical care, PLWHA require special care that includes psychological, spiritual, social, economic and legal support for themselves and their families. In most cases, medical professionals are overwhelmed by the demand of meeting these special needs, making special care for PLWHA unavailable to in the majority of the hospital/health facility based care systems. One of the alternatives of providing care for PLWHA and their families is using the Community Home Based Care (CHBC) approach. Well- tailored and managed CHBC programs can complement over burdened health facilities. This can be achieved through training community health workers on the basic nursing care and treatment of opportunistic infections prevention and nutrition information, psychological support, and referrals to medical facilities and community support services.

Despite its limitations and lack of additional support HBC has become the most important source of care and support for PLWHA in Northern Thailand (Singhatera *et al.*, 2001). In the Coast Region of Tanzania HIV/AIDS, prevalence rates in 2003-04 were 10.5% for women aged between 15-49 years and 3.9% for men aged between 15-49 years hence total prevalence rate is 7.3% (TACAIDS *et al.*, 2005). Research on the effectiveness of HBC service in Rufiji District is important as a basis for designing interventions that will be included in establishing a foundation to guide and strengthen HBC programmes activities in rural areas.

HIV/AIDS induces or deepens poverty. A few surveys on have shown that households whose members have AIDS experience a decrease in income due to, among others, huge rises in medical care spending thus deepening poverty. A decrease in income leads to reduced purchasing power resulting from diminished savings and disserving, Furthermore, AIDS results into a decrease in Labour force causing most of the rural areas to become underdeveloped. This is because not only that the rural areas are the primary sources of production but also most of the affected persons are in the active production age. It is clear that the HIV/AIDS epidemic has the potential of disrupting the achievement of the Millennium Development Goals (MDGs) (URT, 2004). HBC has become a significant contributor in the treatment, care and support of those infected and affected by HIV (Mohamed and Gikonyo, 2005). If treatment, care and support are met then HBC services will be able to improve the quality of life of the PLWHA. This could contribute to the achievements of (MDGs') reduce the speed of HIV, and reduce the impact of HIV/AIDS. Therefore is in line with millennium development goals and the national HIV/AIDS policy and therefore forms the rationale of the study.

1.4 Research Objectives

1.4.1 Overall objectives

The general objective of this study was to examine the effectiveness of HBC and management of PLWHA in Rufiji District.

1.4.2 Specific objectives

Specifically the study was intended to

(i) identify types of home based care offered

(ii) determine Characteristics of PLWHA under HBC system

(iii) determine best practices or bad practices for PLWHA

(iv) determine key stakeholders involved in the care for PLWHA

1.4.3 Conceptual framework

In order to obtain information on the above stated objectives and to identify the variables for data collection a conceptual frame work was developed. The conceptual frame presents a fragmentation of knowledge into diverse segment of unconnected statement. The types of variables shown in the conceptual framework for the research include, background variables such as age, sex, marital status, type and headship of a household. The dependent variables include socio-economic variables namely occupation, family size, education, HH-economic status, and socio-cultural factors namely religion and gender. These variables influence independent variables, effectiveness of HBC services to PLWHA. The conceptual framework is shown in Figure 1 and the key variables are defined in Table 1.

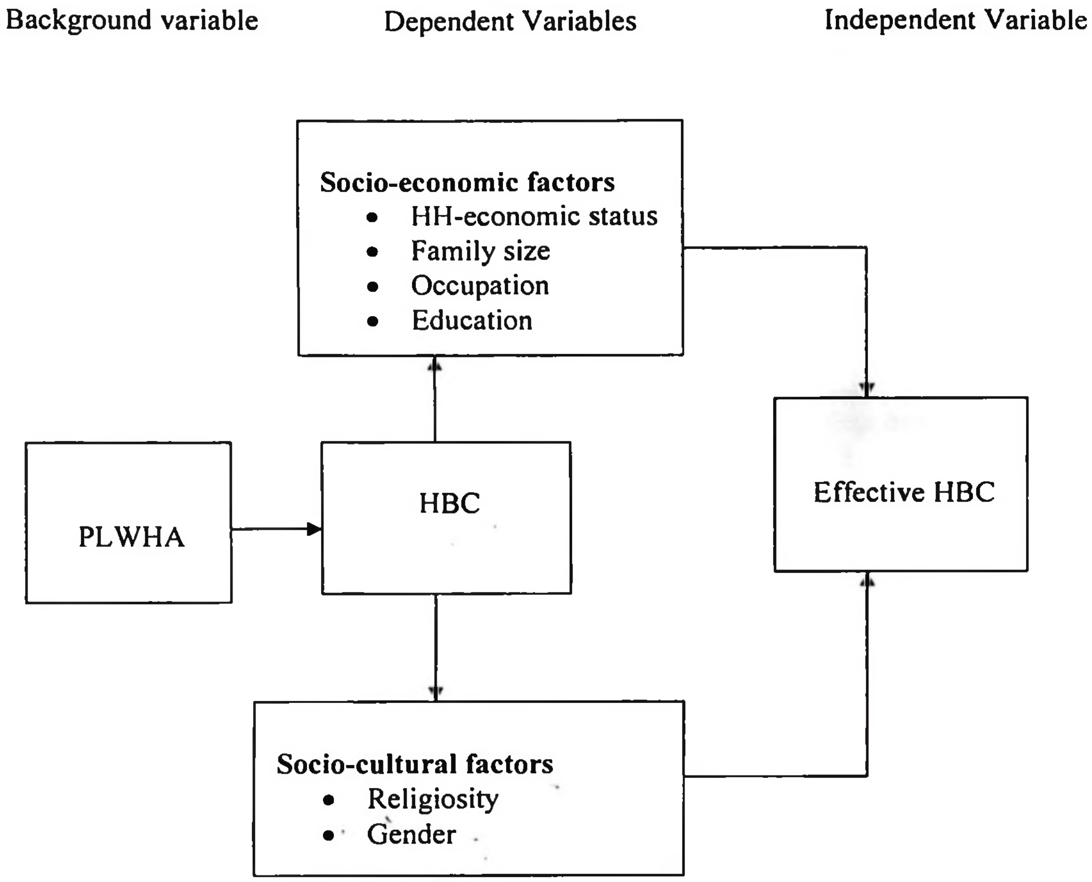

Figure 1: The conceptual frame work for the study of HBC and management of PLWHA in Rufiji district.

Table 1: Definition of the key variables used in the study

Variables	**Operational definition**
Age	No of years of the respondents
Sex	Being male or female in biological sense
Marital status	Married or single
Type of household	Household being headed by male or female
Family size	No. of people in the household
Occupation	Major economic activities performed
Education	Highest level of formal education attained
Religion	Being Christian or Moslem
Gender	Social relationship between male and female

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Overview

This chapter reviews some literature on HBC and management of PLWHA. The chapter begins with the overview, and proceeds with the definition of concepts in Section 2.2. The situations of HIV/AIDS globally are covered in Section 2.3. Section 2.4 describes the impact of HIV/AIDS on the health sector. Section 2.5 dwells on the history of HBC in Tanzania. The advantages and disadvantage of HBC are described in Section 2.6, while the HBC management needs of PLWHA are presented in Section 2.7. The HBC and community participation is presented in Section 2.8 followed by models of HBC which are presented in Section 2.9. Section 2.10 discusses the empirical research on HBC. Finally, the research gaps are presented in Section 2.11.

2.2 Definition of Concepts

2.2.1 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 services (MoH, 2005). 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 life (MoH, 2005). From various studies (MoH, 2005), 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 care giving family members. A well-functioning CHBC program which provides a continuum of care for persons with chronic illnesses beginning from a health care facility to the home environment 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 (MoH, 2005).

HBC has a variety of typologies, each representing a different delivery scheme, mix of services, staff and reach (Mohamed and Gikonyo, 2005). Some of the well known types include facility-based, community-based, and integrated (Mohamed and Gikonyo, 2005). The emphasis of each type of program tends to differ. For example, facility-based programs often focus on medical aspects of care involving teams including health professionals who can provide higher levels of care. CHBC programs emphasize on psychosocial support to PLWHA and their families and deliver their services primarily through volunteer networks in the community together with program staff, not specifically health professionals (Mohamed and Gikonyo, 2005).

2.2.2 The continuum of care

The continuum of care refers to the 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 provides comprehensive services to PLWHAs at three levels, namely facility, community and home levels. The patient receiving care must have access to all the three levels. A functional referral system must link all the 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 advanced stages of illness. Care and support programs are developed as a response to these needs and demands, which are determined by both biological and environmental factors.

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 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 (MoH, 2005).

2.3 HIV/AIDS Epidemic Situation Globally

Governments in the developing world have emphasized on the adoption and development of HBC as one of the strategies of mitigating the impact of HIV/AIDS on the health system. The HBC also is expected to meet the expectations of the sick, the families and the community. The task of providing the required HBC lies on the non-government organizations, communities and civil organizations. This is important especially considering that HIV/AIDS is the leading cause of Burden of Disease (BOD), accounting for about 6% of the BOD globally. More than 40 million people are suffering from HIV/AIDS globally (UNAIDS, 2004).

The HIV/AIDS has affected poor countries the most thus making the global inequality in health care services. About 70% of the global HIV/AIDS affected people live in Sub-Saharan Africa. It has also made the poverty levels in those countries to worsen. There is also a gender inequality with women being more affected than men. The main reasons for this include gender discrimination, socio-economic status, the greater effects of wars, and biological vulnerability (WHO, 2000).

The HIV has been isolated from many body fluids of infected persons. However, only blood, semen, vaginal fluids and breast milk has been implicated in the transmission of the disease. The HIV infection is acquired through unprotected sexual intercourse with an infected partner, exposure to infected blood and blood products, from a mother to the unborn child in the uterus, during delivery and/or during breast feeding. Sexual transmission is the most notorious mode of transmitting of HIV. More than 90% of adults in sub-Saharan Africa acquire HIV infection through unprotected sexual intercourse. There is also a possibility of Transmission of HIV through body fluids other than blood.

The HIV selectively attacks specific white blood cells that are essential for the coordination of the body's immune response. When these cells are destroyed, a process that may take months or years, the infected person becomes more susceptible to various infections than those with an intact immune system. When HIV penetrates the host cell, it produces a DNA copy of its nuclear material which combines with the host DNA cell, thus becoming a permanent part of an infected person's nuclear proteins. As more and more viruses are produced and leave the host cell, the infected cells die, thus reducing the body's immunity, leading to opportunistic infections (MoH, 2003).

