COMMUNITY HOME-BASED CARE

PART I: Caring for Family Members with HIV/AIDS and Other Chronic Diseases

PART II: Implementing a Community Home-based Care Programme

Action Research in Kenya

September-October 2000

World Health Organization
2001
© World Health Organization, 2001

This document is not a formal publication of the World Health Organization (WHO), and all rights are reserved by the Organization. The document may, however, be freely reviewed, abstracted, reproduced and translated, in part or in whole, but not for sale nor for use in conjunction with commercial purposes.

The views expressed in documents by named authors are solely the responsibility of those authors.
Community Home-based Care

PROJECT MANAGER: Dr. Miriam Hirschfeld, WHO HQ, Geneva, Switzerland.

PRINCIPAL RESEARCHER: Dr. Elizabeth Lindsey, Short Term Consultant, WHO, Emeritus Professor, University of Victoria, B.C., Canada

TECHNICAL RESEARCH COORDINATOR: Dr. Elizabeth Ngugi KRN, KRM, KRSC, Senior Lecturer, Department of Community Health; Primary responsibilities: Nursing, Health Education, Educational Methodology, and Counselling University of Nairobi, Kenya

RESEARCH TEAM:
Dr. Violet Kimani, Medical Anthropologist and Sociologist, Professor, University of Nairobi
Dr. Mutuku Mwanthi, Senior Lecturer, Epidemiologist, Environmental and Occupational Health, University of Nairobi
Dr. Joyce Olenja, Senior Lecturer, Medical Anthropologist, Sociologist, University of Nairobi.

ACKNOWLEDGEMENTS:
The conceptual development as well as the research tools are based on many years of family caregiving research by Drs Tamar Krulik and Miriam Hirschfeld. Dr Krulik spent her sabbatical leave in the fall of 1999 at WHO and was instrumental in developing the research protocol.

Without Dr Elizabeth Lindsey’s vast expertise in community care and qualitative research, this project would not have been possible.

Dr Elizabeth Ngugi and the Kenya Team provided the culturally appropriate expertise and knowledge without which such a project could never succeed.

In particular, we would like to acknowledge the important support of Dr Peter Eriki, WHO Representative, Kenya, the Ministry of Health, Nairobi, Kenya, and the WHO Regional Office for Africa

Special thanks to Drs Crump and Edwards, WHO/TDR for allowing to use their photographs for the cover of the publication (Web ID 9204299 and 9604502)

Last but not least, we would like to acknowledge the support of Ms Geraldine Bellevaux, CCL, and Ms H. Mbele-Mbong, OSD, in finalizing the manuscript.
# TABLE OF CONTENTS

**EXECUTIVE SUMMARY** ........................................................................................................... 1

**INTRODUCTION** ....................................................................................................................... 4

**KENYA: AN OVERVIEW** .......................................................................................................... 6
  - Geography ............................................................................................................................... 6
  - Demography .......................................................................................................................... 6
  - HIV/AIDS in Kenya ............................................................................................................... 7
  - Health Sector Reform ........................................................................................................... 9
  - Organization of the Health Sector ....................................................................................... 10
  - Health Service Delivery ....................................................................................................... 11
  - Home-Based Care ............................................................................................................... 12

**PART I: THE STUDY** ................................................................................................................ 15
  - METHODOLOGY .................................................................................................................. 15
  - POPULATION AND SAMPLE ............................................................................................. 15
  - STUDY LOCATIONS ............................................................................................................. 16
  - DATA COLLECTION .............................................................................................................. 17
    - Access to Participants and Informed Consent ................................................................. 18
    - Research Integrity ........................................................................................................... 19
  - DATA ANALYSIS .................................................................................................................. 20

**RESULTS** ................................................................................................................................ 20
  - Demographic Variables of Family and Caregivers ............................................................ 20
  - Illness, Treatment and Caregiving Variables ....................................................................... 22

**THE IMPACT OF CAREGIVING** .............................................................................................. 25
  - Elderly women as Caregivers ............................................................................................. 25
    (a) Providing physical care ................................................................................................. 26
    (b) Feeling exhausted and overwhelmed ......................................................................... 26
    (c) Experiencing abuse, stigma and isolation .................................................................. 26
    (d) Living in poverty ......................................................................................................... 27
    (e) Neglecting their own health ....................................................................................... 27
    (f) Ignorance in the provision of care and access resources ........................................... 27
    (g) Maintaining spiritual beliefs ....................................................................................... 28
  - Young Children as Caregivers ......................................................................................... 28
    (a) Poverty ......................................................................................................................... 29
    (b) Vulnerability ................................................................................................................ 29
    (c) Lost opportunities ....................................................................................................... 29
    (d) Lack of information and support ............................................................................... 30
    (e) Stigma and isolation ................................................................................................... 30
    (f) Foregone age appropriate activities .......................................................................... 30
(g) Lack of moral development ........................................... 30
(h) Rebellion ................................................................. 31

Orphan Care ........................................................................ 31
(a) Family disintegration .................................................. 31
(b) Bereavement and emotional stress .............................. 32
(c) Lack of knowledge about income generation ............. 32
(d) Problems of inheritance rights ............................. 32

Issues Related to the Provision of Home-Based Care ........... 33
(a) Poverty ......................................................................... 33
(b) Stigma, Rejection and Abuse .................................. 33
(c) Lack of Education, Information, Supervision and Support ................. 34
(d) Lack of an Adequate Health Care Infrastructure ....... 36
(e) Vertical Versus Integrated Programmes of Care ........... 38
(f) Desirability and Feasibility of Implementing VCT ...... 39

LIMITATIONS OF THE STUDY ........................................... 41

CONCLUSION ...................................................................... 42

RECOMMENDATIONS ....................................................... 43

PART II: IMPLEMENTATION OF COMMUNITY HOME-BASED CARE ........................................... 50

CONCEPTUAL FRAMEWORK FOR COMMUNITY HOME-BASED CARE ........................................... 50

(i) Nature of the Programme ........................................... 51
(ii) Eligibility Criteria ...................................................... 52
(iii) Eligibility Assessment .............................................. 54
(iv) Benefits ................................................................. 54
(v) Programme Operation ............................................... 56
(vi) Finance ................................................................. 57
(vii) Coverage .............................................................. 58
(viii) Cost ..................................................................... 59

IMPLEMENTATION OF COMMUNITY HOME-BASED CARE IN KENYA ........................................... 60

National-level Responsibilities ........................................... 61
District-level Responsibilities ........................................ 63
Local-level Responsibilities .............................................. 64
Integration of Services ................................................... 66
Quality Assurance ......................................................... 67
Financing CHBC ............................................................ 68
(a) National-level government ........................................ 68
(b) District-level government ......................................... 69
(c) Local-level government ............................................. 69

Eligibility for CHBC ......................................................... 70
Supplies and Equipment ................................................. 71
Human Resources ........................................................... 71

CONCLUSION .................................................................. 72
LIST OF TABLES

Table 1: Results and Interventions ................................................................. 3
Table 2: Key Informant Respondents ......................................................... 18
Table 3: Focus Group Respondents ............................................................ 18
Table 4: Family and Orphan Demography ................................................. 20
Table 5: Demographic Variables of Caregivers ......................................... 21
Table 6: Composition of Caregivers ......................................................... 22
Table 7: Illness Related Variables ............................................................. 23
Table 8: Quality of Life of Caregivers ....................................................... 24
Table 9: Impact of Caregiving ................................................................. 24
Table 10: Level of Satisfaction with Caregiving ....................................... 24
Table 11: Conceptual Framework for CHBC ............................................ 51
Table 12: National-Level Responsibilities for CHBC ............................... 63
Table 13: District-Level Responsibilities for CHBC ................................. 64
Table 14: Local-Level Responsibilities for CHBC ..................................... 65
**LIST OF ABBREVIATIONS**

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>NHSSP</td>
<td>National Health Sector Strategic Plan</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-Government Organization</td>
</tr>
<tr>
<td>PHC</td>
<td>Primary Health Care</td>
</tr>
<tr>
<td>DMS</td>
<td>Director of Medical Services</td>
</tr>
<tr>
<td>CSW</td>
<td>Commercial Sex Worker</td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>DOTS</td>
<td>Direct Observation Therapy System</td>
</tr>
<tr>
<td>STD</td>
<td>Sexually Transmitted Diseases</td>
</tr>
<tr>
<td>IGA</td>
<td>Income Generation Activities</td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
</tr>
<tr>
<td>PWA</td>
<td>Person Living with AIDS</td>
</tr>
<tr>
<td>CHW</td>
<td>Community Health Worker</td>
</tr>
<tr>
<td>CBD</td>
<td>Community-Based Distributor</td>
</tr>
<tr>
<td>CBO</td>
<td>Community Based Organization</td>
</tr>
<tr>
<td>FGD</td>
<td>Focus Group Discussion</td>
</tr>
<tr>
<td>TBA</td>
<td>Traditional Birth Attendant</td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
</tr>
<tr>
<td>CHBC</td>
<td>Community Homes-Based Care</td>
</tr>
<tr>
<td>NACC</td>
<td>National AIDS Control Committee</td>
</tr>
<tr>
<td>NASCOP</td>
<td>National AIDS and STD Control Programme</td>
</tr>
<tr>
<td>MOH</td>
<td>Ministry of Health</td>
</tr>
</tbody>
</table>
EXECUTIVE SUMMARY

In the year 2000 over 2.2 million HIV infected people live in Kenya of which 100,000 are children. Sporadic attempts have been made to develop a home-based care programme for people living with HIV/AIDS and their orphans, but with an over stretched health care budget, and overwhelming health care needs, this important strategy has not been actualised. Recently the World Bank loaned Kenya US$50 million for prevention and care across the continuum for HIV/AIDS infected and affected people. As part of this initiative, this intervention study will contribute to the implementation of community home-based care (CHBC) in Kenya. The overall purpose of this study was to determine the priority needs and the interventions necessary to assess, plan, develop and implement an effective CHBC programme. In particular, this study addressed the following overall objectives:

➢ Explore and describe the impact of caring for ill family members upon older women and children.
➢ Examine the impact of orphan care on families affected by HIV/AIDS.
➢ Identify and strengthen complimentary organizations and supportive community structures for CHBC.
➢ Identify and strengthen mechanisms for referral and support.
➢ Develop intervention strategies to retain the informal caregivers as a valuable resource, complementing the formal health care system.
➢ Develop recommendations for action and change to public policy to provide sustainable support for orphan care and CHBC.
➢ Assess the desirability and acceptability of introducing voluntary counselling and testing (VCT) into community based health care.

Data Collection

Individual interviews were conducted with 53 family caregivers and 27 key informants (including community health workers (CHW) Community-based distributors, nurses, social workers, traditional birth attendants (TBA), community leaders, members of religious organizations and NGOs, health educators and Ministry of Health personnel). In addition 6 focus group discussions were conducted with CHWs, community leaders, TBAs and family caregivers. In total 120 people were interviewed.

Organization of Manuscript

The manuscript is divided into two sections. In Part I, the results and recommendations from of the Kenyan CHBC study are presented. Part II contains a conceptual framework that addresses issues, questions and considerations for implementation of CHBC. This is followed by the application of the conceptual framework to the results and recommendations from the Kenyan CHBC study.
PART I: The Study

The results of the study were organized into three broad categories; (a) the impact on elderly women and children caregivers and orphan care, (b) issues related to the provision of CHBC, and (c) the desirability and feasibility of implementing VCT.

Elderly caregivers complained of physical exhaustion, abuse, stigma and isolation, poverty, personal neglect, and ignorance, while maintaining strong spiritual beliefs. Young caregivers experienced poverty, vulnerability, lost opportunities, lack of information and support, stigma, abuse and isolation, foregone age appropriate activities, lack of moral development, and in some cases, rebellion.

Orphans had similar problems to young caregivers with the added challenges of family disintegration, bereavement and emotional stress, lack of knowledge in job training and income generating activities (IGA), and problems with inheritance rights.

Issues related to the provision of CHBC included poverty, stigma, rejection and abuse, lack of education for health care workers, caregivers and patients, and lack of an adequate health care infrastructure for CHBC. In particular, lack of a functioning infrastructure lead to inadequate referrals, scarcity of supplies at the periphery of care, an unreliable waiver system, poor communication between various health care providers, and lack of an affordable (or free) transportation system. In addition, various health programmes were vertical in their approach to patient care and were poorly integrated into the overall primary health care (PHC) system.

Voluntary testing and counselling was found to be acceptable to community members and would be utilized within PHC.

PART II: Implementation of CHBC

The results and recommendations of the study were then applied to a conceptual framework for CHBC implementation. Issues and questions were raised to determine the exact nature of the programme, the development and assessment of eligibility criteria, what benefits should be provided, how the programme would be operated and financed, who would receive coverage, and what the overall costs of the programme might include. These issues were addressed questions at the national, district and local levels of government. Finally, intervention strategies were suggested for sustainable CHBC in Kenya.

Table 1 provides an overview of both salient findings and recommendations presented in Part I, as well as the intervention strategies suggested in Part II.

This study comes at a critical time in Kenya as responsible partners begin to plan and implement CHBC for PWAs, people with chronic illnesses, orphans, and caregivers in Kenya. This study is seen as an important contribution to this initiative.
<table>
<thead>
<tr>
<th>Results/Recommendations</th>
<th>Intervention Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Implementation of CHBC with active participation of all stakeholders</td>
<td>Involve relevant stakeholders at the national, district and local levels of government, including caregivers and patients</td>
</tr>
<tr>
<td>Use a conceptual framework to develop and implement CHBC</td>
<td>Organize and administer CHBC within a sound operating and monitoring programme for action and sustainability</td>
</tr>
<tr>
<td>Identify elements of CHBC</td>
<td>Identify costs, fiscal responsibility, financial sustainability, benefits, coverage and eligibility criteria</td>
</tr>
<tr>
<td>Integrate CHBC into PHC</td>
<td>Strengthen PHC, provide adequate supplies and resources, integrate vertical health programmes into PHC</td>
</tr>
<tr>
<td>Educate CHBC health and social service personnel, caregivers and patients in care, prevention and treatment at home</td>
<td>Develop multidisciplinary, sustainable education programmes in CHBC prevention, care and treatment</td>
</tr>
<tr>
<td>Strengthen referral system</td>
<td>Develop a system of referral from hospital to the home and vice-versa</td>
</tr>
<tr>
<td>Integrate VCT into continuum of care</td>
<td>Develop sustainable, affordable VCT throughout the healthcare system</td>
</tr>
<tr>
<td>Reduce stigma, rejection, isolation and abuse</td>
<td>Involve leaders, media, educators, health and social service providers in HIV/AIDS awareness and sensitivity programmes</td>
</tr>
<tr>
<td>Promote discussion on death, dying and the provision of wills</td>
<td>Educate CHWs to counsel families about death and dying and inheritance rights</td>
</tr>
<tr>
<td>Alleviate poverty</td>
<td>Develop poverty alleviation programmes such as IGAs, job training, continued schooling, bursary funds</td>
</tr>
<tr>
<td>Integrate orphan care into CHBC</td>
<td>Develop strategies to support the extended family, community and others in orphan care</td>
</tr>
<tr>
<td>Incorporate NGOs, religious organizations and private sector in a continuum of care</td>
<td>Promote partnerships and develop effective communication between complementary organizations and the government health care system; develop contracting and sub-contracting of services within a legal framework anchored in the national health policy</td>
</tr>
<tr>
<td>Promote community empowerment</td>
<td>Develop strategies to promote community mobilization, sustained action, and change</td>
</tr>
<tr>
<td>Support CHW, caregivers and patients</td>
<td>Provide psychosocial support and counselling to CHWs, caregivers and patients</td>
</tr>
<tr>
<td>Provide affordable resources in the community and home</td>
<td>Provide transportation, home-based care kits, supplies and medications in PHC and at home. Develop community health insurance schemes and effective waiver systems</td>
</tr>
</tbody>
</table>
INTRODUCTION

A young girl of 12, living in a small rural area, is caring for her mother dying of HIV/AIDS. Her mother suffers from a cough, diarrhoea, and skin lesions. The daughter wears plastic bags when she provides physical care to her mother. The only treatment the mother receives is for the co-infection of TB. The skin lesions and diarrhoea go untreated. This mother and daughter have no income, however, an aunt and uncle sometimes provide food. The daughter left school one year ago to care for her mother. She states: "I am sad because I am all alone. My friends feel sorry for me because I cannot attend school or play".