The HIV/AIDS pandemic was first described in the early 1980s. In Tanzania the first three AIDS cases were reported in Kagera Region 1983. By 1986 all the regions in Tanzania reported cases of HIV/AIDS (MoH, 2003). HIV infection affects all sectors of the economy and is now one of the major causes of deaths in adults and children (NACP, 2001 cited in MoH, 2003).

The Government of Tanzania recognizes that comprehensive implementation strategies have to be instituted in order to reduce the escalating HIV/AIDS prevalence rate and provide support for those already infected or affected by HIV/AIDS. The Medium Term Plan III (MTP III) identifies care and support for PLWHA and orphans as one of the core comprehensive HIV/AIDS control and prevention strategies in the country. Dar es Salaam City adopted the care and support for PLWHA and orphans in its Medium Term Plan III for the 1998-2002. The 2003-2006 Health Sector HIV/AIDS Strategy for Tanzania also recognizes care and support as a critical component (PI, 2002).

2.4 Impact of HIV/AIDS on the Health Sector

The Impact of HIV/AIDS on the health sector includes excessive loss of lives of productive people thus posing a serious challenge to productivity. These impacts can be categorized according to the levels of the health system, namely the individual, the family, the community, and the health facilities (MoH, 2003)

It is reported that before a person dies of AIDS a normal adult will suffer an average of over 17 illnesses (WB, 1996). The world Bank estimated that in Tanzania an infected person would require over 280 days of care if one adds all life time sick days together, costing Tshs. 56 000/= or US dollars 290 in the nursing and drugs. A child would need a total of 200 days of care at cost of Tshs 37 600 or 195 US dollars (WB, 1996).

At patients, family and community level HIV/AIDS leads to loss of lives, loss of production and increased need and utilization of medical care. It has also been estimated that AIDS expenditure for care could absorb one quarter of the governments recurrent budget, thus the government will have to make difficult decisions regarding treating AIDS versus treating other illness (WB, 1999). As a consequences, HIV/AIDS has also brought with it new challenges of how to provide special care and support to those HIV/AIDS sufferers and their families. HIV has added a great burden to grossly under funded and already overstretched health sector, with a likelihood of compromising the quality of health care provision. The poor economic performance and inequalities in the health sector specifically in Tanzania have compromised the ability to address HIV/AIDS; to mitigate the HIV/AIDS impact in the health system governments have adopted among other strategies the promotion of HBC.

2.5 History of HBC in Tanzania

On searching for alternatives that can efficiently serve the needs and improve the quality of life of PLWHA, the Ministry of Health through DANIDA support established a HBC model in 1995 in the pilot districts (Koshuma *et al.*, 2000). The model extended care from the health facilities to the community, household and families. The support consisted of drugs, supplies, bicycles, and equipments to eight districts in Coast and Rukwa regions. One year later the Ministry of Health and Gesellschaft far Technische Zusammenarbeil (GTZ) (German International Cooperation) established a programme for voluntary counseling and testing (VCT) and an HBC in Mbeya Region. The main aim was to meet the needs of HIV/AIDS infected patients and their families at a reasonable cost. Under this programme in 1996 three hospitals (one mission and two public) started to provide HBC. In their model of HBC they planned to visit PLWHA once every week or as frequent as possible depending on the patients and their family needs. After training all HBC providers were provided with a kit to facilitate the provision of care to the PLWHA and the families. The evaluation which was done later revealed that most of the clients were satisfied. In addition, other benefits included the HBC services being closer to the communities and which also enhanced the acceptance of persons living with HIV/AIDS. The results influenced the decision that it was important for HBC to be included in all District Health Plans in the country. This would result into HBC integration in the District Health Care delivery system, the promotion and strengthening the continuum of care for PLWHA from health facilities to families (Koshuma *et al.*, 2000).

The coverage of HBC has been increasing from time to time. In December 1999 WHO provided drugs, supplies and equipment to Tanzania for the general care of HIV/AIDS patients. This donor support strengthened the continuity of HBC services at the district level. Later in 1999/2000 the UNDP provided an enabling support to extend HBC to Shinyanga and Kigoma Regions. Another development partner support was realized in July 2001 when Tanzania was selected to be among 10 African countries which would benefit from Italian initiative for the fight against AIDS in Africa. The programme aimed at strengthening community Based Care Services in 11 Districts in Tanzania mainland and Zanzibar. Through this support, HBC providers have been trained, medicines and recourses for HBC have been supplied, communities have been made aware of the services and clients in the participating district have being cared for (MoH, 2003).

The 2003 – 2006 Health Sector HIV/AIDS Strategy for Tanzania recognizes care and support as a critical component in the response to the epidemic. Currently, there are several groups providing HBC in the country and most of which are found in Dar es Salaam. In Dar- es – Salaam, the groups include CCBRT, PASADA, Pathfinder International, AMREF, WAMATA, IDC and MUHAS (MoH, 2003). The National Aids Control Programme (NACP) strategy envisages that about 5000 people will be receiving HBC by the year 2006 out of a total of 722 490 AIDS cases that have occurred since the beginning of the epidemic in Tanzania (MoH, 2002).

2.6 Advantages and Disadvantage of HBC

2.6.1 Advantages

The advantages of HBC services include improved health of the patients, identified needs to the community and breaking stigma. Improved health of patients is evaluated from both the patients and providers perspectives. It includes the description of positive changes witnessed among patients. It requires availability of correct interventions one of which is in place to make sure that patients take their medication according to the physician prescriptions. Patients on the other hand appreciate that their needs are met and there is no need to travel long distances for clinical services (SANDoH, 2002).

Community needs could include having the structures in place that will facilitate identification of client referral and other needs. It will also enable caregivers living in the communities through social networks to identify people with needs and problems and bring them to care providers. A formal communication infrastructure is often not unavailable. Therefore, establishing HBC will to large extent facilitate establishing such structures. Stigma has been one of the setbacks in the control of HIV/AIDS, and is one of the biggest challenges facing HBC programmes in Africa (Anderson *et al.*, 2001).

Caring of patients in their home is a means of breaking the cycle of fear for the terminal illness especially due to HIV/AIDS. PLWHA openness would reduce the level of stigma especially when they are satisfied with the care being provided. This will further facilitate constructive discussions and rational decisions on the means of transmission, prevention and cure.

The reduction of stigma and consequent acceptance and satisfaction of HBC by patients and relatives would also enhance the coverage and equity in the delivery of HBC. Instances of patients or family members requesting HBC caregivers to meet them outside their homes or leave their medicine at a shop nearby would be reduced extensively (SANDoH, 2002).

2.6.2 Disadvantages

Constraints facing the implementation of HBC are the lack of common understanding despite the attempts that have been made to adopt it. The lack of common operational understanding of what is HBC could reflect the varying contexts which determine the mode and contents of HBC thus, making common definition not of immediate importance. Due to limited access to HBC services, caregivers spend most of their day walking hours in attending patients (SANDoH, 2002). Stigma that is attached to HIV/AIDS jeopardizes the counseling process, care and support of these patients (MoH, 2002). Furthermore, lack of access to basic nutritional needs makes it difficult for patients to comply with the medication given, and thus exacerbating the attack of opportunistic infections and death rates to PLWHA (MoH, 2002).

HBC has been presented as a cost serving exercise particularly as a large share of hospital costs arise from in patient care. HBC may work in a more organized and densely populated urban setting where there is a level of community based skills, but it is more complicated in the rural areas due to long distances to be covered by any supporting outreach services (Loewenson and Kerkhoven, 1996).

2.6.3 Cost effective of HBC

Notwithstanding the advantage and disadvantages there have been objective efforts to establish cost effective HBC. In 1998 an operational research on cost effectiveness of HBC services and other factors affecting its impact on chronically ill patients to HIV/AIDS was conducted in Bagamoyo District. The main focus of the research was on the total time spent with patients, the distance traveled to see patients, and the drugs used. The findings revealed that the average cost of HBC was Tsh 1,862/= per day for the community located volunteer, Tshs 2,443/= per day for the HBC provided by a health worker. An average hospital base care was estimated to be Tshs. 4,921/= per day at Bagamoyo Hospital (Msumi and Msobi, 2000).

Guided by the information on HBC being cost effective it was decided that by February 2002 HBC services should have been established in 28 districts in the 6 regions. Also, the total numbers of 102 HBC trainers should have been trained in these districts (MoH, 2002).

On the contrary some other studies have not been able to document significant cost effectiveness of HBC. A study on cost and quality of home based care for HIV/AIDS patients done in Zimbabwe (Woelker *and* Hansen, 1998) revealed that the model of care was not significantly cost effective. In any case, however, hospital and home based care should be considered as complementing to rather than substituting each other. It has also been observed that HBC may not necessarily be much cheaper than models relying more intensively on a hospital based (especially if frequent home visits are considered a necessity). Thus HBC should be considered as an extension of the health system to communities and families. However, no one has ever given value to patients' wishes to die at home and the comfort realized from being with relatives and with familiar environment. There is also no sufficient information to conclusively compare home and hospital based care for HIV/AIDS patients since the clinical outcomes and quality of life of patients in the two models remains unclear thus justifying the need for further and extensive studies to evaluate HBC in resource poor countries (Woelker, and Hansen, 1998).

2.7 HBC Management Needs of PLWHA

Globally, it is estimated that 40.3 million people are HIV infected (UNAIDS, 2005) and in Tanzania, approximately 785 865 people are HIV positive (MoH, 2003). Among these less than 5000 patients are under HBC (MoH, 2006). A study done in the neighboring Kenya has shown insufficient number of providers are involved in HBC due to stigma that is still attached to people living with HIV/AIDS. However, there are many people in need of these services. The study findings suggested for moving from awareness creation to assisting the suffering through HBC (Amisi, 2003). It follows, therefore, that meeting the needs of these patients is challenging since many PLWHA feel isolated and overwhelmed. The medical and social services systems are unknown to those most needing them (UNAIDS, 2004). The needs are also defined by the morbidity conditions like diarrhea, nutrition and ulcers. Therefore, PLWHA who are under HBC would require a combination of intervention to meet their needs.

Medical needs are determined by the stage in the natural history of the diseases and the type of morbidity. The most important thing in meeting the patients' needs is the provision of HBC kit that contains medicines and supplies for treating of opportunistic infections and the prevention of HIV transmition (PI, 2002).