A 43-year-old woman is caring for her sister-in-law dying of HIV/AIDS. There are 19 family members (including 3 orphans) living in a 2 room house with no water, mud walls, and no lighting. There have been four previous deaths from HIV/AIDS in this family. The family consider their greatest problems include hunger, retrenchment (Kenya’s economic restructuring policy), drought and orphan care. The family cannot afford treatment for their sick family member. This caregiver explains: "I have lost my friends, they have deserted me".

A 42-year-old woman is caring for a friend involved in a car accident 3 years ago. This man walks with crutches, he lives alone since his wife deserted him, and the rest of the family "don’t want him" (caregiver). The Catholic Mission and the Bora Afya also visit and bring medicines and dressings. He has no money to visit the health clinic. The caregiver helps her friend collect supplies, water, and food. She also helps him with transportation. As she explains: "We have known each other for 20 years. We grew up in the same place. I am like a sister to him". This caregiver’s husband is in hospital awaiting surgery.

A 14-year-old boy is caring for his mother who is dying of HIV/AIDS. His father died last year. This young boy also cares for two siblings aged 5 and 6 years. This family receives some help from the Catholic Centre, and occasionally an aunt supplies food. He explains: "We need an older person to be a caregiver. We cannot afford medicines. I know very little about how to give care because I am young and not trained". This young boy dropped out of school to care for his mother and siblings. He is also isolated from his friends.

Over 2.2 million people are living with HIV/AIDS in Kenya at this time of which 100,000 are children. These are considered conservative estimates as voluntary counselling and testing (VCT) is not well integrated into the health care system, particularly at the district and community level. It is also thought that there are now approximately one million orphans in Kenya with these numbers rising rapidly. Sporadic attempts have been made to develop a home-based care programme for people living with HIV/AIDS and their orphans in Kenya, but with an over stretched health care budget, and overwhelming health care needs, this important strategy has not been actualised. Religious organizations, non-governmental organizations (NGO) and the private sector have made some important contributions in community home-based care (CHBC). However, these efforts are uncoordinated, sporadic and dependent on continued funding.

As a result of these growing problems, the World Bank has recently provided Kenya with a US$50 million loan for prevention and care across the continuum for HIV/AIDS infected and affected people. Other funding agencies have also provided loans
for this important effort. Community home-based care (CHBC) is scheduled to be implemented as part of this initiative.

In order to plan and implement CHBC in Kenya, an action/intervention research study was undertaken in October, 2000. Action/intervention research is a community mobilization process that involves the community as researchers, and also in the needed action and change. The expected outcome of such research is to undertake effective action and to promote sustainable change that will enhance services, and the quality of life of the research participants and others. To that end, members of the Kenyan Ministry of Health (MOH) and the National AIDS and STD Control Programme (NASCOP) were invited to participate on the project. The overall purpose of this research was to determine the priority needs and the interventions necessary to assess, plan, develop and implement an effective CHBC programme in Kenya.

The results and recommendations of this study are presented in Part I of this manuscript. Part II contains a conceptual framework that addresses issues, questions and considerations for implementation of CHBC. This is followed by the application of the conceptual framework to the recommendations from the intervention study presented in Part I. The overall purpose of Part II is to provide a framework for the Kenyan government to follow as they begin to plan and implement CHBC.

This study comes at a critical time in Kenya as responsible partners begin to plan and implement CHBC for PWAs, people with chronic illnesses, orphans, and caregivers in Kenya. This study is seen as an important contribution to this initiative.

---

1 This conceptual framework was first developed by J. Brodsky, J. Habib and I. Mizrahi for the comparison of LTC laws in developed countries (WHO 2000b). It has been adapted by L. Lindsey and the M. Hirschfeld to the reality this study describes.
KENYA: AN OVERVIEW

Geography

Kenya lies across the equator on the east of the African continent. Neighbouring countries include Ethiopia to the north, Somalia to the east, Tanzania to the south, Uganda to the west and Sudan to the north-west. The total area is 582,646 square kilometres, stretching from the Indian ocean to the highland regions and Lake Victoria in the west. The country is divided into eight provinces; Nyanza, Rift Valley, Central, North Eastern, Eastern, Coast, Nairobi and Western Province.

Demography

The population of Kenya is currently estimated at 30 million, of which 5% are under one year, 20% under five years, and 50% under fifteen years. In addition, women of reproductive age (15-49 years) account for 20% of the population. With the advent of AIDS, the life expectancy for Kenyans has been reduced from 60 to 54 years (Ministry of Health, NHSSP, 1999).

Socioeconomic and health indicators reports for 1998 state that Kenya’s gross domestic product (GDP) per capita was US$ 328, with a growth rate of 1.8%. The recurrent health budget was 7.3% of the total government expenditure with a per capita health expenditure of US$ 4.95. The infant mortality rate per 1000 live births was 74, and the mortality rates for children under 5 years was 112 per 1000 live births. In addition, the maternal mortality rates per 1000 ranged from 365-650. The AIDS pandemic is likely to increase mortality rates, reducing life expectancy by about 12 years for males and over 15 years for females (Ministry of Health, NHSSP, 1999).

The 1994 Welfare Monitoring Survey established that about 47% of the rural population and 29% of urban households in Kenya were absolutely poor. However, on October 5, 2000, the Kenyan television business report stated that over 52% of Kenyans are absolutely poor with an unemployment rate of 50%. The implication of these levels of poverty is that families cannot afford any health services and often are without food (Ministry of Health, NHSSP, 1999). Poverty also negatively affects people’s level of education. Primary education is compulsory in Kenya. However, many young people have to drop out of school to help with the family income, to care for sick family members, or to care for their orphaned siblings. The government provides, or assists, in the provision of schools. Families have to pay school fees, the cost of books and school uniforms. This expenditure is often beyond the financial capacity of very poor people. The education system involves eight years of primary (beginning at age 5-6 years), four years of secondary school, and four years minimum of university education. The adult literacy rate in 1990 was 69% with males being at 79.8% and females at 58.5% (http://www.cix.co.uk).

Agriculture is the mainstay of Kenya’s economy, contributing over one third of the GDP. Agricultural crops include tea, coffee, horticultural products, pyrethrum, pineapples, sisal, tobacco, and cotton. Food crops for domestic consumption include maize, beans, cane sugar, wheat, rice, bananas, cassava, potatoes, sorghum and millet. There is also livestock farming. The main industries include food and beverage processing, manufacture of petroleum products, textiles and fibres, garments, tobacco, processed fruits, cement, paper,
engineering products, pharmaceuticals, basic chemicals, sugar, rubber and plastics (http://www.ncf.government).

**HIV/AIDS in Kenya**

According to the National AIDS/STDs Control Programme (NASCOP, 1999), in 1998 it was estimated that there were approximately 1.9 million people infected with HIV, of which, 100,000 were children. In the year 2000, it is estimated that the number of HIV infected people in Kenya has risen to 2.2 million. Voluntary HIV counselling and testing (VCT) is not well established in Kenya with testing facilities available only at the national, provincial and some district hospitals. Therefore, these figures are thought to be considerably lower than the actual number of people living with HIV/AIDS in Kenya (Ministry of Health, 1999). Sentinel surveillance systems are in operation in 13 urban sites and 11 peri-urban and rural sites around the country. These sites are all in antenatal clinics where blood is drawn to test for syphilis. Once the test for syphilis is performed all personal identifiers are removed and the serum is tested for HIV. This provides information on HIV that is unlinked to the person. Each year 200-300 pregnant women are tested for HIV in this unlinked fashion from each site. The sero-positivity of women in antenatal clinics in 1998 ranged from a high prevalence of 20-35% in some areas to as low as 4-10% in others. Estimates from these figures are used to assess the overall HIV infection rate in Kenya for 1998.

Current estimates of HIV prevalence suggest that in urban areas the rate of HIV is about 17-18%, or 430,000 HIV-infected adults. HIV prevalence in rural areas is increasing rapidly and in 1998 there were approximately 12-13% of the adult population infected. Because 80% of Kenyans live in rural areas, these percentages translate to approximately 1.4 million infected adults in rural Kenya (NASCOP, 1999).

There are three important modes of HIV transmission in Kenya including heterosexual contact, perinatal transmission, and blood transfusions. The majority of infections are transmitted through heterosexual contact. Infection rates are exacerbated by STDs such as syphilis and gonorrhea, and by having a large number of sexual partners. In addition, many children are infected perinatally, during pregnancy, child birth or through breast milk. Finally, transfusion with infected blood will almost always transmit HIV. However, in Kenya, close to 100% of the blood is screened for HIV. As a result, this mode of transmission is not thought to be significant (NASCOP, 1999).

A growing body of research (cited in NASCOP, 1999) suggests that a high proportion of Kenya's teenagers are sexually active, with the median age at first intercourse being 17 years. The median age for first marriage is 19 for women and 25 for men. Therefore, there is a significant period of sexual activity before marriage that exposes young people to the risk of HIV infection. Levels of infection are extremely high for girls and young women. The highest levels of infection for women are within the 20-24 age group, while for men, the highest infection levels are found in the 30-39 age group. In addition, in a nation-wide study of 12-24 year old women, one young woman in four said she lost her virginity because she was forced to have intercourse (cited in NASCOP, 1999). Unwilling sex with an infected partner carries a high risk of infection since force can cause cuts and abrasions, and the use of condoms is unlikely.

In 1999 Kenya was reported to have approximately 860,000 orphans as a result of AIDS (NASCOP, 1999). In 2000 this number was reported to have reached one million and it is anticipated that there will be 1.5 million by 2005 (personal communication; Director of NASCOP). NASCOP defines an AIDS orphan as a child under 15 years who looses a
mother to AIDS. It is likely that these children will lack proper care and supervision at a critical period in their lives. These orphans will also place an enormous strain on the health and social service system. At the family level, there is an increased burden and stress for the extended family. Many grandparents are left to care for young children and some families are headed by children as young as 10-12 years old. This increased burden will also be felt at societal level as these children require health care, school fees and sometimes orphanage care. It is reported that many of these orphans will go without adequate health care and schooling, thus increasing the burden on society in the future years. In addition, it is anticipated that AIDS orphans will increase the number of urban street children (NASCOP, 1999).

A 1998 Kenya Demographic and Health Survey conducted interviews with 7,881 women between the ages of 15 and 49 and 3,407 men between of 15 and 54 years. The results illustrated that knowledge of AIDS is widespread and modes of transmission well understood. However, this survey also reported that risky sexual behaviour was widespread. For example, 16% of married men reported having extramarital sexual partners compared to 2% of women. Among those who were single, 60% of men and 40% of women reported they were sexually active, with half reporting more than one sexual partner in the last year. However, this same survey reported that 40% of the respondents correctly identified at least two methods of HIV protection, and about 90% of men and 80% of women reported that they had changed their behaviour in some way to avoid AIDS. Most said they limited themselves to one sex partner. It was also reported that 14% of women and 17% of men would volunteer for HIV testing, with two-thirds of those who had not been tested reporting that they would like to be tested (cited in NASCOP, 1999).

Estimates from NASCOP (1999) suggest that in the year 2000 the care of AIDS patients in hospital will be 3.7 billion Kenya shillings (Ksh). It is anticipated that this figure will rise to 4.8 billion Kshs by the year 2005 (One US$=approximately 77Ksh). This will place a tremendous burden on the basic health care system to provide adequate care for PWAs and still meet the other health care needs of the population.

In order to meet the challenges posed by HIV/AIDS, the Government of Kenya recognized the need for the establishment of clear policy guidelines and effective organizational structures. As a result, in 1996 a national HIV/AIDS policy framework began. This AIDS prevention and care framework was presented in 1997 with the goal "to provide a policy framework within which AIDS prevention and control efforts will be undertaken for the next 15 years and beyond" (cited in NASCOP, 1999, p. 47). Some of the key aspects of this policy framework included the participation of all sectors of society, taking into account socio-cultural issues, legal and ethical challenges, and the particular needs of women, men, youth and young adults, and children. The National AIDS and STDs Control Programme (NASCOP) was created within the MOH, with the mission statement "to provide a policy and strategic framework for mobilizing and coordinating resources to prevent HIV/AIDS transmission and provide care and support to the infected and affected people in Kenya" (NASCOP, 1999, p. 50). In particular, seven key strategies were identified:

- Reduction in HIV prevalence through promotion of behaviour change and advocacy
- Blood safety
- Continuum of care
- Treatment and control of sexually transmitted diseases
- Epidemiology and research
• Prevention of mother to child transmission of HIV and
• Mitigation of the socio-economic impact of HIV/AIDS.

The establishment of a National AIDS Control Council (NACC) is also planned. This will be a high level, multisectoral committee that will be charged with the responsibility for developing, and monitoring the progress of a comprehensive national policy in response to the AIDS epidemic. It is anticipated that NACC will become operational in 2000 and will directly report to the President of Kenya.

**Health Sector Reform**

According to the National Health Sector Strategic Plan (NHSSP) for 1999-2004 (Ministry of Health, 1999), the vision of the Ministry of Health (MOH) for Kenya is “to create an enabling environment for the provision of sustainable quality health care that is acceptable, affordable and accessible to all Kenyans” (p.ix). In response to this challenge, the government developed a Health Policy Framework in 1994, providing a blueprint that stipulates strategies for the development and management of health services in the country. This Health Policy Framework was followed by the development of an implementation plan, and the establishment of a Health Sector Reform Secretariat to spearhead the reform process over the next five years.

However, despite best efforts, progress on the implementation of Kenya’s Health Policy Framework Paper (KHPF) has been slow. Poor health still prevails and many Kenyans lack access to basic health care, safe drinking water, proper sanitation, and adequate nutrition. Preventable and readily treatable diseases remain a big burden. In addition, old diseases such as tuberculosis, typhoid, and cholera have re-emerged with a vengeance, and new strains of malaria have been identified. Added to these preventable diseases is the advent of HIV/AIDS that threatens to consume over 50% of public health resources.

Certain system wide constraints to the adoption of the NHSSP were also identified. These constraints include: the decline in health sector expenditure, inefficient utilization of resources, centralized decision making, inequitable resource allocation, inadequate management information systems, outdated health laws, inadequate managerial skills at district level, worsening poverty levels, increasing burden of disease, and rapid population growth (Ministry of Health, 1999).

To address these growing health concerns a series of consultative meetings and workshops were undertaken to elicit the views of all stakeholders on the development of policy objectives that could be translated into actions to reverse the deteriorating health situation in the country. The National Health Sector Strategic Plan (NHSSP, 1999) has been designed against this background to address the constraints in the health sector, and to adopt a sector wide approach to their resolution. The overall objectives of the NHSSP 1999-2004 plan are to:

• Ensure the equitable allocation of government resources to reduce disparities in health resources.
• Increase the cost effectiveness and the cost efficiency of resource allocations and use.
• Continue to manage population growth.
- Enhance the regulatory role of the government in all aspects of health care provision.
- Create an enabling environment for increased private sector and community involvement in health service provision and finance.
- Increase and diversify per capita financial flows to the health sector.

**Organization of the Health Sector**

The major players in the health sector reform include members of the Ministry of Health and the Ministry of Local Authorities. Other players are non-governmental organizations (NGOs), religious organizations and the private sector. There is a fee for service at all health facilities, however, when a patient is absolutely destitute, this fee might be waived. Health services are delivered through a network of approximately 4200 health facilities with the public health system accounting for 51% of the total. This total comprises of 218 hospitals, 575 health centres, 2523 dispensaries, 191 nursing and maternity homes, and 707 health clinics or medical centres (Ministry of Health, 1999). According to 1996 statistics, for every 100,000 Kenyans there were 14.1 doctors, 2.4 dentists, 5.1 pharmacists, 25.2 registered nurses, 83.2 enrolled nurses, 10.9 clinical officers, 2.0 public health officers, 14.9 public health technicians, and 3.4 pharmacy technologists (Ministry of Health, 1999). In addition to the public health system, there are a number of agencies that provide funds to NGOs, and religious organizations, etc. The most notable funding agencies include UK DFID, the World Bank, USAID, CIDA, the Swedish and Norwegian Red Cross and the Japanese government.

The health system is designed much like the hub and spokes of a wheel. In the centre is the main referral hospital of Kenya, the Kenyatta National Hospital. In addition, there are eight provinces in Kenya, and each has a referral hospital that in turn refers to the national hospital. There are also a series of sub-district or district hospitals within each province that refer to the provincial hospital. Each district also has a succession of health centres. The most peripheral health care facilities are the dispensaries. These dispensaries are located within 4-5 kilometres of each village or community, and are considered to be within walking distance. Throughout this health care system, there are also a number of private health facilities, religious organizations and non-governmental organizations.

The health centres are the first line of referral from the dispensary. These health centres are staffed by a registered nurse/midwife, who is responsible for maternity care. There is also a clinical officer who has a diploma in clinical medicine and diagnoses and treats patients. Each health centre also has a records officer, and some health centres have laboratory and pharmacy technicians, although this is not universal. Other staff that might be available at the health clinics include medical social workers, children officers, public health officers, orthopaedic technicians, and nutritionists. The health centre usually has about five beds for maternity care. These beds can also be used in an emergency if a patient is to be transferred to a district or provincial hospital. Each health centre has a vehicle for transportation.

The dispensary is at the periphery of the health care system, and functions as a primary care facility, providing both curative and preventive health care. These dispensaries are supposed to carry basic drugs and supplies, although these supplies are often unavailable. In addition, they have STD kits that they sell for a small fee. Fees are levied for transportation, drugs and supplies. If the patient is destitute, it is sometimes possible to waive these fees, or provide them at a reduced cost.
Community health is managed and supported by community leaders and a community health team. In addition, the community has a pharmacy that is run under the principles and guidelines of the Bamako Initiative. The purpose of this initiative is to provide people in the community with pharmaceutical supplies that are sold at a minimal cost. The profits from this initiative go into a revolving fund to ensure the sustainability of the programme. Despite the good intentions of this programme, buying drugs at slightly over cost is often beyond the financial means of many people. Therefore, access to essential drugs remains problematic for many people.

The staff of the PHC unit includes an enrolled nurse with a certificate in nursing and midwifery. In addition, there are usually two or more health attendants, such as community health workers (CHW) and community based distributors (CBD) who have 12 years of secondary education and learn their health care role on the job. The CHWs and CBDs are volunteers who are paid ‘in kind’ for their work. The CHW conducts home visits, carries out nutrition assessment, provides information on family planning and distributes condoms. The CBD supervisor also conducts home visits and is responsible for family planning education and distribution of contraceptives, including condoms. The CHWs and the CBDs also provide personal care in the home. The PHC unit also has traditional birth attendants (TBA). At this time, no formal, government run home-based care programme exists. It is anticipated that when the HBC programme is implemented, it will be delivered from the district, health centre and dispensary levels.

**Health Service Delivery**

The Ministry of Health has traditionally favoured centralized planning and resource allocation. However, this centralized system has a number of operational problems that constrain the delivery of efficient and effective health services. In particular, there has been a lack of clearly defined functions, roles, schedules of duties, and work plans throughout the system from headquarters to the periphery. This leads to cumbersome bureaucratic processes leading to long disbursement delays. In addition, despite the organization of the health care system into five distinct tiers, there are considerable problems with referral with no clear guidelines for referral from one tier to another (Ministry of Health, 1999).

Recently, there has been a shift towards decentralization. Evidence to this effect includes the restructuring and strengthening of the Ministry’s district level management capacity under the District Focus for Rural Development and the District Management Boards (Ministry of Health, 1999). This restructuring and reform has the following objectives:

- Reducing the span of control within the different tiers to have a more effective chain of command.
- Transferring increased responsibility for planning and resource allocation to the districts and facilities in the periphery.
- Strengthening provincial, district and community levels.
- Having more effective co-ordination of health services in the country.
- Involving the various stakeholders in program design, planning and implementation, and:
- Ensuring the existence of appropriate structures for effective governance and collaboration with the stakeholders.
This restructuring and reform of the health care system will mean that the role of MOH headquarters will be restricted to policy formation and development, strategic planning, setting standards and regulatory mechanisms, regulating and coordinating health training, coordination of donor activities, overseeing the implementation of the reform process, and ensuring equitable allocation of national health resources. The provincial tier will be strengthened to supervise district projects and implement and enforce health standards for services and the infrastructure. They will also assist the districts in developing their respective health plans and training activities. The district level will be charged with the responsibility of implementing these health reforms. To that end, the districts will be responsible for preparing work plans for the provision of curative, rehabilitative, preventive, and primary health care (PHC) services. They will also be responsible for coordination of services including other health and social service sectors, donor agencies and NGOs. Finally, at the community level, the roles of community health workers (CHW), community based distributors (CBD), traditional practitioners such as traditional birth attendants (TBA), social workers and community leaders will be strengthened to enhance the participation of households in health care activities at the local level. Within this restructuring process, households are considered as key community units in health care delivery. To that end, families will be provided with adequate information and assistance in obtaining and administering simple, safe and effective medications, basic nursing care, and with enough knowledge to judge when to refer patients for further health care. It is within this framework that community home-based care will be formally implemented.

**Home-Based Care**

A formal system of community home-based care (CHBC) has not yet been implemented by the MOH in Kenya. However, there are a number of NGOs, religious organizations, and donor agencies engaged in the provision of home based care throughout Kenya. In addition, in June 1993, the MOH developed national guidelines on CHBC. However, these guidelines could not be made operational due to a lack of funds.

Despite this lack of coordination in CHBC, there have been sporadic government based home care initiatives. For example in 1999-2000, fifty people were trained in CHBC in the districts of Nyando, Kisumu, Rachuonyo, Kuria, and Migori. In addition, 24 people received a diploma in home-based care in Nairobi and the Central provinces. These training programmes were conducted by personnel from Mildmay International, in collaboration with the University of Nairobi, and the Kenya Voluntary Women’s Rehabilitation Centre (KVOWRC). Although these training programmes were helpful in sensitising health care personnel to the care and support needs of people at home, due to a lack of government funds, this training has not been maintained. As a result, CHBC is sporadic in Kenya with no organizational structure or system of delivery in place.

In 1995, Ngugi & Njenga conducted a feasibility study on integrating community-based AIDS care into existing urban health units in Nairobi. The main purpose of this initiative was to integrate HIV home based care into existing health care and support services by complementing these services. In particular, the purposes of this intervention study were to: (a) promote appropriate referrals for PWAs and decrease the number of hospital referrals; (b) maintain the level of other health services provided by CBD supervisors, and CHW; (c) increase positive beliefs, attitudes, and behaviours among PWAs, including behaviour that prevents the transmission of HIV; (d) increase the accessibility of health services; (e) increase positive beliefs, attitudes and behaviours among family caregivers, and their knowledge about health and social support services; and, (f) provide a high quality of home care and support for PWAs and increase
acceptability by their families. The integration of community-based AIDS care and support was accomplished through the training of health workers, the establishment of a supervisory system for these workers, and the establishment of a referral network for PWAs. Quantitative and qualitative research methods were utilized to collect and analyse data from PWAs and family caregivers. Recommendations from this study included: strengthening PHC to include community-based activities and the control of STDs and AIDS; strengthening the referral between and among various levels of health care delivery to support community/home care services; improving the quality of care for PWAs; strengthening existing health facilities for PWAs and establishing effective community care networks; and, planning and procurement of drugs for HIV opportunistic infections into the overall essential drug supply system with distribution guidelines provided. Although this study was an important conceptual contribution to the development and implementation of CHBC, no further action to incorporate CHBC into the existing health care delivery system was taken at that time.

Sporadic and uncoordinated home-based care has continued over the years through NGOs and religious organizations such as the Kenyan Red Cross, and others. However, there is now general acknowledgement that the growing problem of HIV/AIDS has placed an enormous strain on an already under funded and excessively burdened health care system. Therefore, in response to this critical concern, the government of Kenya has successfully negotiated a US$ 50 million loan from the World Bank. This fund is for the prevention and care of HIV infected people across the continuum. The initiation of CHBC is one programme that will receive part of this funding. As a result, the National AIDS and STD control Programme (NASCOP), has begun to develop guidelines2 for the implementation of eight home based care pilot projects in each of the eight provinces of Kenya. These pilot projects will be the start of a phased-in approach to CHBC that will eventually be implemented throughout the country. It is anticipated that the lessons learned from these pilot projects will be used to further modify these guidelines. These will then form the basic principles, practices and procedures for implementation of home-based HIV/AIDS care throughout Kenya. The initial guidelines are in draft form at this time and are under review by key stakeholders. According to these draft guidelines, home-based care is part of a comprehensive continuum of care, treatment, support and preventive services that include the family, community, district, provincial and national services and programmes. That is, home-based care is envisioned to have a holistic approach that will meet the physical and psychosocial needs of individuals and families. Such care will be planned and implemented through collaboration and involvement of all sectors of the health and social service agencies including NGOs, religious organizations, and other care programmes in conjunction with family and community involvement. As such, home-based care (HBC) will encompass medical and nursing care, counselling and social support. In particular, four components are proposed within these guidelines which include:

- Clinical management, with early diagnosis, rational treatment and planning for follow-up care for HIV related illness;
- Nursing care services to promote and maintain good health, hygiene and nutrition;
- Counselling and psychosocial support, including stress and anxiety reduction, promoting positive living, and helping individuals make informed decisions on HIV

---

testing, planning for the future, and behavioural change involving sexual partners in such decisions; and

- Social support such as information and referral to support groups, welfare services and legal advice for individuals and families, including surviving family members to whom assistance can be provided.

These proposed guidelines contain the following objectives:

- To facilitate the continuity of patient care from the health facility to the home and the community.
- To promote family and community awareness of HIV/AIDS prevention and care.
- To empower the family and the community with knowledge to ensure long-term care and support.
- To raise the acceptability levels of PWAs by family and community, hence reducing the stigma associated with AIDS.
- To streamline the patient referral from the health institutions to the community, and from the community to appropriate health and social service facilities.
- To facilitate quality community care to the infected and affected persons.

These objectives and components of CHBC specifically address the needs of the PWA, the family and orphan care. To that end the physical, spiritual, social, and psychological needs of the PWA are addressed. In addition, the physical, social and spiritual/pastoral needs of the family, and the particular needs for orphan care are taken into account. It is anticipated that after the review of the draft guidelines are completed, and revisions made, the pilot projects in each of the eight provinces of Kenya will commence. These pilot projects will begin by training trainers in HIV/AIDS prevention, care, psychosocial support and voluntary HIV counselling and testing (VCT) at the district and community level. This training will then be given to community members, volunteers, families and PWAs. Based on the lessons learned from these pilot projects, CHBC and VCT will be implemented throughout 70% of Kenya (personal communication, October 5, 2000 with Dr. Mohamed, NASCOP).

This home care intervention study comes at a critical time in Kenya as members of government departments, as well as other relevant agencies begin to determine the priority needs and the interventions necessary to assess, plan, develop and implement an effective CHBC programme. The results and recommendations of this study are presented in Part I of this manuscript. Part II then contains a conceptual framework that addresses issues, questions and considerations for implementation of CHBC. This is then followed by the application of the conceptual framework to the results and recommendations of the intervention study.
PART I: THE STUDY

METHODOLOGY

This intervention study used both quantitative and qualitative research methods. The focus of the study was the impact of caregiving by children, youth and elderly women to ill family members at home. In addition, the issues of orphan care were addressed. Background information on demographics, illness and treatment related variables, and resources were collected. The actual work of caregiving including direct physical and emotional care, management of symptoms and medical regimens, as well as the performance of surrogate roles by the caregiver were explored. Data were also collected on the impact of caregiving. Such data included the effects on the caregiver’s physical, mental, social, and developmental well-being, as well as on their health and financial status. Information was also collected on existing resources and the types and processes of referral within the health and social service system. Such information included the resources that are necessary to sustain effective CHBC and the types and processes of referral necessary. Questions were also raised to explore strategies that might support family caregivers in home-based care, and the actions that could be undertaken to support these initiatives. Issues of orphan care were also addressed with suggestions for support and care for these unfortunate children. Finally, the acceptability of incorporating VCT into CHBC was assessed.