Apart from the health care needs the patient and family would need spiritual support and counseling from religious leaders and, psychosocial support from relatives, friends, neighbours and significant other, as well as supply of safe water and proper basic sanitation. The patient also needs legal support accessible and affordable housing, disinfectants and equipments like gloves, gauge and bandages (MoH, 1999).

HIV/AIDS related diseases exert a high demand on high nutritional value foods by patients particularly because of the rapid deterioration of the patient's physical condition due to inadequate food intake. The provision of adequate nutrition is thus a critical component of AIDS case management. There is a need for collaboration with other sectors which deal with food production while giving education to patients and family caregivers about nutrition supplements using locally available food (MoH, 2003).

Although care at home is provided freely, it has a lot of cost to the caregivers (WHO, 2004). Therefore there is need for political commitment and continued support is crucial for the success and sustenance of HBC.

At the national level, policy makers and politicians should address issues favouring HBC. There should be multi-sectoral and international collaboration on poverty eradication, employment opportunities, women empowerment and support on the vulnerable groups such as orphans, children living in the streets and drug abusers (MoH, 1999).

2.8 HBC and Community Participation

In principle, HBC has the potential to incorporate three forms of participation. Firstly, in the terminal stages of AIDS, little specialist hospital care can be given to patients in low-income countries where access to drugs and conventional medical treatments are restricted. In such settings, given appropriate training and support, lay people can be enabled to offer adequate rudimentary nursing skills. Most patients prefer to die with dignity in their familiar home surroundings, rather than in the alien environs of a hospital (Uys, 2003). In such context, HBC could be said to offer the environment most appropriate to the need of dying patients.

Secondly, in the light of increasing arguments for the close link between the provision of adequate aids care and the success of HIV prevention, it is reported that HBC provides a useful catalyst for counseling and education about HIV/AIDS amongst local families and communities. This is in the face of patchy levels of knowledge about HIV/AIDS in some communities, and the stigma, rejection and isolation suffered by so many people living with HIV/AIDS. Caring for the dying people in the communities rather than in more isolated hospital settings promotes firsthand awareness of the dangers and effects of HIV/AIDS, which are have argued to have played an important role in the reduction of HIV transmission in Uganda (Low-Beer and Stoneburner, 2003). Caring could also potentially encourage acceptance of aids patients in the community, especially through educating people that HIV is not transmitted by ordinary household contact such as sharing cups or touching.

Thirdly, in an ideal situation, local networks of home-based care could serve as channels for mobilizing local people to lobby for the interests of people living with AIDS not only at the local community level but also through regional and national structures. Ideally, such mobilization would enable local people to exert an influence on government policies and interventions at wider levels. It would also generate a community solidarity which might strengthen communities' abilities to address other challenges to their health and well-being. Small pockets of local participation (such as groups of HBC care givers working in small and geographically isolated area) may form the basis of wider social movements through which otherwise marginalized people might access the ears of more powerful social actors in articulating their needs and interest. The potential importance of such links is increasingly appreciated in the growing emphasis on the role of ‘partnerships’ in the discussions about how to strengthen communities to deal with the HIV/AIDS epidemic (Campbell, 2003).

2.9 Models of HBC

There are many stakeholders in the provision of HBC as there are HBC models that could be influenced by the provider. The analyses of 67 HBC programmes in Zimbabwe have been very informative on this issue (Woelker, and Hansen 1998). The analysis revealed the information on minimum package depending on type of HBC offered. These include financial assistance to patients and caregivers, provision of gloves, bleach and medical supplies, first visit within one week of discharge, seriously/terminally ill being visited at least once a week, full – time trained health worker programmes, structured training in nursing and counseling volunteers, access to as many health care supplies as required and access to as much food supplements as required by the patients (Msumi and Msobi, 2000).

In Tanzania, there are several modalities of HBC delivery. The Ministry of Health has and social welfare adopted the following model of HBC services delivery: hospital or facility based outreach using HBC provider, NGOs based using employed personnel, and community rooted using community volunteer and PLWHA frontline health care networks. This is HBC provision by patients together with their families with a strong focus on supportive and spiritual care (Msumi and Msobi, 2000).

These modalities provide a level of care that is qualitywise acceptable, and is cost – effective. Each modality has its advantages and disadvantages but the prime quality is that the shared responsibility of HBC will depend on the cost at the family and health facility levels, appropriate administration, logistics and supplies (Msumi and Msobi, 2000).

Table 2: Continuum of care: Models of HBC

Model Type	Description	Weakness	Strengths
Hospital – initiated	Hospital staff provide outreach care services	Costly, strong focus on medical care, no direct benefit to family and stigmatized	Easy monitoring and supervision, good link with supplies, access to professional staff and hospital referral possible
NGO – initiated (e,g., faith based, PLWHA associations)	Support groups established by NGO provide counseling, medical care, and home care	Eligibility may be biased or selective, weak links with hospitals, Isolated from supplies and hospital back – up, sustainability and coverage difficulties	May provide compressive care, accessibility, innovative and flexible
NGO – coordinated	NGO trains community members and / or family members to provide CHBC services; NGO provides follow up	-	Sustainability, Innovative, and considers specific community needs
Integrated	Patient support units established at hospitals where patients are counseled during their stay and discharge plans are made, which include follow – up care that is closer to home and / or home care	-	Government and community structures linked, hospital – referral possible, reduce stigma

Source: FHI (2004)

2.10 Empirical Research into HBC

At the individual level, various studies highlight how care givers are hindered by the lack of knowledge about how to deliver care in the most effective way. Thus, for example, a study done in Malawian highlights how care givers of children with AIDS often waste time and resources by needlessly seeking hospital treatment for the management of minor ailments which can be treated at home (Zimba and McInerney, 2001). The authors emphasize the need to adequately prepare care givers for their role – and to ensure regular home visits to reinforce the knowledge they have, and to fill any gaps. A study done in South African highlights how home based care givers in the absence of adequate training, mentoring and support experience considerably stress and distress than medical care personnel (Wainwright, 2002). Many other studies point out the ways in which care givers are undermined by the traumatic physical and psychological effects, including burnout and exhaustion in caring for dying people (Lindsey *et al.*, 2003). Lack of knowledge about pain control emerged as a key burden for care givers in a mult-country study (Harding *et al.*, 2003). A study in Uganda pointed out the strong emotional challenges facing care givers of children with AIDS, and who might already have witnessed these children falling sick, become incapacitated, lose their jobs, become stigmatized, and die (Sayson and Meya, 2001).

A study in Tanzania highlights how caring for AIDS patients in the terminal stages requires between three and seven hours a day in patient care-related activities alone (Nnko *et al.*, 2000). The study also highlights the immense challenges of nursing the needy and sometimes-difficult dying patients – some of whom may have had diahorrea 15 to 20 times a day; in situations where water had to be carried from a distance, and bed linen was a luxury. One care givers reported that her patient was so abusive that relatives advised her to abandon the patients altogether. Another spoke of her stress when her dying patient repeatedly begged her to adopt her three children after her death. The fact that she was unable to make this promise was a source of distress both to the caregiver and to the dying patient (Campbell and Foulis, 2004).

It is nearly always women, including young girls that carry the heaviest burden of care. Another study in Zambia described women as suffering from "unspeakable physical exhaustion, mental strain, economic hardship and emotional and social deprivation'' (Chabinga, 2002). At the household level, the study done in Ugandan highlighted how the demands of care givers distracted women from fulfilling other vital household roles, and other forms of income generating activities as well as non-AIDS related caring duties, particularly in female-headed households (Taylor *et al.*, 1996). A pioneering study in Malawi has had some success in mobilizing men as volunteer home-based care givers, although the authors emphasize that many challenges still remain (Bacon *et al.*, 2002). For example, children may be the least acknowledged care givers of terminal AIDS patients. This is backed up by studies in Zimbabwe and Botswana, where Lindsey *et al.* (2003) report that young girls in caring roles often miss school with some reporting depression, social isolation and sexual abuse.

In Tanzania a study on the impact of HIV/AIDS on rural livelihoods was cynical about the romanticized way in which the concepts of 'household and community resources' and 'household and community coping strategies' are used in talking about AIDS care (Rugalema, 2000). The author argues that masks the way in which many rural households may be completely destroyed by the social, economic and personal demands of caring for the AIDS patient. Households are often forced to 'cope' by curtailing food consumption, with drawing children from school (to save money, or free children to help with caring responsibilities), and selling vital survival assets such as livestock or even land. Such short term coping strategies often have long-term costs that jeopardize household recovery once the patient has died. According to Rugalema (2000) the use of concepts such as community resources and local assets serve as an excuse by governments and development agencies to do nothing or too little to alleviate the epidemic's effects on the impoverished care givers in households and communities.

Another study in India reported of the effectiveness of HBC as being influenced by pre-existing patterns of support and discord within the family (Campbell and Foulis, 2004). The author concludes that interventions might need to be tailored differently in different contexts depending on whether the household and family responses are positive or negative.

At the community level of analysis, several studies highlighted how the home-based care givers task is undermined by the stigmatization of PLWHA (Campbell *et al.*, 2004). This trend severely hinders the support the patients and care givers get from the community, making many patients to bank on the promises of confidentiality from their care givers, or attempt to hide the nature of their illness from their care givers altogether (Maimne, 2004). A study in South Africa (Russell and Schneider, 2000), highlights on how care givers often feel undermined by their obligation to maintain the confidentiality of their patient's diagnosis. One volunteer cited her despair at seeing the husband of one of her deceased AIDS patient involved unprotected sex with numerous women after his wife had died, and not being able to warn his sexual partners. Another one spoke of the tensions around having to lie about why she visited certain families so frequently, or how to explain why she devoted all her attention to only one patient the AIDS sufferer, in houses where there were also other (non-AIDS) sick or disabled people. Confidentiality of the service provision also meant that other community members with HIV/AIDS were not always aware that care and support were available.

2.11 Research Gaps

Previous studies on HBC in Tanzania have focused on the multi-level factors that undermine care givers on performing their duties. These include lack of knowledge, skills and support – both at the individual and organizational levels, physical and psychological burnout, and the destruction of household economic in the face of the demands of care, community stigma, and rejection. Little has been done to examine the determinants of effectiveness of HBC and management of PLWHA. Therefore, there is an information gap on the determinants of home-based caregivers to effectively care for their patients. This study attempted to fill this gap and the information obtained was intended to assist in designing and evaluating interventions on the HBC management of PLWHA in rural areas.