The purpose of this study was also to recommend strategies that would reduce the burden on family caregivers, and enhance their quality of life as they care for ill family members and orphans in home-based care. As such, this research incorporated the philosophy and processes of action/intervention research (Metaggart, 1993). Action/intervention research is considered a cyclical process toward effective action, in which empirical decisions on the research topic and on the action embedded within, as well as continuous evaluations are conducted with all partners involved in the process (Wadsworth, 1997).

This cyclical process of action/intervention research was facilitated through close collaboration with members of the MOH and NASCOP, and the University of Nairobi research team. A final report with recommendations was presented to the directors of NASCOP, the Director of Medical Services (DMS) at the MOH, and other key stakeholders. This study comes at a critical time in Kenya as responsible partners begin to plan and implement CHBC for PWAs, people with chronic illnesses, orphans, and caregivers in Kenya. This study is seen as an important contribution to this initiative.

POPULATION AND SAMPLE

The study population was a convenience sample (Morse, 1991) of caregivers to PWAs and people with other chronic illnesses, and orphans. In addition, key informants such as community health workers (CHW), community-based distributors (CBD), nurses, social workers, community health team, health educators, community leaders and a chief, traditional birth attendants (TBA), and members of NGO’s and religious organizations involved in CHBC were included in this study. Finally, data were collected from personnel from the NASCOP and educators involved in issues related to CHBC and HIV/AIDS.
STUDY LOCATIONS

The study was conducted in three urban districts of Nairobi (Korogocho, Kariobangi, and Huruma) and several locations within one rural area of Machakos.

Korogocho: This is a slum area of Nairobi with a population of approximately 200,000. The houses are constructed with homemade bricks made of earth mixed with cement, and the roofs are of corrugated iron. Most houses consist of one or two rooms. The people share a pit latrine, and there is open sewage running between the houses. Water is collected in jerry cans from communal stand-pipes, often a distance from the homes. This water, which is mostly contaminated, has to be bought. Typhoid, tuberculosis and HIV/AIDS is very prevalent in this community, however, actual numbers are not known. The houses have earthen floors, there are paraffin lamps, and cooking is done on paraffin or gas stoves, or with wood or charcoal fires. The houses have few windows, and ventilation is poor. This area is densely populated with considerable overcrowding. Many of the houses have wire mesh enclosures attached to the house where livestock such as cows, goats, pigs, and chickens etc. are contained. A second enclosure is often used for children to play in. At the time of this study, a child had been abducted, and the community was on heightened alert for the safety of their children.

Wheelbarrows are often used to transport goods throughout the community. These wheelbarrows resemble a stretcher with two wheels. They are made of wood with a flat bed of woven rope or leather. Mostly goods are transported in such a manner, however, if people are too sick to walk to the dispensary or health centre, they too are often transported in this manner. Another form of transportation is the human stretcher whereby people link arms to carry the person to the health care facility. There are also buses and minibuses, however many people cannot afford this form of transportation. Although most people living in this community are very poor or destitute, they have to pay rent, buy water, paraffin, wood, charcoal, drugs and other medical supplies, transportation, food, school fees, uniforms and books for the school children, and fees for health care. The main form of income appears to be shop keeping, and selling fruits and vegetables. Some people work in other parts of Nairobi.

There is one government health centre within this community, as well as religious organizations, NGOs, and private health services. All drugs and health treatments have to be paid for although the people are often too poor to pay. If a family is destitute, it is possible to waive the cost of the drugs and health supplies, but this is seldom done and people have to pay, even if only a small amount.

Kariobangi: This district is divided into Kariobangi North and South with a total population of approximately 100,000. The northern section consists of more middle class dwellings, while the southern area appears to be relatively poor. The middle class area has concrete apartment buildings that appear to be in good repair. There is electricity, indoor plumbing and tarmac roads. The poorer areas also have concrete apartment buildings as well as some single-family dwellings. There are also slum dwellings of mud and corrugated iron. In between the houses and apartment blocks there are stretches of land where people plant vegetables and fruit. There are private dispensaries, private pharmacies and one local government health centre. There are also shops and stalls selling a varied selection of goods. There are more cars, buses and trucks in this area.

Huruma: This district has a mixture of poor housing and slum dwellings with a population of approximately 100,000 people. The housing in Huruma is similar to the slums of Korogocho and the poor dwellings of Kariobangi. Transportation is by wheelbarrow, bus, truck or car. Water, lighting, and cooking fuels have to be purchased,
and rent has to be paid. Government run dispensaries and health centres as well as church organization health centres can be found in this district. All medicines, medical supplies, and transportation to and from the health facilities must be paid for by the sick person or the family. As in the other districts, waivers can be given if the family is completely destitute, although some form of payment is usually required.

**Machakos:** This is a rural district with Machakos headquarters being 47 kilometres from Nairobi. The population consists of approximately 600,000 people, with many small villages stretched across a wide expanse of land. There is a district hospital in the centre of Machakos with primary health clinics and dispensaries in the outlying communities. This area is experiencing a drought and much of the land is barren where vegetables and fruits usually grow. The cattle look thin and the people are suffering from severe food shortages. The study team visited 20 villages. Each village has a population of between 100-300 people. The houses are mostly made of mud with thatch or corrugated iron roofs. Most houses consist of two rooms, even for families as large as 14 people. The floors are often earthen, but some homes have concrete floors. There is no electricity or running water. Water is collected from the river (now dangerously low), communal standpipes (at a cost), or, in one case, at a well. Cooking and heating are done over open wood fires. Often, the only source of light is the wood fire although some homes have paraffin or hurricane lamps. There are some pit latrines, however many people use the bush.

**DATA COLLECTION**

Data were collected by the use of three questionnaires. The first questionnaire focused on the experiences and perceptions of caregivers in caring for ill family members and orphans at home (see Appendix A). Researchers interviewed the family caregivers in their local language and wrote the caregiver responses onto the questionnaire in English. A total of 53 caregiver interviews were conducted in this manner. The second form of data collection involved open-ended interviews with key informants (see Appendix B). Key informants included members of NGO’s, religious organizations, CHWs, CBDS, nurses, social workers, personnel from National AIDS and STD Control Programme (NASCOP), health educators, community health committee members, and a former village chief. These interviews were conducted either in English or Kiswahili, depending on the language skills of the respondent. All responses were written onto the questionnaire in English. Twenty seven key informant interviews were conducted in this manner. Finally, focus group discussions (FGD) were conducted with CHWs, CBDS, TBAs, community leaders, and caregivers (see Appendix C). These focus group interviews were conducted in the local language and the responses written in English. Six focus group interviews were conducted, with a total of 40 participants. Through these three data collection methods, a total of 120 respondents participated in this study.

Table 2 provides an overview of the composition of the key informants in the individual interviews, and Table 3 provides an overview of the respondents interviewed through focus group discussion (FGD).
Table 2: Key Informant Respondents

<table>
<thead>
<tr>
<th>Key Informant</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-governmental organization personnel</td>
<td>3</td>
</tr>
<tr>
<td>CHW &amp; CBD volunteers</td>
<td>9</td>
</tr>
<tr>
<td>Health Educators</td>
<td>5</td>
</tr>
<tr>
<td>Community Health Nurses</td>
<td>2</td>
</tr>
<tr>
<td>Social Workers</td>
<td>2</td>
</tr>
<tr>
<td>Community Health Coordinators</td>
<td>1</td>
</tr>
<tr>
<td>Secretary, Primary Health Care</td>
<td>1</td>
</tr>
<tr>
<td>Community Chief</td>
<td>1</td>
</tr>
<tr>
<td>Village Health Committee member</td>
<td>1</td>
</tr>
<tr>
<td>Personnel from NASCOP</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>27</strong></td>
</tr>
</tbody>
</table>

Table 3: Focus Group Respondents

<table>
<thead>
<tr>
<th>Focus Group</th>
<th>Respondents</th>
<th>Number per FGD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>CHW</td>
<td>10</td>
</tr>
<tr>
<td>2</td>
<td>CHW</td>
<td>6</td>
</tr>
<tr>
<td>3</td>
<td>Caregivers</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>Caregivers</td>
<td>9</td>
</tr>
<tr>
<td>5</td>
<td>Community Leaders (Men and Women)</td>
<td>6</td>
</tr>
<tr>
<td>6</td>
<td>CHW (3) &amp; TBA(3)</td>
<td>6</td>
</tr>
<tr>
<td><strong>Total number of Respondents</strong></td>
<td><strong>40</strong></td>
<td></td>
</tr>
</tbody>
</table>

**Access to Participants and Informed Consent**

The study locations were decided upon with the collaboration of the University of Nairobi researchers and personnel from the Ministry of Health. The Director of Medical Services at the MOH, and the Programme Director of NASCOP both wrote letters supporting the study and requesting participation. Permission was then sought from the local health teams to conduct the study. The researchers from the University of Nairobi had worked with these communities on various health care, educational and research projects and were well known and respected in the communities. Therefore, study participants were recruited through networking and the snowball effect. The research team met with community members and explained the focus of the study in both English and Kiswahili. At this meeting family caregivers were identified and a plan for visiting the research sites was made. Members of the research team then visited the identified respondents where the purpose of the study was explained. It was stressed to the research respondents that refusal to participate in the study would in no way jeopardise their care, support and access to necessary resources. Permission was then sought to interview the respondents. It is
interesting to note that no caregiver or key informant refused to be interviewed. The research team thought that there were two reasons for this general acceptance. First, the research team was well known and respected within the communities as they had been involved in several successful research, health care and educational projects. Second, it was known that the government intended to implement a CHBC programme, and the community members and caregivers were anxious to share their experiences and suggest strategies for action.

**Research Integrity**

The principal researcher and author of this report is not from Kenya and cannot speak Kiswahili. For this reason, the research team was very sensitive to issues of translation, observation and sharing knowledge about local customs and practices. The principal researcher visited all the study sites, and some of the homes. At various times throughout the study, the research team met to discuss issues related to data collection and contextual understanding. As data were collected it was found that some questions needed further elaboration. For example, the system of waivers for medicines and supplies needed further discussion between the research team and the principal researcher. It appeared that the waiver system was implemented without clear policy guidelines and depended on the attitude and judgement of the individual health or social service practitioner. Some people received a waiver, while others had to pay, if only a small amount, still others were turned away from the health facility if they could not afford to pay. In addition, further discussions were necessary on the delivery of health care in Kenya. There appeared to be little coordination between government health care facilities, various religious organizations, NGOs and the private sector. These various issues were discussed between the University of Nairobi research team and the principal investigator. In this manner, the principal researcher gained a broader understanding of how these issues and practices affected patients and caregivers.

Regular research team meetings were also held throughout the study to discuss preliminary findings. As part of this process, certain issues were elaborated upon and contextual issues clarified. In this way, the research team paid particular attention to cultural, traditional, contextual and semantic issues related to the research. In addition, a draft copy of the report was given to the research team for their confirmation, elaboration or correction. Only after the research team had vetted the results and made corrections, was the report presented to the Director of Medical Services at the Ministry of Health and to the WHO Representative for Kenya.

A total of 80 individual interviews were conducted for this study (53 caregivers, and 27 key informants interviews). In addition, 6 focus group discussions (FGD) were undertaken with a total of 40 respondents. In keeping with qualitative research methods, the purpose of determining sample size was to reach redundancy or saturation of the data. It is believed that such saturation was achieved in this study. For example, within 28 caregiver interviews, the main issues identified in this report had come to light. The remaining caregiver interviews, key informant interviews and focus group discussions served to provide depth of understanding to the identified concerns and to elaborate and confirm these findings. There was a remarkable consistency between the issues and concerns raised by the caregivers and those of key informants and focus group discussion participants.
DATA ANALYSIS

Data analysis was conducted using qualitative research methods. The caregiver interviews were analyzed using content analysis (Manning & Cullum-Swan, 1994). Each question was coded and these codes were later combined to provide categories of responses with some numerical components. The key informant interviews and focus group meetings were analyzed using thematic analysis (Huberman & Miles, 1994). Interviews were first read to get a sense of the data as a whole. Units of meaning relevant to the research questions were then identified and coded into early themes. These themes were then combined with the caregiver interview codes. Finally, patterns and meta-themes that exemplified the perceptions and experiences of family caregivers and key informants were identified.

RESULTS

Demographic Variables of Family and Caregivers

There were 53 individual caregiver interviews conducted with 46 females (87%) and 7 males (13%). The total number of people per family, the number of children in families and the number of families caring for orphans are presented in Table 4.

Table 4: Family and Orphan Demography (N=53)

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of household members</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 – 4</td>
<td>16</td>
<td>30%</td>
</tr>
<tr>
<td>5 – 8</td>
<td>23</td>
<td>43%</td>
</tr>
<tr>
<td>9 – 12</td>
<td>11</td>
<td>21%</td>
</tr>
<tr>
<td>12+</td>
<td>3</td>
<td>6%</td>
</tr>
<tr>
<td>Number of children in family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 – 2</td>
<td>25</td>
<td>47%</td>
</tr>
<tr>
<td>3 – 5</td>
<td>21</td>
<td>40%</td>
</tr>
<tr>
<td>6 – 8</td>
<td>7</td>
<td>13%</td>
</tr>
<tr>
<td>Number of families caring for orphans</td>
<td>8</td>
<td>15%</td>
</tr>
</tbody>
</table>

It is important to note that 70% of households had five or more family members. The vast majority of these households were reported to be very poor with houses that contained only one or two rooms. In addition 85% of households had up to five children, while 13% had six children or more. In addition, there were eight families caring for orphans with a total of 33 orphans reported in this study.

The demographic data for age, years of education, socioeconomic and employment status are summarized in Table 5.
Table 5: Demographic Variables of Caregivers (N=53)

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 – 20 years</td>
<td>9</td>
<td>17%</td>
</tr>
<tr>
<td>20 – 26</td>
<td>11</td>
<td>21%</td>
</tr>
<tr>
<td>27 – 55</td>
<td>24</td>
<td>45%</td>
</tr>
<tr>
<td>56+</td>
<td>9</td>
<td>17%</td>
</tr>
<tr>
<td>Years of Education:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 – 2 years</td>
<td>9</td>
<td>17%</td>
</tr>
<tr>
<td>3 – 6</td>
<td>17</td>
<td>32%</td>
</tr>
<tr>
<td>7 – 9</td>
<td>25</td>
<td>47%</td>
</tr>
<tr>
<td>10 – 12</td>
<td>2</td>
<td>4%</td>
</tr>
<tr>
<td>Socioeconomic status:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>52</td>
<td>98%</td>
</tr>
<tr>
<td>Middle class</td>
<td>1</td>
<td>2%</td>
</tr>
<tr>
<td>Wealthy</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Employment status:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>11</td>
<td>21%</td>
</tr>
<tr>
<td>Unemployed home-maker</td>
<td>42</td>
<td>79%</td>
</tr>
</tbody>
</table>

Figures in Table 5 indicate that the most caregivers were in the middle to older age brackets, however, 38% of the caregivers were under 26 years of age. In fact, 9 caregivers were under 20 years with three of those caregivers being 12, 14 and 15 years old. The majority of the caregivers (47%) had 7-9 years of education, however, a total of 49% had from 0 to 6 years of education. The older women were the least educated with 8 having received no formal education. The overwhelming majority of the caregivers were poor (98%) with 79% being homemakers, subsistence farmers or unemployed. Of the eleven caregivers who reported to have some employment, they mostly had casual work, while one sold illegal beer, and two others sold vegetables. Only one family was reported to be middle class, and they owned a shop.