CHAPTER THREE

3.0 RESEARCH METHODOLOGY

3.1 Overview

The aim of this chapter is to explain the procedures used in the research. The chapter is divided into seven sections. Apart from overview in section 3.1, Section 3.2 presents the location of the research area and justification for its selection; Section 3.3 presents the research design used. Section 3.4 presents the sampling procedures that were employed. Section 3.5 presents the data collection process, followed by Section 3.6 which presents the data processing and analysis. Finally, Section 3.7 presents the methodological limitation encountered during the data collection process.

3.2 The Research Area and Justification for its Selection

The study was conducted in Rufiji District, Coast Region in Tanzania Mainland. The target populations were PLWHA who are members of Care International. Rufiji is one of the districts of that Tanzania which has a substantial number of PLWHA. This was revealed by the local authorities during my exploratory study, though no actual number was given at that time. Another reason for the selection of the place was that it convenient for the study in terms of short traveling time and monetary budget.

3.2.1 Geographical location and administrative units

Rufiji district is about 178 kms south of Dar es Salaam. The district is among the six districts in the Coast Region. The others being Bagamoyo, Kibaha, Kisarawe, Mafia, and Mkuranga. Rufiji district, located in the south of the Region, has 6 divisions with 19 wards, and is divided into 94 registered villages and 385 hamlets. The district covers an area of about 14,500 km^2 as shown in Figure 2.

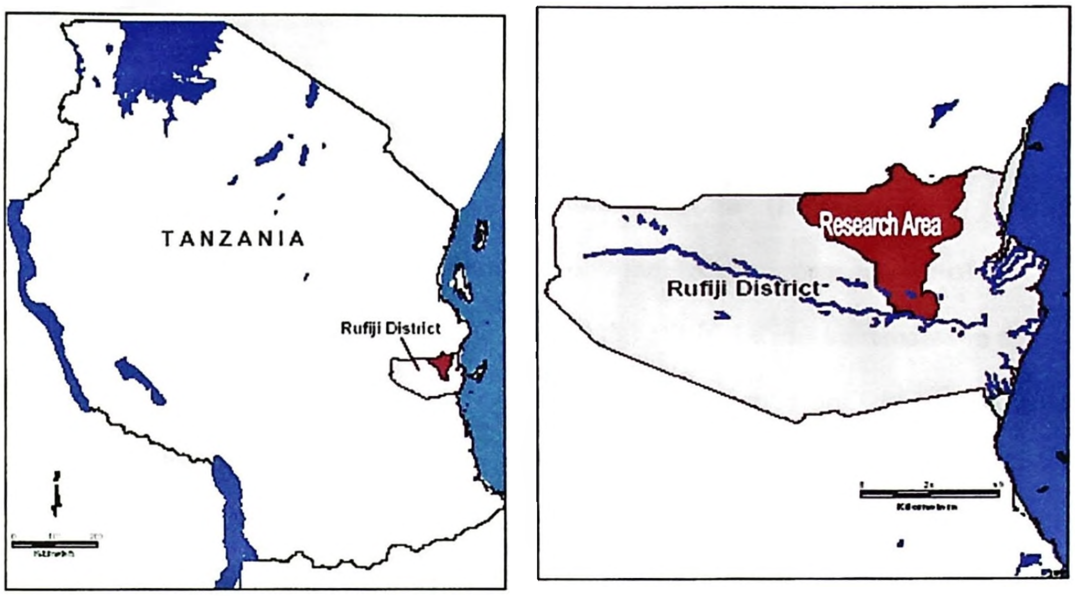

Figure 2: Location of Rufiji District research area, Tanzania

Source: Rufiji DSS, Tanzania 2002

3.2.2 Population and cultural aspects

According to Population and Housing Census General Report (2002), the district has a total population of 202 001 (TBS, 2002). The population density in the district is 12.5/km^2. The mean household size for the whole district is about 5.0 (TBS 1994). The district is largely rural, but the population is clustered around Utete (district headquarters), Ikwiriri, Kibiti, and Bungu townships.

Rufiji District is home to several ethnic groups. The largest of these is the Ndengereko, who, according to oral tradition, are the original inhabitants of the area. Other groups include the Matumbi, Nyagatwa (concentrated in the delta area), Ngindo, Pogoro, and Makonde. The majority of the people are Muslims, with a few Christians and followers of indigenous religions. In addition to local languages, Kiswahili is widely spoken; English is not commonly used in the area (Mwageni *et al.*, 2002).

3.2.3 Climate

Rufiji has a mean altitude of about 500 m above sea level. Its vegetation is mainly tropical forest and grassland. The district has hot weather throughout the year and two rainy seasons: short rains (October–December) and long rains (February–May). The average annual precipitation in the district is 800–1000 mm. A prominent feature of the district is the Rufiji River, with its large floodplain and delta it is the most extensive in the country. Mangrove forests flank the tributaries of the delta. The river, from which the district takes its name, divides the district geographically into roughly equal halves. The district is also a gateway to Selous Game Reserve which has a variety of wild animals, such as zebras, buffalo, hartebeest, monkeys, lions, hyenas, warthogs, and elephants (Mwageni *et al.*, 2002).

3.2.4 Socio – economic aspects of Rufiji District

The majority of the people in Rufiji are subsistence farmers. Farming areas are often set at a distance from family homes to take advantage of periodically flooded alluvial soils. With temporary houses located on farmland, this means that some households are often split geographically for up to 4 months of the year. The major crops in the district include cassava, maize, rice, millet, sesame, coconut, and cashew nuts. Fruit such as mangoes, oranges, pineapples, pawpaws, and jackfruits are also grown. Some residents are involved in fishing or small-scale commercial activities, such as selling wood products (for example, timber, furniture, and carvings).

The district has one hundred and eleven primary schools, (with standard grades 1–7), twelve secondary schools (all are Governments), a Folk Development College — a postprimary polytechnic (located in Ikwiriri township) and forty nine COBET centres

(Mwageni *et al.*, 2002). According to the 1988 population census (TBS 1994) more males (66%) than females (34%) are literate in the district.

Most villages in the district have a central shopping place and a market. The dwellings are simple, comprising a mixture of huts with walls made of mud and wooden poles with thatched or corrugated roofs as well as conventional brick houses in the townships. In the Rufiji floodplain, *dungus* (traditional shelters on stilts built to deal with flooding) are a common feature. Tap-water supply is very limited, and the majority of people rely on communal boreholes or natural-spring or river water for domestic purposes — a few use harvested rainwater (Mwageni *et al.*, 2002).

3.2.5 Transportation networks

The districts' main transportation route is the north–south that is Dar es Salaam – Lindi and Mtwara trunk road, most of which is paved. Unpaved feeder roads and tracks link most of the villages to this trunk road. Telephone facilities in the district are located in the three townships which includes Utete, Ikwiriri, and Kibiti and mobile phone networks is located in almost all the four townships. The district is not connected to the national power grid, but Ikwiriri Township has 24-hour diesel-generated electric power from the Tanzania National Electricity Supply Company (TANESCO). Other places that have electricity depend on private generators (Mwageni *et al.*, 2002).

3.2.6 Health infrastructure

The district has 58 health facilities: 2 hospitals (1 government and 1 mission), 5 government health centres, 44 government dispensaries, and 7 non-government dispensaries. Also drugs are available from many private shops and kiosks in the villages.

Many people also obtain services from traditional healers, including traditional birth attendants.

Malaria and waterborne diseases such as cholera and diarrhea are the major health problems in the area, according to both the health services and the local people. The major causes of mortality include acute febrile illnesses (including malaria), acute lower-respiratory infections, tuberculosis, AIDS, and perinatal illnesses. Immunization coverage in the area ranges from 85% for BCG (tuberculosis) to 66% for measles for children between the ages of 12–23 months old. About 89% of the population lives within 5 kms of a formal health facility. All villages and health facilities in the district have been positioned using GPS and mapped in a GIS database of the district health resources (Mwageni *et al.*, 2002).

3.3 Research Design

The cross-sectional research design was used in this study. This method allows data to be collected at one point in time and establishes relationships between variables for the purpose of testing the hypotheses (Babbie, 1990). This method is considered to be useful because of the time limit and resources available.

3.4 Sampling Procedures

3.4.1 The population

The population from which the sample for this study was drawn was PLWHA who are members of Care International. The sample also involved care givers of the patients who were too sick to be interviewed. Care International is the non-governmental organization working in the Coast Region, and deals with several development issues. The organization has been in the frontline in the war against HIV/AIDS. Care International provides a number of services to PLWHA including counseling and HBC Programmes.

3.4.2 The sample

The sample size for the research was determined by using the following formula recommended by (Kothari, 1993).

$n = Z^2pq/e^2$,

Where;

n = Desired sample size (when population is greater than 10,000).

Z = Standard normal deviate, set at 1.96 (in simple at 2.0) corresponding to 95% confidence level.

p = Proportion in the target population estimated to have a particular characteristic (in this case National HIV/AIDS prevalence of Coast region is 7.3%)

q = $1.0 - p$

e = degree of accuracy desired, usually set at 0.05 or occasionally at 0.02 (since the estimate should be within 2% of the true value)

Therefore the sample size was:

$$n = Z^2pq/e^2 = (1.96)^2 . (0.073) . (1 - 0.073)/(0.05)^2$$

$$= 3.8 \times 0.073 \times 0.927/0.0025$$

$$= 102.85992$$

To adjust for non-response, two respondents were added to make a sample of 104.

3.4.3 Sampling technique

At the organization level, purposive stratification sampling procedure was used to ensure the desired representation of specific subgroups; males and females (adults, elderly, youth/children). The stratification involved identifying Female-Headed Households (FHH), Male Headed Household (MHH) and Child Headed Household (CHH). Purposeful sampling was also used to sample key informants to obtain supplementary information on HBC management of PLWHA. Respondents were chosen using systemic sampling during pre – testing of the questionnaire which was done prior to the actual survey to establish the validity of the questionnaire.