Socioeconomic status was determined by family income and from the living conditions of family members. Of the 53 caregivers interviewed, 52 lived in poor housing. The living conditions of these caregivers were described in detail under the study location section of this report. In addition, many of the families had experienced retrenchment (becoming redundant). Some family members still managed to get some casual labour, however, for many families, all forms of income had ceased. Issues of poverty will be further elaborated upon under the impact section presented later in this report.

The caregiver’s relationship to the sick family member is provided in Table 6. Mothers were the most common caregivers, with wives caring for their sick husbands second. Daughters, and daughter-in-laws were the next most common caregivers. Interestingly, there were five friends as caregivers. They explained that they had known their friend since childhood, often from the same school or village, and felt obligated to care for this friend during their illness. One friend was a commercial sex worker and had worked in this trade with her friend and felt it important to care for her during her sickness. There were three sons caring for a sick family member. These young boys were all under the age of 20 and also cared for younger siblings.
Table 6: Composition of Caregivers (N=53)

<table>
<thead>
<tr>
<th>Caregiver</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wife</td>
<td>10</td>
</tr>
<tr>
<td>Husband</td>
<td>1</td>
</tr>
<tr>
<td>Mother</td>
<td>13</td>
</tr>
<tr>
<td>Daughter</td>
<td>8</td>
</tr>
<tr>
<td>Sister</td>
<td>4</td>
</tr>
<tr>
<td>Daughter-in-law</td>
<td>6</td>
</tr>
<tr>
<td>Son</td>
<td>3</td>
</tr>
<tr>
<td>Sister-in-law</td>
<td>1</td>
</tr>
<tr>
<td>Friend (2 commercial sex workers)</td>
<td>5</td>
</tr>
<tr>
<td>Father</td>
<td>1</td>
</tr>
<tr>
<td>Cousin</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>53</strong></td>
</tr>
</tbody>
</table>

*(7 male, 46 female)*

**Illness, Treatment and Caregiving Variables**

Of the 53 caregivers interviewed, nine were caring for one or more family members with HIV/AIDS. However, it is interesting to note that an additional 24 caregivers (45%) were caring for a family member with many of the signs and symptoms of HIV/AIDS however, the caregiver or patient stressed that the illness was TB, malaria, or typhoid. While these illnesses might have been opportunistic infections, there was no doubt that the patient had AIDS. This conspiracy of silence caused serious problems. The caregiver was either unaware of, or afraid to mention that the family member had HIV/AIDS. Therefore, no particular precautions were undertaken in their care. That is, no condom use or other precautionary measures such as gloves, aprons or mackintoshes were used. This put the sexual partner and other caregivers at risk for HIV transmission. In addition, because of the family’s reluctance to name the diagnosis (or be aware of the diagnosis), other health care providers also refrained from mentioning their suspicions. The researchers also experienced this difficult dilemma. Therefore the conspiracy of silence prevailed among all people associated with the family. Issues of stigma will be addressed later in this report.

There were 20 caregivers reported to be caring for a family member with chronic illnesses other than HIV/AIDS. Table 7 provides an overview of the variety of illnesses being cared for at home.

Very few caregivers had any knowledge about what caused the patient’s illness. Only nine caregivers believed that a virus caused HIV/AIDS. Others said they did not know and gave a variety of different reasons, including cold weather, draft, working with toxic substances, being bewitched or cursed, pregnancy, and famine. The commercial sex workers were most knowledgeable about HIV/AIDS. They were also the caregivers who had the least difficulty in stating the patients’ diagnosis.
Table 7: Illness Related Variables (N=53)

<table>
<thead>
<tr>
<th>Illness</th>
<th>Number of Patients</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV/AIDS</td>
<td>9</td>
<td>17%</td>
</tr>
<tr>
<td>HIV/AIDS (unreported)</td>
<td>24</td>
<td>45%</td>
</tr>
<tr>
<td>Cancer</td>
<td>2</td>
<td>4%</td>
</tr>
<tr>
<td>Stroke</td>
<td>2</td>
<td>4%</td>
</tr>
<tr>
<td>Arthritis</td>
<td>3</td>
<td>5%</td>
</tr>
<tr>
<td>Blindness</td>
<td>2</td>
<td>4%</td>
</tr>
<tr>
<td>Polio</td>
<td>1</td>
<td>2%</td>
</tr>
<tr>
<td>Motor Vehicle Accident</td>
<td>2</td>
<td>4%</td>
</tr>
<tr>
<td>Fracture</td>
<td>1</td>
<td>2%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1</td>
<td>2%</td>
</tr>
<tr>
<td>Tuberculosis (with no other symptoms of HIV/AIDS)</td>
<td>5</td>
<td>9%</td>
</tr>
<tr>
<td>Ectopic pregnancy with anaemia</td>
<td>1</td>
<td>2%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>53</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

When asked who helped with the care of the patient, there were very mixed responses. Community health workers (including CBDs and TBAs) were reported to be helpful as were members of the Catholic Church. There was also mention of other religious organizations and NGOs. However, there was a general concern that all these helpers were stretched to the limit, and that some had ceased providing services to people at home. A focus group of community health workers summed up this concern:

*NGOs used to help, but they seem to be disappearing. We only see the Catholic Church now.*

And a caregiver noted:

*The church people only come and visit occasionally, the church health workers cannot cover all the corners of the community.*

The vast majority of caregivers said they were not satisfied with the care they received. Kenya does not have a home-based care programme, so any help that caregivers and patients received in the home came from voluntary health workers, religious organizations, the private sector or NGOs. The urban areas were better served than the rural sites. In the rural areas, caregivers could not identify one NGO and only identified the Catholic Church as providing some care in the home. Volunteer community health workers were found in both rural and urban areas, however, they were reported to provide only a limited amount of home care. Respondents reported a profound lack of supplies, including drugs, gloves and other protective coverings, soap and disinfectant. Transportation was also a problem. However, the most profound need was a lack of information and education. Very few caregivers had received any information on how to use universal precautions or to provide basic nursing care, including nutrition. In addition community health workers
reported a severe lack of knowledge about caring for people with HIV/AIDS, and how to counsel, educate and support caregivers and patients at home. These issues will be further elaborated upon later in this report.

When asked how many hours the caregivers devoted to caring for their sick family member, 21 (40%) said they devoted over 12 hours of care each day, while 10 (19%) caregivers said they devoted between 5-12 hours to caregiving activities, and 22 (41%) caregivers said that they devoted between 2-4 hours of caregiving each day. These caregiving activities included both personal care such as bathing, feeding, dressing, mobilization, and help with elimination, and instrumental activities of daily living such as collecting water and wood, cleaning, obtaining health supplies and shopping, cooking and dealing with finances.

Three questions were asked to caregivers about; (a) how they rated their quality of life, (b) how they rated the impact that caregiving has had on them, and (c) the caregiver’s level of satisfaction with their caregiving role. The results of these questions are found in Tables 8, 9, and 10 respectively.

Table 8: Quality of Life of the Caregivers N=52 (one missing respondent)

<table>
<thead>
<tr>
<th>Descriptor</th>
<th>Very Poor</th>
<th>Poor</th>
<th>Neither good nor bad</th>
<th>Good</th>
<th>Very Good</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>26 (49%)</td>
<td>12 (23%)</td>
<td>11 (21%)</td>
<td>3 (6%)</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 9: Impact of Caregiving N=52 (one missing respondent)

<table>
<thead>
<tr>
<th>Descriptor</th>
<th>High</th>
<th>Medium</th>
<th>Low</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>34 (65%)</td>
<td>12 (23%)</td>
<td>6 (11%)</td>
</tr>
</tbody>
</table>

Table 10: Level of Satisfaction with Caregiving N=52 (one missing respondent)

<table>
<thead>
<tr>
<th>Descriptor</th>
<th>High</th>
<th>Medium</th>
<th>Low</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>24 (45%)</td>
<td>19 (36%)</td>
<td>9 (17%)</td>
</tr>
</tbody>
</table>

There appear to be some contradictory findings in the Tables 7-9. The vast majority of the caregivers (49%) found their quality of life to be very poor, and the impact on caregiving to be very high (56%). However, when asked about their level of satisfaction in providing care to a sick family member, the majority of the caregivers rated their satisfaction as high. That is, although they felt overburdened and had a poor quality of life, they gained satisfaction from their caregiving role. The following quotes from caregivers shed some light on this apparent contradiction:

*I am very satisfied and motivated. It is my Godly duty. Complaining would only be like drawing anger from God. I know I try my very best.*

There were also reports of caregivers experiencing low satisfaction in their provision of care. As one 18 year old girl remarked:
I try the best I can with no money, no employment, no food. I feel I could do better.

The respondents who reported the impact of caregiving to be high (65%) described a sense of feeling overwhelmed, without money, unable to provide food, drugs, pay for transportation and other health care needs for the patient. In addition, these caregivers spoke of their ignorance on how to provide basic care including precautionary measures when caring for the patient. A 12 year old caregiver summed this experience up when he said; “It is too much for me”.

THE IMPACT OF CAREGIVING

The following section identifies the themes that emerged from the interviews that exemplify the impact of family caregiving on older women and children. This will be followed by a review on the growing problems of orphan care. Finally, general issues related to caregiving will be presented. These issues include the overwhelming problems of poverty, lack of education and an adequate infrastructure for home-based care, and problems associated with vertical versus integrated programmes of care. Finally, despite all these problems, the value of community mobilization and sustaining the community spirit will be presented.

Elderly women as Caregivers

Case Example: A mother is caring for her daughter with AIDS. Her daughter’s husband and a second daughter died last year. Her daughter needs complete care with all activities of daily living such as washing, feeding, and elimination. The caregiver also travels a considerable distance to collect wood and water. She has to buy whatever meagre food the family can afford and do all other household tasks. In addition, the mother has to care for six family members including one orphan from her deceased daughter. The sick daughter has two children and the mother will be responsible for their continued care after her daughter’s death. One of these children (a young girl) had to leave school because the family cannot afford school fees, books and uniforms. The mother gives her daughter’s diagnosis as typhoid although the health care workers confirm the diagnosis as AIDS. This daughter suffers mostly from diarrhoea and vomiting. The mother explains:

I have many problems. I have just come from the chief’s office to ask for assistance for food rations and to pay for medicines. Some people are now laughing at my misfortune some even want my land. All my friends deserted me once the problems came. I am now all alone. No one cares for me. Even my relatives have deserted me.

When asked about any support mechanisms or resources available to her she said:

There is no support given. I had to sell almost everything in order to care for my daughter. I have to sell my property.

When asked about how she cares for her daughter she states:

This is my daughter. Even when she spoils the bed I still wash her with my bare hands. We share the same utensils. She is my daughter and she once toiled for me, and I do the same for her.

As this case example portrays, older women faced many challenges in caring for sick family members at home. Key informants and caregivers identified these challenges to include: (a) being physically unable to provide personal care to the sick family member; (b)
feeling exhausted and overwhelmed; (c) experiencing abuse, stigma and isolation; (d) living in poverty; (e) neglecting their own health; and (f) being ignorant in the provision of care and accessing resources. Despite these adversities, the older women (g) maintained their belief in God and turned to spiritual support and guidance.

(a) Providing physical care

Older women had considerable difficulty providing physical care to the sick family member. These women had to cook, clean the house, do laundry, and collect water, food, wood and other supplies. In many instances they also had to provide care for the children of the PWA and other family members. In addition, these caregivers had to provide physical care to the PWA such as bathing, feeding, turning, changing, washing soiled clothes and bed linen, disposing of excrement, administering medication, changing dressings, massage, oral hygiene and other personal care requirements. These caregivers were often exhausted and overwhelmed. As one CHW noted:

They [the older women] have no strength to care for the patient. They lack protective devises and many are ignorant and cannot follow instructions.

A second CHW explained:

The older lady may have a poor memory, and can’t know how to help the patient. She may not be able to cook and do other domestic activities for the patient. She is also old and does not feel better than the patient. She may not be physically able to help the patient.

(b) Feeling exhausted and overwhelmed

The women were often old and infirm and the caregiving duties and other responsibilities were beyond their ability to cope. They could see no end to these responsibilities because, even when the patient died, the grandmother would resume orphan care. One CHW summed up these problems:

This care of HIV/AIDS is too much for the older women. She has to worry about food, rent, her grandchildren, and their education too.

Some of the caregivers had come from their rural homes to take care of their child, or an in-law in an urban setting. They did not know their surroundings, neighbours, or social groups. They found it difficult to negotiate normal daily activities like shopping and accessing health care. Caregivers who did not relocate also experienced isolation from their normal support networks as their daily activities consumed their time.

(c) Experiencing abuse, stigma and isolation

Family members often neglected the older caregivers. In many instances, they received little or no support (either financial, social, emotional or physical). In addition, some experienced verbal abuse from the family regarding their inability to perform certain tasks, their general role as house-keeper and about their caregiving activities.

Some patients were also abusive to their caregivers. This abuse might be the result of AIDS mental deterioration, or from longstanding problems within the family. One woman explained how her daughter abused her when she tried to encourage her to take her medications. There was no food in this family and the patient was taking pills on an empty stomach. This caused stomach pains and the daughter abused her mother for trying to persuade her to take the treatments. A mother explained:
She gets angry with me when I try to help her eat. She shouts at me and pushes me away.

One CHW noted:

*Sometimes the patient is uncooperative and they chase the caregiver. The pains they experience is translated into aggression to the caregivers.*

Some of the older caregivers were ignored or taken for granted by family members. In addition, if the family member was thought to have HIV/AIDS, the caregiver was often shunned by neighbours and friends. There was a belief that the family was cursed or bewitched, and the caregiver was discriminated against. This experience lead to a sense of isolation and loneliness and in many cases, the caregiver did not know where to turn for support. One caregiver describes her experience:

*They (friends) used to come and visit me. Now they stay away. They are afraid they will catch this disease. I am left alone with no-one to help me.*

(d) Living in poverty

Poverty was a pervasive theme throughout the data. Caregivers often had to cease employment or other income-generating schemes to care for the sick family member. In addition, in many instances, the main income earner in the family was either the sick family member, or that person had already died. For the vast majority of caregivers the illness had devastated the family’s ability to financially support themselves. As one elderly caregiver explained:

*I have been forced to sell four cows, it has cost me a lot of money. I have had to give up my shamba [small plot of land] to take care of my daughter-in-law. I have also stopped going to church to take care of her.*

(e) Neglecting their own health

There were many reports of older women performing tasks that were beyond their physical capabilities and sustaining injuries. There were examples of caregivers providing meagre food supplies and other amenities to the sick person or to the children and neglecting their own needs. As a result, these women became sick and disabled.