3.5 Data Collection Methods

3.5.1 Instruments for data collection

The main instrument that was used to collect data in this study was a structured questionnaire that contained open and closed – ended questions. Every sampled individual among the PLWHA was interviewed. Those who where too sick to be interviewed were presented by their caregivers on behalf of other members of the households. The instrument was supplemented with a guide to semi structured interview administered to key informants so as to obtain more information on HBC management of PLWHA. The questionnaire were translated into Kiswahili so as to facilitate the interview, which were pilot tested to PLWHA in Ikwiriri, Kibiti and Bungu by interviewing 10 respondents and three key informants, in October 2006. The purpose of the pre - testing was to determine the validity of the instruments. Based on the results of the pre – testing, the questionnaire were amended and duplicated to get the final versions (Appendix 1), which were used, in the actual data collection.

3.5.2 Secondary data

Secondary data were obtained from Care International, the Ministry of Health and Social Welfare its departments such as NACP, Tanzania Commission for AIDS, Sokoine National Agriculture Libraries, Muhimbili University College of Health and Allied Sciences Medical Libraries, UN Agencies, collaborating NGOs, Regional and District Medical Officers, Regional and District AIDS Coordinators, and published and unpublished research papers from the Internet. The focus was on obtaining the data which could not be obtained sufficiently through primary data sources.

3.6 Data processing and Analysis

The data were coded, summarized and entered into a spread sheet manually before they were entered into a computer. Moreover, before the analysis, the data were cleaned and verified. The data analysis was done using the Statistical Package for Social Sciences (SPSS) of the Development Studies Institute (DSI) of the Sokoine University of Agriculture (SUA). Both qualitative and quantitative data analysis were done.

3.7 Scope and Limitation of the Study

a) This study has presented findings from a survey conducted in Rufiji District to examine the determinants of effectiveness of HBC and management of PLWHA Based on different levels of development, availability of health facilities, economic differences, socio – cultural differences and differences on modalities. The findings from this study cannot be used to draw a generalized conclusion representing the whole country; except shedding light on the general HBC Management of PLWHA services provided that might not differ much from those in other district not included in this study. Thus, if time allowed and funds were available it would have been appropriate to cover more districts for the purpose of obtaining more information which could be used to make more objective and more meaningful conclusion.

b) There was a problem of some of the respondents selected for the study of refusing to be interviewed without appointments and information from their volunteer care services provider. This made the study to postpone the interview till the appointments were made by the service provider.

c) There was a problem of accessibility to some of the respondents homes selected for the study. For instance, some of the respondents in Ikwiriri, Kibiti and Bungu area where the study was to be conducted were up to 10 kms from the area where the population was clustered. Sometimes, the researcher and his assistance had to walk long distances to reach the respondents selected for the study. In some cases bicycles were hired as a means of transport to such places.

d) Some of the questions asked in this study were sensitive, touching one' personal and private behaviour (i.e. sexual behaviour) in some cases, it took a long time to interview one person. Thus the overall process was time consuming as failure to do so could have led to getting false information. However, this does not mean that there were no outliers. Generally, the majority of the respondents gave correct information since it was counterchecked by FGDs information.

CHAPTER FOUR

4.0 RESULTS AND DISCUSSION

4.1 Overview

This chapter presents the results and discussion of the study on HBC and management of PLWHA in Rufiji District. It is divided into four main sections. Apart from the overview, Section 4.2 discusses the characteristics of the PLWHA under HBC system, Section 4.3 describes practices for PLWHA, followed by Section 4.4 which shows the types of HBC offered, and finally Section 4.5 looks into key stakeholders involved in the care for PLWHA.

4.2 Characteristics of PLWHA Under HBC System

The characteristics of the respondent include demographic variables namely. sex, age, marital status, type of household, head of household, number of household members. In addition, socio-economic characteristics of the respondents that are occupation, education and religion are also presented.

4.2.1 Demographic characteristics of the respondents

The respondents were asked to state the exact year in which they were born. The exact ages were then grouped into five-year age groups. This grouping was done because it is standard way of grouping ages. The results in Table 3 show that nearly one quarter of the respondents (23.1%), was in the age group of 30 – 34 years. Age distribution of the respondents revealed that the disease has the strongest impact on the individuals in the prime time of their working and childbearing years.

Table 3: Demographic characteristics of the respondents (%)

Categories	Male	Female	Total (N = 104)
Age in years (N = 104)			
0 – 4	5.6	2.9	3.8
10 – 14	5.6	.0	1.9
15 – 19	.0	4.4	2.9
20 – 24	5.6	16.2	12.5
25 – 29	11.1	8.8	9.6
30 – 34	25.0	22.1	23.1
35 – 39	19.4	17.6	18.3
40 – 44	16.7	8.8	11.5
45 – 49	5.6	11.8	9.6
50 – 54	2.8	4.4	3.8
55 – 59	2.8	2.9	2.9
Marital status (N = 104)			
Single	33.3	20.6	25.0
Monogamous	36.1	27.9	30.8
Polygamous	5.6	7.4	6.7
Divorced	.0	23.5	15.4
Widow/Widower	.0	16.2	10.6
Separated	19.4	2.9	8.7
Cohabiting	5.6	1.5	2.9
Total	**34.6**	**65.4**	**100.0**

The respondents were also asked about their marital status. The categories used to classify the marital status of the respondents were, monogamously married, single, divorced, widow/widower, separated, polygamous and cohabiting. The summary of the findings presented in Table 3 show that the majority of the respondents interviewed are married (37.4%) i.e. monogamously married (30.8%) and polygamously married (6.7%). This implies that these respondents who are in the union of marriage have a high rate of contracting HIV/AIDS than other groups. A quarter of respondents are single which include children, students and those who are not yet in the legal age of marriage. The remaining respondents are in the categories of widowed, divorced and separated. Females in this group are more affected than males; this can be termed as the victim of AIDS and discrimination as the result of their sero-positive status.

Sexwise PLWHA under HBC in the study are more likely to be female than males. This can be explained by the fact that in the context of the HIV/AIDS epidemic, biological and socio economic factors make women particularly vulnerable, and most of the HIV positive women contract the disease during antenatal clinic where each pregnant woman during her first visit to the clinic is are required to attend VCT for HIV/AIDS. Those who are found positive opt for HBC for the well being of their health as well as for avoiding transmitting HIV to their unborn children.

4.2.2 Housing conditions/characteristics

4.2.2.1 Type of household and leadership

Whether a household is headed by a female or male may influence care and wellbeing of the family within the household. The respondents were asked to state their type of household. The results in Table 4 show that about two thirds of the HHs (62.5%) are male headed and one third are female headed household. Despite the fact that households are headed by males socially women are still assigned the role of care givers, as wives, mothers and grandmothers.

The respondents were also asked whether they themselves are the heads of the households. The results in Table 4 indicate that more than fifty percent (57%) of the respondents are not directly responsible on the caring of family matters which means most of them are still under the care of parents and other relatives. The results also show that about two fifth (42.3%) are the actual heads of HHs of the PLWHA.PLWHA and who are also head of household have great burden on the care of family.

Table 4: Housing characteristics (%)

Categories	Male	Female	Total (N = 104)
Age profile of household members			
0 – 4	22.2	23.5	23.1
5 – 9	16.7	10.3	12.5
10 – 14	2.8	11.8	8.7
15 – 19	2.8	2.9	2.9
20 – 24	2.8	4.4	3.8
25 – 29	5.6	2.9	3.8
30 – 34	16.7	14.7	15.4
35 – 39	19.4	10.3	13.5
40 – 44	2.8	7.4	5.8
45 – 49	5.6	4.4	4.8
50 – 54	0.0	2.9	1.9
55 – 59	2.8	2.9	2.9
55 +	0.0	1.5	1.0
Number of HH member (Mean 4.4)			
1 – 5	72.2	58.8	63.5
6 – 10	25.0	35.3	31.7
11 – 15	2.8	5.9	4.8
Heads of household			
Yes	52.8	36.8	42.3
No	47.2	63.2	57.7
Type of household			
Male headed household	77.8	54.4	62.5
Female headed household	22.2	45.6	37.5
Total	**34.6**	**65.4**	**100.0**

4.2.1.2 Number of household member

Taking into account that the size of a household may affect the family welfare situation within the household, the number of the household members was recorded. The results show that the average household size among the surveyed household was 4.4.

The surveyed households were grouped into "five year age group" of members in the households. The results in Table 4 show that over half (62.5) of the respondents reported belonging to a household size from 1 to 5 members. The second group had the household size of 6 to 10 members with less than one third (31.7%) followed by another group with 11 to 15 members –there were few households (4.8%) in this category. This implies that more than a half of the respondents belonged to a household with at least five members.

The larger the families size the more the household expenditure that is required to maintain the family welfare. This implies that there is a high expenditure requirement in meeting family needs apart from caring for the sick.

4.2.1.3 Age profile of household members of the respondents

Age profiles of household members of the respondents are presented in "Five year age grouping" to facilitate data analysis. The findings show that age profile of household members ranged from a minimum of 0 years to a maximum of over 55 years. The data in Table 4 indicate that about one fifth (23.1%) of the household members are within the range of 0 – 4 age group. The households of PLWHA have high number of dependants below the age of 20. The age profile of the household members has a larger proportion in the younger age than in the older ages; these are children who have high risk of becoming orphans soon after the death of their parents or guardians.

4.2.3 Socio – economic characteristics of the respondents

4.2.3.1 Occupation

In order to determine whether there is any influence of economic activities of the PLWHA under the HBC services, the respondents were asked to state their principle occupation. The categories used to capture the information on the main occupation of the respondents were classified as none, agriculture, petty trade, fishing, business, carpenter, student, formal employment, casual labour, livestock and mechanic. The findings presented in Table 5 show that almost one third of the respondents were engaged in agriculture. These findings were expected since agriculture is the backbone of our economy in Tanzania. However, there is a considerable proportion of PLWHA involved in other activities such as petty trade, fishing, business, carpenter, student, formal employment, casual labour, livestock, mechanic and other related activities. Generally, the occupational structure of rural sector as is the case in many developing countries is an agriculture based. The agriculture sector remains the main employing sector and more females employed in agriculture than males. It implies that there is a substantial economic and social impact on the affected individuals, households and the whole nation because of the reduction of labour availability (due to poor health and mortality) and a reduction in capital resources allocated to production (in favour of care-giving and funeral expenses). The reduction and loss of labour through illness and then death lead to a direct loss in production and productivity of food and cash crops, and hence the reduction in income as well as a reduction in food security.

4.2.3.2 Highest level of education attained

Education provides PLWHA with the knowledge and skills that can lead them to a better understanding of HIV/AIDS information and health education related to their condition. During this study the highest level of education attained by respondents were asked. The categories used to classify information on person's education level were no formal education, completed primary school, few years in primary school, completed secondary education and student. The results in Table 5 show that the highest level of education reached by respondents is primary school (45.2%), followed by no formal education at all reported by few of the respondents (37.5%). In contrast, males are more educated than females. It is impressive that most of the respondents had some formal education that could enable them to read leaflets with information on HIV/AIDS and hence be able to act accordingly.

Table 5: Socio-economic characteristics of respondents (%)

Categories	Male	Female	Total (N = 104)
Current occupation			
Agriculture	22.2	39.7	33.7
None	13.9	22.1	22.1
petty trade	8.3	23.5	18.3
Fishing	22.2	1.5	8.7
Business	5.6	5.9	5.8
Carpenter	13.9	4.8	4.8
Student	5.6	.0	1.9
Formal employment	.0	1.5	1.0
Casual labourer	2.8	1.0	1.0
Livestock	.0	1.5	1.0
Mechanic	2.8	.0	1.0
Highest level of education attained			
No formal education	33.3	39.7	37.5
Few years in primary school	8.3	13.2	11.5
Student	5.6	.0	1.9
Completed primary school	47.2	44.1	45.2
Completed secondary education	5.6	2.9	3.8
Religion			
Moslem	64	94.1	93.3
Christian	4	5.9	6.7
Total	**34.6**	**65.4**	**100.0**

4.2.3.3 Religion

Addressing spiritual needs is an important aspect in any type of care; chronically ill patients often lose hope and reason to continue to live. This is often relieved through reassurance and spiritual care. Thu the respondents were asked to state the religion to which they belong. The results in Table 5 revealed that the vast majority of the respondents (93.3%) are Moslems. This implies that if religion aspects would be used to mobilize HBC services to PLWHA they would play a great role in encouraging the affected persons to have a positive view of life and to forgive others and oneself for any misconceptions and liabilities.

4.3 Best Practices or Bad Practices for PLWHA

There are services that can dramatically reduce – off – life suffering and improve the lives of PLWHA. This depends on the appropriateness of the services provided to PLWHA

According to this study, the services were categorized into bad and best practices in accordance to the effectiveness of the services provided to PLWHA in enhancing their quality of life.

4.3.1 Best practices for PLWHA

4.3.1.1 Getting medical support at home

The respondents were asked whether they were provided with medical services at their home. The findings in Table 6 show that almost half (53.8%) of the respondents interviewed reported having been provided with medical support at home.

Table 6: Best practices for PLWHA (%)

Categories	Male	Female	Total (N = 104)
Getting medical support at home			
Yes	58.3	51.5	53.8
No	41.7	48.5	46.2
Services obtained for behaviour change			
IEC material (flyers and posters)	36.1	45.6	42.3
Medial source (radio, TV, newspapers, pamphlets etc.)	33.3	26.5	28.8
Trainings	16.7	16.2	16.3
Group meetings	13.9	11.8	12.5
Information about HIV / AIDS			
Yes	58.3	76.5	70.2
No	41.7	23.5	29.8
Care on hygiene practices			
Yes	52.8	63.2	59.6
No	47.2	36.8	40.4
Involved in any faith - based domination / organization			
Yes	55.6	63.2	60.6
No	44.4	36.8	39.4
Referral to clinic or health facility			
Yes	69.4	69.1	69.2
No	30.6	30.9	30.8
Total	**34.6**	**65.4**	**100.0**

The explanations for this could probably be due to the fact that most of the care givers are within the areas of their clients PLWHA. Also there is a good communication between them. The numbers of male who receive medical support at home are higher (58.3%) compared to female clients (51.5%), this is because males are unlikely to go to the clinic or health facility to obtain services. It is perhaps the cultural inhibitions that men must not display emotions and doing the contrary is not to be considered manly.

4.3.1.2 Services provided to the respondents for behaviour change

The respondents were asked to state whether they obtained services for behaviour change through various sources of information on HIV/AIDS. The aim of the question was to determine the level of awareness and to investigate the commonest sources of HIV/AIDS information services obtained for behaviour change.

In respect to with the services provided on sources of HIV/ADS information for behaviour change, the results in Table 6 show that the most common sources of information for both males and females are IEC material (flyers and posters), media source (Radio, TV, newspapers, pamphlets), with almost about one third (36.1%) of the male respondents and about a half (45.6%) of female respondents citing IEC as the main source. Furthermore, one third (33.3%) of the male and about a quarter (26.5%) of the female respondents receive information through media source. Similar findings were reported in the 1996 DHS, whereby males were reported to have been more likely than female to cite media source such as newspapers and pamphlets as sources of information on AIDS (Mkama, 2006). On the other hand, women are more likely than males to receive information on about AIDS from health workers using IEC materials (flyers and posters).

4.3.1.3 Information about HIV/AIDS

The respondents were asked to state if they have enough information about HIV/AIDS. According to Table 6, about three-quarter (58.3%) of male respondents and about three quarter (76.5%) of female respondents indicate that they have adequate information about HIV/AIDS from various sources. This implies that due to their sero-positive status PLWHA make various efforts to obtain much information on HIV/AIDS that will enable them to enjoy longer quality and productive life.

4.3.1.4 Care on hygiene practices

The respondents were asked whether they obtain care on hygiene practice or not. The results in Table 6 show that about three fifth (59.6%) of the respondents indicated that they obtain care on hygiene practices. Also the data in Table 4.4 show that two fifth (40.4%) of the respondents reported that they do not obtain care on hygiene practices. The findings revealed that PLWHA maintaining personal hygiene practices. These practices would help to prevent them from getting problems associated with poor hygiene practices. Good hygiene helps to prevents diseases that could worsen the condition of PLWHA.

4.3.1.5 Involvement in faith - based domination/organization

To ascertain involvement in spiritual affairs the respondents were asked if they are involved in any faith – based domination/organization. Table 6 show that there are more PLWHA who are involved in faith based organization (60.6%) than those who are not. This implies that PLWHA will growth spiritually. After they have grown spiritually they would be able to cope with the disease.

4.3.1.6 Referral to clinic or health facility

The respondents were asked to state whether or not they have had obtained referral services. The results Table 6 show that about two thirds (69.2%) of the male respondents and also about two third (69.1%) of the female respondents had obtained referral services. This means that services and resources provided by volunteer service providers are not able to meet the PLWHA immediate needs. Referral is very essential to ensure continuity of quality care for PLWHA at all times.

4.3.2 Bad practices for PLWHA

4.3.2.1 Times when medical support was not available at home

The findings about whether or not there was a time the respondents had missed medical support is presented in Table 7. The respondents were asked to state if there is a time they had missed medical support. It is observed that the majority of the respondents (67.3%), reported to have missed medical support at home at one time or another. This reflects a prevalence of drug shortage some times and that PLWHA do not get and use drugs as recommended by their physicians.

Table 7: Bad practices for PLWHA (%)

Categories	Male	Female	Total (N = 104)
Time missed medical support at home			
Yes	61.1	70.6	67.3
No	38.9	29.4	32.7
Information about where to get legal aid			
Yes	41.7	33.8	36.5
No	58.3	66.2	63.5
Participate in physical activities			
1 - 2 days	52.8	41.2	45.2
3 - 4 days	25.0	44.1	37.5
5 - 7 days	22.2	14.7	17.3
Days of taking balanced diet			
1 – 2 days	58.3	48.5	51.9
3 – 4 days	33.3	30.9	31.7
5 – 7 days	8.3	20.6	16.3
Consideration in food (quality) from the family			
Yes	25.0	32.4	29.8
No	75.0	67.6	70.2
Home member received training on caring for PLWHA			
Yes	38.9	36.8	37.5
No	61.1	63.2	62.5
Psychosocial support from home members			
Yes	44.4	39.7	41.3
No	55.6	60.3	58.7
Getting support from family members for taking medications			
Yes	36.1	27.9	30.8
No	63.9	72.1	69.2
Suffering from loneliness and neglect from family and community			
Yes	61.1	64.7	63.5
No	38.9	35.3	36.5
Spiritual care from the faith based organization			
No	83.3	89.7	87.5
Yes	16.7	10.3	12.5
Total	**34.6**	**65.4**	**100.0**

4.3.2.2 Information about where to get legal aid

Access to care and treatment is a basic human right for any one with HIV/AIDS irrespective of age, sex, socioeconomic status or race. The respondents were asked to state whether they have had any information as to where to get legal aid. The results in Table 7 show that two thirds of females (66.2%) and about three fifth (58.3%) of males have had no information on where to get legal aid. This implies that PLWHA are probably likely to miss their basic rights of information on aspects regarding to writing of will, PLWHA support groups, and access to care and treatment.

4.3.2.3 Participation in physical activities

Data in Table 7 presents the data on the number of days the respondents participate in physical activities. From the data the respondents reported to have been participating in physical activities (45.2%) in 1 -2 days, followed with (37.5%) in 3 – 4 days and lastly is (17.3%) in 5 – 7 days. The findings revealed that PLWHA participate in physical activities in a number of days in a week. This means that participation in physical activities help them to remain in good health, but it would be much better if their participation in physical activities is done daily. Exercises make lungs work better and hearts beat stronger. It also helps the limbs from being stiff as well as relieving stress improves one's mood, and reduces anxiety and depression (AMREF, 2005).

4.3.2.4 Days taking balanced diet

Nutrition is an important aspect in the management of PLWHA. The respondents were asked to state the number of days they used to take balanced diet in a week. The results shown on Table 7 indicate that almost half (51.9%) of the respondents used to take balance diet in 1 – 2 days, followed by (31.7%) of the respondent who used to take balanced diet in 3 – 4 days (31.7%), and lastly (16.3%) of the respondents who were used to take balance diet in 5 – 7 days. This implies that PLWHA would not be in a position to restore their health and protecting their body against opportunistic infections. Taking balanced diet daily strengthens the body's defence system thus protecting the body against infections and improves the well being of the body.

During FGDs one of the participants said,

> *"we are dealing with people who have long treatment regimes and nutritional problems so there is a need to involve and encourage the other public sector agencies dealing with social welfare, education food and nutrition to be key players and share responsibilities in providing HBC"*

4.3.2.5 Consideration in food (quality) from the family

The respondents were asked to state if their families care about the quality of food they eat. The results in Table 7 show that the majority of the respondents (70.2%) did not obtain consideration in food (quality) from the family and few respondents (29.8%) obtain consideration in food (quality) from the family. This means that PLWHA do not obtain any food required of their choice in appropriate time from their family.