(f) Ignorance in the provision of care and access resources

Rarely had these caregivers received education about how to care for a sick family member at home. There were very few examples of caregivers receiving instruction on universal precautions, general nursing care, nutrition, or how to access needed resources. These women remained ignorant and often put themselves at risk. There was also general ignorance about survivors rights and rights of succession. As a result, once the patient died, the women were left destitute.

Members of a focus group summed up this general lack of knowledge:

*There is a lack of information. The caregiver is not given adequate information on care. The patient is discharged when they are very weak... There is an urgent need for them to learn how to care for themselves as caregivers.*

27
(g) Maintaining spiritual beliefs

Despite the overwhelming challenges facing older caregivers, most of the respondents reported a strong belief in God. For some, this belief had been strengthened. They turned to their church or to spiritual leaders for support and guidance. In addition, they prayed and helped the patient and other family members pray. They reported feeling comfort and solace from this spiritual connection. As one older caregiver described:

I worship and pray more regularly now. My faith has increased. I think I have become better in prayer and stronger in faith since this happened.

In summary, the words of a rural health educator describe the problems encountered by older women providing care to sick relatives and other family members at home:

They physically have no strength, they had limited knowledge in caring for the sick at home. They have no source of income and sometimes food is scarce. They have no money to buy drugs for the sick. They have limited time for the many tasks she has to perform, including looking after animals, cooking, fetching water, firewood and shopping. They lack knowledge in universal precaution skills and can easily be infected with HIV.

Young Children as Caregivers

Case Example: A 19 year old girl is caring for her father dying of AIDS. Her mother died last year. She lives in a rural part of Kenya with a house of mud walls, a corrugated roof, and earthen floor. There are two rooms with 5 household members. This girl has 3 younger brothers aged 16, 15, and 12. Her father is bedridden and requires total care. He suffers from diarrhoea and vomiting and the young girl cleans him without the aid of gloves or other protective clothing or bedding. She is also responsible for caring for her brothers. She cooks, cleans their clothes and helps them with their schoolwork. She has no free time. Her father is very irritable and shouts at her a great deal, “for no good reason”. When asked what she does to care for her father, she states:

I just do what I can, and leave what I can’t do. For instance, I can’t turn him by myself. Two nurses in the hospital used to do that, but I can’t. He now has bed sores. I have to wait for my brothers to come home from school to help me lift him. I don’t know much, no one taught me anything.

The family is very poor and cannot afford medications, medical supplies or other resources. They receive some food from a grandmother but not on a daily basis. This young caregiver explained:

When I left school I wanted to do a tailoring course. Now I have to become a mother to this family. Everyone calls on me all the time. I feel ruined. I have no life of my own. My friends shun me.

When asked if she gets depressed she stated:

I feel sad all the time. I see myself stuck with the children always. Where would they go? I must always be around. My former friends shun me, they say this family is under a curse. They fear to visit us in case they too get the curse. Children should be in school instead of doing adult work.

Younger children, both boys and girls, were often left as the primary caregiver in the family. This usually happened when one of the parents was ill and the other parent was working away from home, had died, was also ill, or had deserted the family. If there was a
young girl in the family she usually took on the caregiving role. However, if there was no
girl in the family, then the young boy would resume the caregiving responsibilities. These
young people were left with responsibilities that were beyond their years of maturity. They
often had to provide physical care to a parent and act as a surrogate parent to younger
siblings. In particular, young caregivers experienced: (a) poverty; (b) vulnerability; (c) lost
opportunities; (d) lack of information and support, (e) stigma and isolation; (f) foregone age
appropriate activities; (g) lack of moral development; and, in some instances (h)
rebellion.

(a) Poverty

By the time the children became caregivers in the family, the family had usually
exhausted all their financial resources. Sometimes one parent might still be employed, but
the majority had very little source of family income. Other relatives might provide some
financial assistance, but this was rarely consistent and reliable. Therefore, these young
caregivers and their remaining family members lived in absolute poverty. There were
reports of families and the sick family member going without food, water, heating fuels,
and necessary medicines and health care supplies. These young caregivers were often left
to fend for themselves, their sick parent and their siblings. As a result, they were often open
to abuse and exploitation.

(b) Vulnerability

In some instances family poverty was so profound that young girls turned to
commercial sex work to help the family survive, or to better her own financial situation.
These girls became vulnerable to sexually transmitted diseases (STDs) and HIV/AIDS.
Thus the cycle of poverty, hardship and illness continued. In addition, there were reports of
young caregivers being abused by family members. Uncles or other family members were
reported to sexually abuse some of the young girls. There were reports of rape and other
forms of physical, emotional and sexual abuse. As one key informant noted:

They [young girls] often go to the family for support, but the uncle might
abuse her. She cannot say anything, especially if he is giving her money.

Conflict between the sick family member and his/her own children was also
problematic. This conflict usually came in the form of complaints about care or refusing to
accept the care that was offered. The sick family members often complained that the young
caregivers provided inadequate care, or were neglectful of their responsibilities. As one
young female caregiver explained: “He (the ill father) has become very irritable of late. He
shouts at us all of the time for no good reason”.

(c) Lost opportunities

Many of the young caregivers experienced lost opportunities. The most commonly
reported loss was school attendance. Heavy caregiving responsibilities and/or family
poverty that precluded the purchase of school uniforms, books and school fees were the
main causes. Young girls were more vulnerable than boys, however, both boys and girls
experienced this loss. Being forced to leave school lead to other losses such as advanced
education and job training. Thus their ability to seek adequate future employment was
effected. Young girls were also less likely to marry or be considered a good marriage
partner. As one CHW remarked: “her destiny is changed”. Several quotes highlight the
devastation felt by young people as they gave up any opportunities they saw for themselves
and their future:
Since the time he became so ill I had to forget all plans of any further learning after secondary school. My chances of getting a job are narrow.

I dropped out of school due to lack of money for school fees and uniforms. I have no vocational training. My poor status limits my opportunities to secure a job.

(d) Lack of information and support

Rarely were these young caregivers provided adequate information on how to care for the sick family member or how to access resources and supplies. They were uninformed about universal precautions, or general information about HIV/AIDS prevention and care. As a result, these young caregivers put themselves at risk for infection. Emotional support was also reported to be lacking. They were often left to fend for themselves and their families, without any form of social, emotional or physical support.

(e) Stigma and isolation

Young people experienced stigma at school and in their communities if it were known (or suspected) that a family member had HIV/AIDS. They were shunned at school and were often not allowed to play with their friends and classmates. They were also isolated from friends due to caregiving responsibilities. They were too busy in the home to join friends in school or at play. One young man who had been on the school football team described how he had to leave the team when he was forced to leave school. He explained:

My friends don’t visit me anymore. I can’t play on the team now and they don’t come round.

(f) Foregone age appropriate activities

Young caregivers were reported to “grow up before their time”. They did not participate in age-appropriate activities such as play, sport or generally ‘hanging out’ with friends. Instead, they were burdened with the responsibilities of caregiving, housework and trying to access various health and social services. As a result, they often felt demoralized, with a sense of hopelessness and helplessness for their future. These young caregivers explained that their concerns were not taken seriously by authority figures as they were considered to still be children. They described a sense of burden and feeling overwhelmed by their responsibilities. As one health care worker reported, “they are denied their childhood”. In some instances these children were reported to be incapable of providing the kind of care that was necessary for the sick family member, as well as performing household chores, caring for other siblings, and accessing health and social support. In such circumstances, the family began to disintegrate from lack of care.

(g) Lack of moral development

Due to the sickness or death, many young caregivers went without moral teachings. Traditionally, the mother would take the role of ensuring the moral development of her children. This would be done over the childhood years, through discussion and by example. However, due to sickness or death of the mother, or from her overwhelming responsibilities, this moral guidance was often lacking. Thus, some children were reported to be growing up without the moral, ethical or legal knowledge required to fully participate in society. As a result, they sometimes turned to crime, commercial sex work, or lived outside the traditional norms and values of their family and culture. As a member of an
NGO explained: "The girls miss maternal care and end up in prostitution to earn a living, so the problem of HIV continues."

(h) Rebellion

Due to immaturity or to the excessive burden placed upon them, some young caregivers rebelled against these responsibilities and refused to provide the necessary family care. There were examples of children leaving home, going out with friends, attending bars or other activities despite the needs of the family. A CHW described the experience she had with rebellious young people:

There is a lack of communication between the girl and her elders. She sees the work as a big bother. She does not want to wash the bedding, she feels like it is a waste of time.

Orphan Care

By 2000, it is anticipated that Kenya will have over one million orphans (NASCOP, 1999). Children in orphan-headed households faced similar problems as young caregivers described in the previous section. That is, problems of poverty, vulnerability, loss of opportunities, lack of information and support, stigma and isolation, foregoing age appropriate activities, lack of moral development, and in some instances, rebellion were similar to both types of young caregivers. In addition, orphans faced unique challenges such as: (a) family disintegration; (b) multiple bereavement and emotional stress; (c) lack of knowledge about income generation; and, (d) loss of property rights.

(a) Family disintegration

After the death of parents, the extended family (if available) had to make decisions about the continued care of the children. In most instances, the extended family assumed this responsibility. However, this often put an incredible financial burden on the extended family and on their ability to physically house these additional children. One nurse summed up this concern:

The extended family is too stretched. They can't take the extra children. They are usually taken in but there is a lot of suffering and hunger. Some children are left alone but someone will watch over them, but not much in the way of provisions.

There was an example of one family who had to absorb the care of six orphans upon the death of their mother. This family already had another daughter dying of AIDS and was caring for her son with TB.

In some instances children had to be split up and sent to different relatives. This meant the family constellation was affected with children growing up without the love, support and companionship of their siblings. Siblings were often relocated to other districts or provinces, and their ability to see or keep in touch with each another was compromised.

In other cases the extended family could not undertake the additional burden of care. In such instances children either lived in child-headed households, or were cared for by neighbours and/or the community.

If all else failed, children were put into orphanages managed by NGOs or religious organizations, or they ended up on the street. Kenya has a growing problem of street children. As a staff member of NASCOP noted:
There is no strategy for addressing orphans. The vast majority are cared for by relatives, but this is putting a huge stress on the family and putting them into debt.

Despite these overwhelming problems, there were also reports of communities, neighbours, and families banding together to support and care for orphans, even when these additional responsibilities put a substantial burden on their existing resources.

(b) Bereavement and emotional stress

Orphaned children experienced considerable emotional stress and bereavement. They suffered multiple bereavements as they witnessed the death of both parents, and in some cases, other family members. Their natural sources of love and support had gone. They felt alone, helpless and in many instances, hopeless. As a 12 year old boy explained; “I am sad because I am all alone”. These orphans felt vulnerable to the decisions made by others regarding their care. Because the extended family had additional burdens and responsibilities, these emotions were rarely expressed. These children often hid their feelings, or acted out in inappropriate ways. This inappropriate behaviour often contributed to them ending up on the street. There were very few support mechanisms available for orphans. In some instances, community leaders, health workers, neighbours and others made every effort to support these children, while for others, their material and emotional support needs went unmet.

(c) Lack of knowledge about income generation

Orphan-headed households experienced profound poverty. They received little or no education or training in farming techniques, or other forms of income generation. Therefore, although they were reported to be willing to generate income, they did not have the knowledge or skills to do so. As a result, these orphaned children relied on the goodwill of the community to survive. In some instances, this goodwill was forthcoming, and in other instances, it was not. As one health worker explained:

These children could be taught to farm, or to do other income generating activities. They want to, but there is no education in place.

(d) Problems of inheritance rights

There was a general reluctance and fear about openly discussing death. People lacked the necessary skills to encourage sick family members in making adequate provisions for their surviving family. As a result, many people died without leaving a will or providing other forms of documentation for survivor inheritance. Orphaned children were therefore left without their parents having formally expressed their wishes for the surviving children and their inheritance. In some cases, this inheritance was so meagre or non-existent, that this lack of provision was unimportant. However, cases were reported where the children should have inherited a house, money, a piece of land and cattle, but they were denied this inheritance due to lack of planning by the parents. In these cases, the children were sometimes turned off the property and land that should have rightfully been theirs. As one nurse explained: “They (patients) need to die organized. They need to plan for their death and inheritance, particularly the land”.
**Issues Related to the Provision of Home-Based Care**

The data also revealed general issues that affected all caregivers and orphans in CHBC. These general concerns included the overwhelming problems of poverty, stigma, rejection and abuse, lack of education, lack of an adequate infrastructure for home-based care, and problems associated with vertical versus integrated health care programmes. Although some of these problems have been addressed earlier in this report as they relate to young and older caregivers and orphans, further consideration is warranted in relation to CHBC in general. In addition, the Director of Medical Services (DMS) at the Kenyan MOH requested that the desirability and feasibility of introducing voluntary counselling and HIV testing (VCT) into community health care be incorporated into this study. Results from this portion of the study will also be reported.

**(a) Poverty**

One of the most pervasive themes throughout this research was the experience of poverty. Kenya is experiencing a profound drought at this time. Rivers are without water with crops burning in the fields. Large tracts of land have been ploughed and prepared for planting, but without rain, no crops have been planted. As a result, the markets have very few fruits and vegetables and what is available has become expensive. In better climatic conditions, families grow their own food for family consumption and sale. However, this form of food supply and family income has been severely compromised. Cattle are thin and dying of dehydration and starvation. There were reports of famine as families struggled to secure food from meagre food supplies and with very little money.

The purchase of water was also a problem. In urban areas many families were required to purchase water from a central location. This was particularly true for families living in the slums of Nairobi. The purchase of water was also reported to be a problem in the rural districts. However, some people walked many kilometres (up to four hours a day) to collect water from rivers and lakes. The cost and inaccessibility of water resulted in use for human consumption, and not for washing and other sanitary purposes.

The government of Kenya has adopted a programme of retrenchment to address some of the financial problems facing the country. This is particularly true for government employees, however, retrenchment has also affected the private sector. At this time, Kenya has an unemployment rate of 52%. As a result, there were many instances where families were living in absolute poverty and destitution.

Caring for a sick family member at home also created poverty. The costs of health care, drugs, medical supplies, and transportation had to be borne by the family. As a consequence, families used what little financial resources they had on caring for their ill family member. In addition, the sick person was often the family income earner. Therefore, families became increasingly poor as they tried to provide adequate care to sick family members at home.

**(b) Stigma, Rejection and Abuse**

Throughout this report, reference has been made to the experience of stigma and abuse suffered by caregivers and orphans. In addition, a “conspiracy of silence” regarding the patient’s diagnosis was pervasive. This problem was most noticeable in families caring for a person with HIV/AIDS however stigma was noted, regardless of the patient’s diagnosis.
Stigma was reported to lead to discrimination, isolation, rejection, family disintegration, and abuse. One of the most prevailing problems was family disintegration and desertion. Husbands and fathers were reported to desert the family if his wife became ill. This desertion was more problematic if the wife had (or was suspected to have) HIV/AIDS. These men deserted their families without providing any form of support and began another relationship without knowing their HIV status. A focus group with CHWs discussed this problem:

When a woman is unwell, the husband does not seem to care for her or the children.... Husbands and wives desert each other. Men do this more than women. In other diseases it is different, but when one partner gets AIDS, there is a difference. The reason is that infectious diseases are feared, so people stay away.