4.3.2.6 Training on caring for PLWHA to family members

Respondents were asked whether or not their home members had received training on caring for PLWHA. Data in Table 7 shows that about three fifth (62.5%) of the respondents family members did not receive any training on caring for people living with HIV/AIDS and about one third (37.5%) of the respondents had received training on caring for PLWHA. This implies that the families provide care for their relatives in the absence of any training or support. Also, the data indicates that training is provided to PLWHA relatives mainly during critical stages of illness. It is important that the family is involved and educated about the needs of the PLWHA.

4.3.2.7 Psychosocial support from home members

Psychosocial support is an important part of long- term management and support of any chronic illness. The respondents were asked to state if they have had any psychosocial support from their home members. The results in Table 7 show that about three fifth (58.7%) of the respondents reported not to have received psychosocial support from their home members. The data also revealed that almost two fifth (41.3%) of the respondents have had received psychosocial support from their home members. This implies that it is very possible for PLWHA to avoid being involved in social activities which they can manage in the community/family for example community meetings or church/mosque and this can be because of the stigma or discrimination attached to the HIV/AIDS.

4.3.2.8 Getting support from family members on medications

The respondents were asked whether they were getting support from their family members on taking their medication. The results in Table 7 show that the majority of the respondents (69%) do not get support from family members on taking medication. This implies that PLWHA are at a high risk to consequences of poor ARVs adherence such as inadequate viral suppression, incomplete immune reconstitution, viral resistance to current drugs, limited future treatment options and consequently negative impact on the durability of drugs regimes. The support from a family, friends and other people outside the HBC team is very important to ensure adherence to ARVs medication.

4.3.2.9 Suffering from loneliness and neglect from family, neighbours or community members

The respondents were asked to state if they were suffering from loneliness and neglect from family, neighbours as well as community members. The results in Table 7 show that the majority of the respondents (68.9%) reported to have been suffering from loneliness and neglect from family, neighbours as well as community members. These findings reveal that PLWHA are more vulnerable to sickness and death because of the likelihood of not getting psychosocial support. PLWHA need a lot of support, encouragement and acceptance from family and community members.

During FGDs, stigma and discrimination were reported in all the study sites. This has been revealed after the participants were asked to state the problems they faced during delivering HBC services to PLWHA. The respondents reported that PLWHA were being characterized as the "walking dead people", "people of low social morale", and as "promiscuous people".

4.3.2.10 Spiritual care from the faith - based organization

Given the evidence that spiritual support is an effective means of helping PLWHA to cope with their feelings and is an important aspect in any type of care. The respondents were asked to state if they had obtained any spiritual care from faith-based organization. Results in Table 7 show that the vast majority of the respondents (87.5%) reported not to have obtained care from faith-based organizations groups. This means that the community/religious groups are not mobilized to play part in the provision of home based care services to PLWHA. This implies that PLWHA are visited as patients with chronic illness and not because of their openness as PLWHA.

During FGDs, participants were asked about the aspects of home based care they considered to be important in their area. One of the key informants commented as follows:

> "*Dealing with HBC for PLWHA require a multi-sectoral approach, one that involves different implementing partners including donors, international non-governmental organizations, community based organizations, the government, influential leaders, faith-based organizations, community leaders, PLWHA, and HIV/AIDS prevention, care, and support activities that allow clients to receive HBC linkages to facility-based care,*

linkages to socio-economic and food support, psychological counseling, and legal support".

4.4 Determining the Types of Home Based Care Offered

This aspect was reported during FGD, after the participants were asked to state the kind of HBC that were offered, they reported that the kind of HBC offered was the one which involved NGO's. The reflection of this is found in the following response by one of the participants:-

> *NGO trains community/family member on how to provide HBC services to PLWHA. Also, there is a regular supervision by NGO's officers to each care provider and his/her clients to asses the extent to which the services is provided and the development of the patients and the care provider in general.* This information is reflected in the data presented in Table 2.

4.5 Key Stakeholders Involved in the Care for PLWHA

4.5.1 Responsibility of provision of care during sickness in the household

There is clear evidence that family members always play a big role in the caring of PLWHA in their homes. The respondents were asked to mention responsible relatives who provide care to the sick in the household. The results Table 8 show that about two fifth (47.2%) of the male respondents and about three fifth (58.8%) of the female respondents mentioned female relatives as being responsible for providing care for the sick at home. The data also reveal that one quarter (25.0%) of the male respondents and about one third (35.3%) of the female respondents also stated that it is the responsibility of female child to provide care when PLWHA fall sick. Also, one sixth (16.7%) of the male respondents and one twentieth ninth (2.9%) of the female respondents reported that it is the responsibility of male relatives to provide care when PLWHA fall sick. Furthermore, one ninth (11.1%) of the male respondents and one twentieth ninth (2.9%) of female respondents reported that it is the responsibility of male children to provide care when PLWHA fall sick. From the findings it is revealed that female followed next with female child that carry the heaviest burden of caring for PLWHA.

Table 8: Key stakeholder involved in the care for PLWHA

Categories	Male	Female	Total (N = 104)
Responsible for caring during sickness in the household			
Female relative/mother	47.2	58.8	54.8
Female child	25.0	35.3	31.7
Male relative/further	16.7	2.9	7.7
Male child	11.1	2.9	5.8
Visits to provide services for PLWHA			
Volunteer service provider	66.7	80.9	76.0
Nurse practitioner or a physician	13.9	16.2	15.4
Family members	19.4	2.9	8.7
Total	**34.6**	**65.4**	**100.0**

4.5.2 Visits by a care provider from community home – based care programme

The respondents were asked to state caregivers who frequently visit their homes to provide services to PLWHA. The results in Table 8 show that about two thirds (66.7%) of the male respondents and four fifth (80.9%) of the female respondents reported to have been frequently visited by volunteer service providers. Also, one seventh (13.9%) of the male respondents and about one sixth (16.2%) of the female respondents reported to have been frequently visited by nurse practitioner or a physician. Furthermore, about one fifth (19.4%) of male respondents and one twentieth nine (2.9%) of female respondents reported to have been frequently visited by family members. This implies that PLWHA are visited by care providers who have formal and practical training or with low level of practical training as well as those who have no training at all such as family members. Findings also revealed that female are more visited (80.9%) than males (66.7%). This can be explained by the reason that disclosure for females higher than that for males. The efficiency of HBC services for PLWHA is solely depends on the type of HCB visiting programmes implemented by the caregivers visiting the patient's homes.

CHAPTER FIVE

5.0 SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

5.1 Overview

In the previous chapter, the results and discussion of the findings of the research were presented. This chapter presents the summary of the research findings, conclusions, recommendations and areas for further research.

5.2 Summary of the Main Findings of the Study

5.2.1 Characteristics of PLWHA under HBC system

5.2.1.1 Demographic characteristics of the respondents

A total of 104 respondents participated in the study out of these 68 were females and the remaining 36 were males. The majority of the respondents were aged 30 – 34 years. The age of the respondents revealed that the disease has the strongest impact on individuals in their prime working time and childbearing years. Most of the respondents interviewed were married.

The majority of the households with PLWHA were MHHs. Furthermore, the study found out that most of the respondents were not directly responsible for the caring of the family matters which means they were are still under the care of parents and other relatives.

On the number of household members, the results show that the average household size among the surveyed household with PLWHA was 4.4 people.

The findings of this study also show that the age profile of household members ranged from the minimum of 0 years to the maximum of over 55 years. The data indicate that about one fifth (23.1%) of household members are in the age group of 0 – 4 years. The age profile of the household members has a larger proportional in the younger age than in the older ages.

5.2.1.2 Socio – economic characteristics

In terms of the socio – economic characteristics of the respondents, the majority of the respondents had primary level of education. It is revealed that males are more educated than females. Regarding occupation of PLWHA, almost one third of the respondents (33.7%) were engaged in agriculture activities. A few were involved in petty trade, fishing, business, carpenter, students, formal employment, casual labour, livestock and mechanic.

Among the important cultural variables to HBC and the management of PLWHA is religion. The study found out that the vast majority (93.3%) of the respondents were Moslems. This implies that if religion was used to mobilize HBC services to PLWHA, it would play a great part in encouraging the people to have positive altitudes to life and to forgive others and oneself for any misconceptions and liabilities.

5.2.2 Best or bad practices for PLWHA

Services that can reduce – off – life suffering and improve the lives of PLWHA, according to the appropriateness of the services provided to PLWHA, and which were categorized as bad or best practices for PLWHA depending on the effectiveness of the services provided in enhancing the quality of life for PLWHA.

5.2.2.1 Best practice for PLWHA

Regarding information on HIV/AIDS the findings show that most of the respondents have adequate information about HIV/AIDS from various sources. This implies that due to their sero-positive status PLWHA make efforts to obtain much information on HIV/AIDS that will enable them to enjoy longer quality and productive life.

In respect with services on sources of HIV/AIDS of information on behaviour change, the study has shown the most common sources of information for both male and female are IEC material (Flayers and posters), medial source (Radio, TV, newspapers, pamphlets etc), also respondents reported medial source as their means of getting information on HIV/AIDS.

The findings of this study also revealed that PLWHA maintain standard of personal hygiene to help prevent themselves from getting problems associated with poor hygiene practices.

5.2.2.2 Bad practices for PLWHA

It is revealed that majority of the respondents (67.3%), reported to have missed medical support at home at one time or another. This reflects prevalence of drug shortage at times and that PLWHA do not get and use drugs as recommended by their physicians. The findings of this study also have shown that PLWHA lack information about where to get legal aid. This implies that PLWHA are probably likely to miss their basic rights in areas such as in heritance, writing of wills, PLWHA support groups, and access to care and treatment.

The findings of this study also have shown that family members of the PLWHA did not receive training on HBC for PLWHA. This implies that the families provide the care for their relatives in the absence of any training or support. Also, the data indicate that training is provided to PLWHA relatives mainly during critical stages of the PLWHA illness. It is important that the family is involved and educated about the needs of the PLWHA.

Also, the findings of this study have revealed that PLWHA are suffering from loneliness and neglect from family, neighbours as well as community members. This implies that PLWHA are more vulnerable to sickness and death because of being less likely to obtain psychosocial support. PLWHA need a lot of support, encouragement and acceptance from family and community member.