Another focus group of community leaders commented:

It will depend on how the relationship has been, but in general most of the break up is blaming each other.

Health care workers were also reported to stigmatise PWAs and their families. There were examples of health personnel announcing the sero-status of a patient in a busy waiting room. In addition, there were reports of PWAs being refused care because of their status. Issues of confidentiality were reported to be breached, with disrespectful behaviours toward PWAs and their families. As one health educator noted:

There are a lot of staff in hospitals still demoralizing patients because they are announcing loudly that the patient has AIDS. The patient’s hope is lost when they hear this. Actually, confidentiality is lost.

Stigmatised people believed they had no recourse to these pervasive attitudes and behaviours. They reported feeling vulnerable to the abuse of others and were unaware of any support mechanisms available to them. There were no examples of people speaking out about their experiences. They feared the repercussions of openly acknowledging these stigmatising and abusive behaviours.

(c) Lack of Education, Information, Supervision and Support

There was a profound need for education throughout the system. Nurses, social workers, community health volunteers, family caregivers and patients all expressed a need to know more about the care and prevention of illness at home. This need was most marked in the care of PWAs, although knowledge about caring for other chronic illness was also problematic. Community health volunteers, caregivers and patients received little or no education on basic nursing care, nutrition, use of universal precautions, administration of drugs, use of medical supplies and other forms of patient care. As a result, patients were receiving substandard care and family members were putting themselves at risk for infection. One young caregiver reported on this problem:

I don’t know how to care for her (her mother). No one has come to show me what to do. They discharged her from hospital with pills, but I don’t know how to care for her sores. I use polythene bags but they break. I don’t even have any soap or disinfectant. There is no one to show me what to do.
A focus group with CHWs provided some suggestions for this caregiver education:

_The CHWs could teach this during home visits and through the barazas [community meetings]. ... We need a team to train caregivers. ... This is the most effective way to provide this community education._

Community health workers also reported a need for continued education. They reported a lack of knowledge about various treatments for opportunistic infections, and about specific nursing care and treatments for other chronic illnesses. These workers voiced dismay at their inability to provide the kind of service they knew they should. They also acknowledged their ability to train family caregivers in basic health care practices. These health workers spoke of the need for continued education on health care matters and how best to counsel and support patients and families. As one focus group of CHWs stated:

_We lack appropriate skills. We need continued training so that we can give training to the caregivers. There is very little education on patient care. We need counselling skills to reduce the tension and also to assist the people to live positively. We need to help with community awareness so that people are able to ask questions and to understand and deal with their situation. We need seminars to become enlightened._

Health workers also voiced concern that they did not know how to provide emotional support and counselling to individuals and families. Therefore family members not only lacked education on the necessary knowledge and skills required to care for the patient at home, they were also deprived of much needed psychosocial support and counselling. A focus group of CHWs summed up these concerns:

_We need education in counselling. We feel we need to learn more about how to establish rapport with patients; how to care for the patient, particularly caring for someone with AIDS._

Kenya does not have a CHBC programme. Therefore, very few health workers visited the homes. The caregivers had to go to dispensaries or health centres to learn what little they could about patient care. Some members of NGOs used to visit the home, but as the problems of caring for people with HIV/AIDS grew, these services become overwhelmed. As a result, many of the caregivers had never received a home visit from any health or social service personnel.

Voluntary counselling and testing is not well established in Kenya, and the data revealed a general ignorance about the full magnitude of the problem of HIV/AIDS. This general ignorance contributed to stigma and discrimination. Reports also highlighted a general lack of awareness about the patient’s diagnosis. One nurse explained how blood was taken in the hospital and tested for HIV, however, if the diagnosis was HIV positive, this news was not always shared with the patient. Even if the patient was aware of his/her diagnosis, there were many instances where this diagnosis was not shared with the family and caregiver. In addition, key informants reported on incidents where patients were discharged from hospital without CHWs being aware of the diagnosis and recommended course of treatment. If the patient failed to report to the dispensary (usually due to lack of funds), the CHWs were often unaware of the patient’s diagnosis or their health care needs.

Finally, health care workers expressed the need for continued support. They explained that caring for chronically and terminally ill patients and their caregivers was emotionally draining and often lead to burnout. In order to continue this important work, they expressed their need for psychosocial support.
(d) Lack of an Adequate Health Care Infrastructure

An adequate infrastructure to support the care of sick family members at home was noted to be a pressing issue. Specifically the following infrastructure requirements were reported to be necessary: (a) an adequately functioning referral system; (b) the provision of supplies at the periphery of care; (c) the development of a transparent, egalitarian waiver system; (d) better communication between NGOs, church organizations, private health care and the public health care system; (e) maintaining the value of complementary organizations; and, (f) the provision of affordable (or free) transportation.

(a) Adequately functioning referral system

Data from both key informants and caregivers provided mixed results about the efficacy of the referral system. Some health workers thought the system of referral worked well. They described the discharge planning and discharge summary cards that accompanied a patient from the hospital to the home and community. They reported that this discharge summary was sufficient to continue the prescribed regimen of patient care at home. However, other respondents described serious gaps in the referral process. These gaps appeared to be most acute between the community health facility, the dispensary and the home. One health educator commented on this gap in services:

We need to establish a continuum of care from hospital to home and home to hospital with no gaps in care. This care needs to be systematic and comprehensive. The gaps happen mostly between the health centre and the home. There are major gaps.

If a patient failed to go to the dispensary or health centre (usually due to lack of funds), these patients could go without the prescribed treatment and care. In addition, many of the caregivers were unaware of the services and resources available to them. There appeared to be no directory of services available at any of the study locations. This meant that patients, families and health and social service providers were sometimes ignorant of available resources. This ignorance was reported to lead to a lack of referral to necessary agencies and services.

The referral system between hospital and home consisted of a discharge summary card for the patient to take to the relevant health care agency. However, key informants noted a lack of referral between the home and the health facility. That is, no formal policy was in place to support referral from the periphery to the central health care agencies. In addition, community health practitioners reported that their judgements regarding patient referral were seldom respected by health personnel at the hospital or health centre. Moreover, the judgement of patients or families regarding the need for referral were seldom respected by health care practitioners. Therefore, referral from the home and community to the necessary health care facility was reported to be severely compromised. One focus group of CHWs described this problem:

Communications with health care workers at the hospital is not good because there is no prompt attendance when you bring the patient to the hospital. Sometimes we are abused and cursed by the health workers at the facilities, especially in the city council ones. Sometimes the social worker assists when we run into problems.

(b) Supplies at the periphery of care

There was a lack of essential medicines and supplies at the dispensary, health centre, and sometimes at the district hospital. This lack of resources severely compromised
effective referral. If these supplies were not available at the appropriate referral point, then patients and families were forced to move up the system until they found the supplies they needed. This led to inappropriate and costly use of more central health care agencies. In addition, medications and other necessary health care supplies were not available to health care workers to take to the home. Respondents noted that a constant supply of home-based kits would be required in order for home-based care to be successfully implemented.

(e) Transparent, egalitarian waiver system

Although Kenya has a waiver system for people who cannot afford to pay for health care, supplies and transportation, data revealed that many people were unaware of how to successfully access this waiver system. An example was given of a community health worker (CHW) who brought a patient to the hospital for treatment. However, the CHW could not access a social worker, and so the fee waiver was not given. As a result the CHW and the patient went home without anyone examining the patient or prescribing treatment. Because of the severe poverty, it is necessary that a waiver system be implemented that is easily accessible, open to all who need it, and transparent in its delivery. Such a waiver system should be seen as a preliminary measure. The government of Kenya must explore options to ensure sustainable financing for health care (including home care) where payment at the point of delivery is not required by the family or patient.

(d) Communication between NGOs, church organizations, and the private and the public health care system

There was general agreement among the study participants that religious organizations NGOs, and private health care facilities were doing most of the work in caring for people in the community and home. They described these organizations as a valued resource within the overall health care system that should be maintained and supported. As a focus group of CHWs noted:

The government is concerned with the health of the people, however in this area, only the Catholic Church seems concerned.

And a caregiver also noted:

The government does not seem to have anything for the sick and the poor. Only the rich NGOs or the Church can help.

However there was a lack of communication between these complementary organizations and the government health care system. Communication was also lacking between the various tiers of the government health care system. This meant that patient care was sporadic and uncoordinated with gaps in reporting the patient’s condition and prescribed treatment of care. As a result, patient care across a continuum was severely compromised. Key informants from NGOs and religious organizations stressed the need for better communication between the complementary health and social service agencies and the government system. This need was confirmed by nurses at health centres, and by community volunteers. As one CHW noted:

We find people at home with pills, and we don’t know what they are for, and neither does the family. We are left being unsure what we should be doing to help the patient.

(e) The value of complementary organizations

Throughout this investigation, the value and contribution of religious organizations, NGOs and private health facilities was acknowledged. However, these complimentary
organizations were vulnerable to changes in funding. The ‘National Health Sector Strategic Plan: 1999-2004 (Ministry of Health, 1999) acknowledged the value of these non-governmental health services. However, strategies and government policies must be put into place to ensure the survival of these valuable resources.

(f) Affordable (or free) transportation

Access to health facilities was severely compromised by poverty. If patients and families were unable to pay for transportation, then visits to the relevant health care agency would not occur. There were examples of severely ill patients being transported by wheelbarrow, or by human stretcher as other forms of transportation were unaffordable. As one nurse commented:

*The home becomes a dumping discharge as patients can’t afford to come to the health centre for treatment.*

Transportation was also a problem for health workers. Very few areas had transportation for health care workers to undertake home visits. Some motorbikes and vehicles were available, but not enough to implement home visits by health care workers.

(e) Vertical Versus Integrated Programmes of Care

Specific health programmes such as Tuberculosis Direct Observation Treatment Service (TB DOTS), family planning, and antenatal care were available in communities. These programmes were reported to serve an important function in providing specific care and treatment for different health conditions. However, health care workers in these programmes did not look beyond their specific focus of care to encompass broader health and illness concerns. That is, these programmes remained vertical in their delivery without any integration of services to address the overall health and illness concerns of their patients.

The TB DOTS programme is well established in Kenya and caregivers and patients were well versed in obtaining and administering TB treatments. However, health care workers administering the DOTS programme appeared to be ignorant of the health and support needs of people who might be suffering from AIDS with TB as a co-infection. In addition, some community workers appeared to be confused about the relationship between TB and HIV/AIDS. These health workers provided TB medication and teaching to patients and families without mentioning or advising them on the possibility of HIV/AIDS as a co-infection. This was particularly distressing to the researchers as they identified many patients with HIV/AIDS and TB as a co-infection. There were reports of people receiving TB medication while serious symptoms of other opportunistic HIV/AIDS infections went undiagnosed and untreated.

A similar problem was noted with family planning programmes. As one health educator noted, community health workers trained in family planning were still recommending the birth control pill or injection over the use of condoms. They appeared to be unaware of the double advantages of condoms, as a means of family planning, and as a preventive measure against HIV/AIDS.

The Kenyan government is in the process of implementing VCT. However there is very little HIV testing at this time. Sentinel surveillance is undertaken in antenatal clinics, but there was little evidence of VCT being available for pregnant women and their partners. Women attending antenatal clinics or visiting TBAs were not routinely counselled about HIV/AIDS or to the potential problems of mother-to-child transmission.
These specific health programmes were noted to be performing a useful function in primary health care. However, the fact that they had not broadened their scope of practice to diagnose and treat other illnesses, in particular HIV/AIDS, was problematic. Study participants were hopeful that with the introduction of VCT, these vertical programmes would broaden their mandate and become integrated into overall care and prevention in primary health care.

(f) Desirability and Feasibility of Implementing VCT

In response to a request from the DMS at the Kenyan MOH, two questions on VCT were included in the questionnaires. These two questions included: (a) Do you think voluntary counselling and testing for HIV should be available in your community? and (b) If voluntary counselling and testing were available to you in your community, would you volunteer to be tested for HIV? Each question provided a “yes”, “no” response with space for respondent explanations.

Of the 80 individual interviews conducted, 71 (89%) respondents thought VCT should be available in their community. In addition, 62 (77.5%) stated that they would be willing to take an HIV test. Of the respondents who thought that HIV testing should be available in the community, some of the explanations for this decision were:

- It would help people to be better informed. To help the infected not to give up and to control the spread to others. (family caregiver)
- It would help the sick, they would need kind people to give counselling. (family caregiver)
- So that people can know their status and make decisions about sex, fertility and marriage. Also generally how to live. (health educator)
- Yes, with proper counselling, that is very important. Pre and post-test follow up is essential. It would help in attitude change, coping and behavioural change and prevention. It would destigmatize AIDS. It should be like TB. (nurse)

Respondents who thought that VCT should not be available in the communities provided some of the following explanations:

- I don’t think it is good for people to be tested for AIDS as it has no cure. Even if you go to the hospital, so what is the use? (family caregiver)
- Even though I am tested and the result is negative. of what use will that be to me at home? (family caregiver)

Respondents willing to undergo an HIV test provided the following explanations:

- I would know my status and thus take better care of myself and avoid infection. (family caregiver)
- Yes, but this must be done alongside other conditions for example diabetes. This way people will come, however, they will not come for HIV alone. (village chief)

People who thought they would decline testing gave the following responses:

- Only if they were well prepared, psychologically, emotionally and not stigmatised and victimized. They must be assured confidentiality. They must also be assured support and on-going counselling. We don’t have enough
counsellors for this. We need to educate more. Long term counselling is very necessary. We also need continuous education for counsellors. (health educator)

Why should I go for testing when there is no treatment, or care. People will loose hope and die faster (family caregiver)

Although data revealed a majority of respondents believed VCT should be available in the community and that they would take the test, they raised some concerns about this programme. In particular, they were concerned that VCT be supported by a clearly managed and implemented infrastructure of education, support, ongoing counselling and provision of necessary health care resources. These issues have been raised in the previous quotes, but will be attended to in more detail.

(a) Counsellor education

Health care workers should receive adequate education, practical training and ongoing support to become knowledgeable and effective counsellors. Pre and post-test counselling and support would require considerable education and practical training. The need for ongoing counselling would be necessary for many people. Therefore, these health care workers would need to be fully educated about the risks and modes of HIV transmission and be ready to answer the many questions that people may have. In addition, VCT counsellors would need adequate education and practical training on how to conduct effective counselling sessions. In particular, attention should be paid to emotional support and guidance as well as to ongoing counselling and support for HIV-infected people.