5.2.3 Type of HBC offered and key stakeholders involved in the care for PLWHA

The kind of HBC offered is the one which involves NGO's. The provision of care during sickness in the household was found to be the responsibility of female relative followed next with female child, that carry the heaviest burden of care.

5.2.4 Conclusions

The study findings have shown that PLWHA have adequate information about HIV/AIDS. Most common media sources of information for both male and female are IEC material (Flyers and posters), media source (radio, TV, newspapers and pamphlets). The study findings have also shown that PLWHA are being supplied with medical support at home. It further revealed that PLWHA had times that have missed medical support at home. Further more the study has revealed that there is little knowledge on the balance diet and it's important in the management of HIV/AIDS; women are much better on the knowledge than males. The study also observed that female relatives and female child are the one responsible on provision of caring of the PLWHA during sickness in the household. The majority of PLWHA family members did not receive training on caring of people living with HIV/AIDS. The majority of PLWHA reported that they are suffering from loneliness and neglect from family, neighbours as well as community members.

5.3 Recommendations

a) Programme/policy

i) For effective HBC to PLWHA, HIV/AIDS education and volunteer services training should be culturally appropriate and gender specific. It is therefore recommended that policy makers should listen to what PLWHA think and believe to ensure acceptable and appropriate programme.

ii) The study results have shown that the majority of PLWHA interviewed reported to have been visited by volunteer service provider. It is recommended therefore that policy makers should be aware that HBC programme cannot be successful unless they revive active support and participation from the government, NGO's and communities.

iii) The study recommended that policy makers should propose stigma and discrimination in HBC to be treated/identified as a separate goal to be overcome when implementing HBC services to PLWHA in the community.

b) NG'Os

i) The study finding have shown that a good proportion of PLWHA interviewed were not aware as to where to get information on legal aid. It is recommended therefore, that programmes that promote legal aid awareness be introduced or strengthened along side with other services provided to PLWHA. Waiting for the promotion of legal aid awareness to those who are already at advanced stage of illness may be too late for them to access legal information and hence care and treatment for HIV/AIDS.

ii) The study findings have also revealed that there is little involvement of faith-based organization on spiritual care in the provision of services for PLWHA. It is recommended, therefore, that, intervention programmes need to involve faith – based organization so as to strengthen the effectiveness of HBC programme for PLWHA.

b) Service care provider

The study findings have shown that are times when PLWHA have missed medical support at homes. This calls for strong improvements of HBC drug kit to service care provider

c) Community

The study results have shown that a large percentage of PLWHA interviewed have enough information about HIV/AIDS. Intervention programmes need to look more into stigma and discrimination behind services for PLWHA among the community than it does into lack of information. It is recommended to that awareness programmes that promote discussion and mobilization for formation of groups of PLWHA in the community be instituted. Such programmes can help to overcome barriers towards misconceptions and myths on PLWHA and HBC services.

5.4 Areas for Further Research

In all the focus group discussions held with key informants it was suggested that dealing with HBC for PLWHA require a multi-sectoral approach involving different implementing partners for effectiveness delivery of HBC to PLWHA. If partners have indeed to play such a key role in supporting HBC for PLWHA, there is a need for effective and various partnerships style and strategies. This is an issue that needs to be looked at through further research.

i) As have been observed in the study, stigma and discrimination is clearly associated with HBC for PLWHA. Therefore, it would be particularly useful to proceed with research about stigma and discrimination with HBC to PLWHA.

ii) The study has highlighted a Moslem dominance. Religion constitutes an important component when dealing with the beliefs and morals of people. Consequently, it would be meaningful to conduct research in areas with different cultural settings and make a comparison on how faith based institutions deal with HBC for PLWHA.

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APPENDINCES

Appendix 1: Questionnaire on home based care and management of people living with HIV/AIDS in Rufiji District

People living with HIV/AIDS questionnaire

Interviewer's code: [ ]

Questionnaire No: [ ][ ]

Date of interview: [ ][ ] [ ][ ] [ ][ ]

Date Month Year

INTRODUCTION

Good morning/Good afternoon,

My name is ....from Sokoine University of Agriculture, Morogoro I am carrying a study in home based care and management of people living with HIV/AIDS in Rufiji district. Recommendations from the study findings are expected to contribute towards improving contexts for effective home based care of PLWHA. You have been selected among the PLWHA from which data will be collected. I assure you that all the information provided during this interview will be treated confidentially and be used for the purpose of this study only.

Section one: Background characteristics

1. Name of the Hamlet ……………………………..…..House No………………

2. Name of the respondent ………………………………………………………

3. Age: (in years) [ ]

4. Gender (Please observe) Male/Female

   1 = Male; 2= Female [ ]

5. What is your current occupation?

   1 = Formal Employment; 2 = Self employment; 3 = Casual labourer

   4 = Business; 5 = Petty trade; 6 = Carpenter; 7 = Mason;

   8 = Mechanic; 9 = Agriculture; 10 = Livestock; 11 = Fishing

   12 = Student; 13 = None; 14 = Other (specify)……………………… [ ]

6. What is your marital status?

   1 = Single, 2 = Monogamous married; 3 = Polygamous marriage;

   4 = divorced; 5 = Widow/Widower; 6 = Separated;

   7. Cohabiting; 8 = Other (specify)………………………………………[ ]

7. What is the type of your households?

   1 = Male headed household; 2 = Female headed household;

   3 = Other (please specify)……………………………………………[ ]

9. Are you head of household?

   1 = Yes; 2 = No [ ]

8. What is your religion?

   1 = Christian; 2 = Moslem; 3 = Traditional

   4 = No religion; 5 = Other (specify) ……………………………………[ ]

10. What is your highest level of education attained?

   1 = Few years in primary school; 2 = Completed primary school;

3 = Few years in secondary education; 4 = Completed secondary education

5 = Higher education; 6 = No education; 7 = Student

8= Other (specify) ....[ ]

11. Did any member of your home receive training on caring for PLWHA (or home – based care?

1= Yes; 2 = No [ ]

12. Do you get (provided with) medical support at your home?

1 = Yes; 2 = No [ ]

13. Is there any time that you missed medical support at your home when your actually needed it?

1 = Yes; 2 = No. [ ]

14. Have you ever been referred to clinic or health facility?

1 = Yes; 2 = No. [ ]

15. What kind of assistance did you receive? *(With probing to obtain the response, tick all that was obtained)*

1 = Drugs for prevention/treatment of infectious disease [ ]

2 = Pain relief medications [ ]

3 =Medication for opportunistic infections [ ]

4 = Drugs for Tuberculosis (TB) treatment [ ]

5 = ARV services [ ]

6 = Nutrition care and support [ ]

7 = Other *(please specify)*................................ [ ]

16. Do you get psychosocial support (e.g. supportive counseling) from our home members?

1 = Yes; 2= No [ ]

17. At present how many are you in your household? .... [ ]

18. What is the age profile of your household members?

Household member	Age	Household member	Age
1.		3	
2		4	

19. Within the household, who provide most care especially when you are sick?

1 = parents; 2 = Relatives; 3 = Older child; 4 = Wife/husband; 5 = others (please specify)... [ ]

20. Do you get enough food from your household?

1 = Yes; 2= No [ ]

21. How many times per day do you take food?

1 = Once/day; 2 = 2 times/day; 3 = 3 times/day; 4 = times/day [ ]

22. How many of the last seven days have you taken a balanced diet with all six-food groups?

1 = 1-2; 2 = 3 – 4; 3 = 5 – 7 [ ]

23. Do you get consideration in food (quality) support from the family to ensure adherence of preventive therapies, to ARV and other prescribed medications to suit your condition?

1 = Yes; 2 No [ ]

24. Do you get support from your family members for taking your medications, including taking life-long medications such as, ARVs? (For those taking ARVs)

1 = Yes; 2 = No [ ]

25. What assistance do you receive when receiving ARV treatment?

1 = Drugs; 2 = Nutrition care and support;

3 = Food assistance; 4 = Adherence counseling [ ]

26. What is the frequency of visits by a care provider from community home-based care programmes?

1 = None; 2 = Monthly; 3 = Fortnight; 4 = Fortnight; 5 = weekly/Daily [ ]

27. Who frequently visit you at your home to provide HBC services?

1 = Volunteer; 2 = Professional trained staff; 3 = Family members [ ]

Section two: Services provided for PLWHA

28. Do you obtain care on hygiene practices (e.g. oral, skin, hair and environmental care (toilet facilities) at your home?

1 = Yes; 2 No [ ]

29 Do you obtain the emotional support from the family members especially during times of any chronic illness?

1 = Yes; 2 No [ ]

30. Are there times that you think you suffer from loneliness and neglect from your family, neighbours or community members?

1 = Yes; 2 No

31. After you known to be living with HIV/AIDS do care givers interact with you and include you in decisions regarding your care?

1 = Yes; 2 No [ ]

32. Are you involved in any faith-based dominion/organization?

1 = Yes; 2 = No [ ]

33. Do you obtain spiritual care from the faith-based organization you are involved?

1 = Yes; 2 No [ ]

34. Do you obtain information about where to get legal aid that you may need(e.g. areas such as inheritance, writing of wills and human rights, join PLWA support groups)?

1 = Yes; 2 No [ ]

35. What services have you obtained on behaviour change in the last twelve months?

1 = training

2 = Group meetings

3 = IEC materials (flyers and posters)

4 = Media sources (radio, T. V. Newspapers, pamphlets/posters, T-shirts, painted walls, road signs, meetings, plays, stickers) ;

5 = Other (please specify).. [ ]

36. Would you say you have enough information about HIV/AIDS?

1 = Yes; 2= No [ ]

37. On how many of the last seven days did you participate in at least 30 minutes of physical activity? (Total minutes of continuous activity, such as walking, swimming, biking) other than you do around the house or part of your work?

1 = 1-2; 2 = 3 – 4;3 = 5 – 7 [ ]

38. Have you experienced changes in living standards after being living with HIV/AIDS?

1 = Yes; 2 No [ ]

Appendix 2: Guidelines for focus group discussion (FGD) and key informants

1. What home based care services are you offering to PLWHA?
2. What are your sources of funds?
3. What kind of HBC are you offering?
4. What are the problems facing you in delivering HBC services to PLWHA?
5. Do you receive any assistance from government? If yes, which assistance?
6. What aspects of home based care do you consider to be important in your area?
7. In your opinion, what aspects should be considered in examining the determinants of effective HBC management of PLWHA?

SPE