(b) Support, supervision and continued education for counsellors

Peer education, supervision and support were considered essential. In addition, educational updates should be available so that counsellors remain current and responsive to people’s counselling and information needs.

(c) Promoting shared confidentiality and disclosure of HIV

Considerable evidence throughout this report suggests that denial of HIV status leads to poor treatment and care, and to the risk of HIV transmission. However, evidence also suggested that people fear disclosure because of the resultant stigma, discrimination, isolation, rejection and abuse that often accompanies disclosure. Results from other studies have shown that shared confidentiality can lead to a better quality of life, increased hope and a better system of care for the PWA and his/her family. Therefore, counsellors should be educated on how to promote disclosure and shared confidentiality, and how to support the client and the family as disclosure is undertaken. Counsellors must be trained to help clients and families through this sensitive disclosure process and to counsel them about the potential repercussions of disclosure.

(d) Provision of resources

Concern was raised that knowledge of HIV status might lead to fear and premature death, including suicide. Some respondents thought they would have a better quality of life if they were unaware of their diagnosis. However this lack of knowledge could lead to serious ramifications, including HIV transmission. Therefore, respondents stressed the need for a system of support, care, counselling and education available and accessible to all people.
(e) Cost of HIV testing

Questions were raised as to whether VCT should be free, or offered at a small cost. Although opinions varied on this topic, there was overall consensus that testing include a small cost for those who can afford to pay. However, for those who are destitute, this fee should be waived. Respondents thought that a small fee could help support a revolving fund for the VCT programme. If government funds are made available, respondents believed these funds must also cover the development and maintenance of an adequate infrastructure to support VCT.

LIMITATIONS OF THE STUDY

This study has provided some important insights into the experiences of caregivers providing care to sick family members and friends at home. In addition, the study has shed light on the general infrastructure that is required to incorporate an effective and responsive home-based care programme in Kenya. Finally, the experience of orphan care has also been explored. However, despite this comprehensive review, certain study limitations exist.

As a qualitative research study, the decision on how many people to interview rested on reaching data saturation or redundancy (Lincoln & Guba, 1985). Members of the research team believed that data saturation was achieved. The team began to hear the same issues repeated by research respondents, sometimes on many occasions. Therefore, it appeared that 86 interviews with 120 people provided enough data to be confident that these results adequately represented the experiences and perceptions of the research respondents. However, in keeping with the tenets of qualitative research, no claims to generalizability of these findings can be made. (Huberman & Miles, 1994)

Generalizability is considered in light of the “fittingness” or “applicability” (Sandelowski, 1986) of the research results to other populations of caregivers engaged in caring for sick family members and orphans at home. That is, reliability and validity of the research depends, to a large extent, on testing the “fittingness” or “applicability” of the findings to other study populations. This study was conducted in the urban slums of Nairobi and in one rural area consisting of 20 villages. Despite the diversity of study locations, the data from respondents at both locations identified very similar issues. Therefore, it would appear that although claims to generalizability cannot be made, it is very likely that the findings of this study reflect the experiences of caregivers throughout Kenya. It is also important to note that some of the study findings had already been documented by the Kenyan Ministry of Health. That is, the findings from this research confirmed findings from previous home-care studies and reports. Finally, this study was a replication of a previous home-care study conducted in Botswana in March 2000 (WHO, 2000a) and many of the issues identified in this report were also identified in the Botswana study. Therefore, it can be assumed that the findings of this study and the previous Botswana study provide some salient perspectives on the experiences of providing care to sick family members and orphans at home, regardless of the study location.

This study also investigated the perceptions and experiences of caregivers and key informants in providing orphan care. Orphans were not interviewed for this study. It is recommended that future research should endeavour to investigate the experiences of orphans who head households. That is, the experiences of orphan children who head households of other orphan siblings should be investigated. Such a study would provide depth to the findings of this study.

This research investigated the impact on caregivers caring for family members and friends with HIV/AIDS and other chronic illnesses at home. Only seven respondents
identified HIV/AIDS as the patient’s diagnosis although a further 24 patients were identified by health workers and the research team to have HIV/AIDS. Another 22 caregivers provided care to family members with other chronic illnesses. Although it would appear that much of the impact on caregivers is similar, regardless of the patient’s illness, this cannot be verified. For instance, issues of stigma surrounding HIV/AIDS might not apply to caring for other chronic illnesses. However, in this study there appeared to be similar problems with stigma regardless of the patient’s diagnosis. What was different between these two groups was the secrecy surrounding the patient’s diagnosis. On the whole caregivers caring for a person with a chronic illness were able to identify the diagnosis, whereas caregivers caring for a family member with HIV/AIDS were either unaware of the diagnosis or were reluctant to state the diagnosis to the research team, other health care workers or even family members. Future researchers might consider studying these populations separately.

The interviews with caregivers, many of the key informants, and all focus group discussions were conducted in Kiswahili and the responses recorded in English (see research integrity section for details). The research team believed they took extraordinary steps to ensure that the data fully represented the experiences and perceptions of the research respondents. However, it is possible that details were lost in translation. Frequent debriefing sessions and full discussions among the research team attempted to alleviate this problem, however, it must be recognized that some detail could have been lost.

The principal researcher and author of this document is not from Kenya. Every effort has been made to understand and capture the cultural, traditional and contextual elements of this study. However, it is possible that some misunderstandings and misconceptions still remain. A first draft of this document was given to the research team before departure from Kenya. Feedback from this initial draft was incorporated into this report. That is, corrections, elaborations and suggestions for greater accuracy and clarity were included in this report.

CONCLUSION

This study revealed a wide variety of issues and concerns associated with the provision of care to sick family members and orphans at home. However, despite these overwhelming problems, there were also reports of exceptional acts of kindness and support by individuals and communities. This help was often given by people who were, themselves, very poor. There were reports of community health volunteers providing food, money, and other supplies to needy families. Communities were also noted to rally to the aid of families in need. Harambee, or the mobilization of the community to help families in severe distress, were reported to be a function of most communities. As part of this Harambee spirit, community groups coordinated their efforts to support and provide instrumental and financial assistance to families in desperate need. Instrumental assistance might include providing care to the patient, helping with washing, feeding, or other care activities. Instrumental support was also evidenced in people helping with cultivation or tending animals to help sustain the provision of food for the needy family. As one key informant noted:

*Our cultural practice is to care for one another. We need to support and strengthen this desire with adequate infrastructure support for people to be cared for in their homes.*

These acts of kindness and generosity were heartening to note. However, data from this report also revealed a desperate need for a comprehensive, integrated CHBC.
programme. Family caregivers, health care workers and organizations providing care to people at home are stretched to breaking point. Poverty, lack of education, lack of an adequate infrastructure of care, issues of abuse, stigma and discrimination, and a lack of an integrated health care system were identified as major problems in the provision of care and support to families caring for sick family members or orphans at home. The Kenyan government, with funds from the World Bank, is beginning to develop guidelines for the implementation of CHBC. It is anticipated that the results of this study will contribute to the implementation of CHBC in Kenya. To that end, the following recommendations are made.

RECOMMENDATIONS

1. Implementing Community Home-Based Care (CHBC)
   - The development of CHBC must involve all stakeholders. That is patients, caregivers, community health and social service workers, community leaders, members of NGOs, religious organizations, the private health sector, and representatives from the Kenya Ministry of Health must all be involved.
   - CHBC must be funded by the Kenyan government but managed (financially and logistically) by community leaders and the community health team.
   - CHBC must become part of a larger system of care across the continuum. This care should involve government-funded health and social service programmes as well as religious organizations, NGOs, and private health care facilities.
   - Routine evaluation of CHBC should be undertaken. Plans and guidelines to evaluate CHBC must be developed at the planning stage and inexpensive and planned evaluation should be undertaken at stated times throughout the CHBC programme. Based on these evaluations, necessary changes or modifications to the programmes must be applied and reinforced.
   - CHBC kits should be made available for people at home. These kits must contain the essential drugs to treat opportunistic infections, and other medical and preventive supplies such as gloves, aprons, mackintoshes and condoms. These kits must be in constant supply and accessible to all families in need. That is, health care workers should take these kits to the patient’s homes.
   - CHBC kits should be available free of charge, or with minimum payment to families that can afford to pay. That is, CHBC kits must be available to all family caregivers in need, regardless of their ability to pay.
   - The government should have policies and practices in place to ensure an adequate and consistent supply of medicines and other health supplies at the primary health care level. That is, there must be provision of all essential health care supplies at the periphery of care. Dispensaries, health centres and district hospitals must have the needed health care supplies to support caregiving in the home.

2. Training for Health Care Workers, Family Caregivers and Clients
   - Training and ongoing education must be available to all health and social service personnel associated with care, support and management of sick people at home.
   - This training and ongoing education should be provided to multidisciplinary teams. That is, education of health and social service personnel should be offered to multidisciplinary teams that might include nurses, social workers, clinical officers,
physicians, community health workers, community based distributors, traditional birth attendants and other workers, paid, or voluntary, that are associated with the care of the sick at home. The purpose of educating a multidisciplinary team is to share information and knowledge across health and social service disciplines, and to develop a team approach to CHBC.

▷ Education of health teams must include information on the care and prevention of HIV/AIDS, opportunistic infections, and the management of other chronic illnesses.

▷ Education to health teams should include basic counselling skills. Counselling education should include individual and family counselling, issues of disclosure, and for certain team members, pre- and post-test counselling for VCT.

▷ Health teams must be educated on how to educate family caregivers and patients in the home.

▷ Caregivers should be educated by the community health team on the care and prevention of illnesses. This education should include basic nursing care, nutrition, the use of universal precautions, administration of medications, the use of medical supplies and other therapeutic regimens.

▷ Training programmes must be evaluated on a systematic basis to ensure that information, education and training is responsive to the needs of health workers, and to family caregivers and clients.

▷ Counsellors providing VCT must be given continued education, peer supervision, and support.

▷ Psychosocial support should be made available to members of the community health team, including counsellors.

3. **Strengthening the Referral System and Provision of Supplies of Resources**

▷ A comprehensive system outlining the continuum of care should be developed. This system should outline the various levels of health and social service agencies and the overall system of referral. This continuum of care could then be used to support an effective referral system.

▷ Policies and practices must be developed and implemented to facilitate patient referral, both from the health care facilities to the community and home and vice versa. That is, attitudes of health professionals, changes to ensure that the judgements of patients, families and community health workers are respected and adequately responded to.

▷ Health care practitioners in government hospitals must be sensitised to the work of informal caregivers. This sensitising process would help promote effective referral from the home to the hospital.

▷ A directory of available services and resources should be drawn up for each community and district. In this way, patients, families, as well as health and social service personnel can refer and access necessary resources.

▷ Adequate health care supplies (medicines, aprons, mackintoshes, gloves, condoms, soap, detergent etc) must be available at the primary health care level.

▷ These health care supplies must be available on a consistent basis.

▷ Health care supplies must be affordable (or free when necessary) to patients and family caregivers.
4. Integrating Services

- Vertical programmes such as the TB DOTS, family planning, STD/HIV clinics and antenatal care should be integrated into the general health care system. In order to accomplish this aim, health care workers should: (a) be sensitised to the problems of other infections (including HIV/AIDS), and (b) be educated and given the responsibility to diagnose and treat health care problems that are traditionally outside the mandate of their particular programme.

- When necessary, CHBC kits should include treatments for TB, HIV/AIDS opportunistic infections, family planning, and other health care needs. These home-based care kits should be tailored to the needs of the particular patient. The family should be educated in the administration of treatments at home. That is, necessary patient treatments should be integrated into general CHBC.

5. Supervising CHBC

- CHBC should be supervised by nurses working in the community. These nurses should do regular visits to the patient’s homes.

- Trained community health workers should visit people’s homes on a regular basis to provide patient/family education, general nursing care, and other instrumental and psychological support. These health workers should have CHBC kits with the necessary supplies and medications appropriate to the specific needs of the patient.

6. Implementing VCT Throughout the Health Care System

- Voluntary counselling and testing should be made available to people throughout Kenya.

- The development and implementation of VCT must include key stakeholders. These stakeholders should include educators, community leaders, community health workers, PWAs and caregivers.

- Counsellor education in pre- and post-test counselling (including shared confidentiality) must be broadened to include ongoing individual and family counselling and support.

- VCT should be integrated into the overall health and social service system. That is, VCT should not be a vertical programme.

- Confidentiality (including the promotion of shared confidentiality) should be fully respected by all health and social service personnel.

- VCT must be affordable, accessible and acceptable to people. Some fees for VCT could be administered, however, VCT should be available to all people regardless of their ability to pay.

7. Reducing Stigma

- National and community education campaigns should be developed to provide information on prevention and care of HIV/AIDS. These campaigns can be mobilized through the mass media, community meetings, rallies, school curricula, and other mass educational opportunities. Stigma, discrimination and isolation should be addressed as part of these mass education campaigns.
Communities should be mobilised to raise awareness of HIV/AIDS issues, particularly issues of stigma, isolation, and discrimination. Community meetings, led by respected leaders should raise the awareness to the problems facing PWAs and their families on a regular basis.

Shared confidentiality should be promoted and encouraged. This practice will reduce the "conspiracy of silence" that is a barrier to effective HIV/AIDS prevention and care.

Education sessions should be provided for health and social service workers, on a regular basis, to help them become sensitised and responsive to the needs of PWAs and their families.

Stigma demonstrated by health care workers should be dealt with in supervisory and team meetings and collectively, effective strategies to address stigma should be identified.

8. Providing Anticipatory Guidance

- Community leaders should encourage people in their communities to begin to talk about death and dying. As far as possible, this practice should become cultural norm within communities.
- Bereavement counselling should be available to individuals and families in need.
- Anticipatory guidance for the provision of wills and other settlements of inheritance rights must be promoted. People should be encouraged to discuss death openly and to make wills for inheritance rights of their survivors.
- Parents dying of HIV/AIDS should be encouraged and supported to make arrangements for the future care of their children.

9. Alleviating Poverty

- The government must implement poverty alleviation programmes. These programmes must be prioritised and organized to ensure that those in most need are helped first.
- The government should instigate a destitute fund whereby people in absolute poverty can access funds to help them maintain their home-based care-giving activities.
- Food programmes must be funded whereby destitute families can get the nourishment they require for the sick family member, as well as for other household members.
- The government should collaborate with other funding agencies to implement a revolving fund for income generating activities (IGA).
- Knowledge and policy guidelines should be developed for funded IGA programmes. These policy guidelines must be based on sound economic experience and include: (a) education for people wishing to access funds and manage small businesses, (b) strict guidelines on how funds will be awarded and administered, (c) strict guidelines on loan and interest repayment, (d) strict checks and balances to avoid misappropriation of funds, and (e) strict accounting practices that provide a revolving fund for loans. This revolving fund should be supported by small interests paid on the loans.
IGA programmes should be funded by the central government and administered and managed by the local community leaders based on principles of fairness and in recognition of market and cultural determinants. A strict auditing process should be in place.

10. Promoting Community Mobilization

- Community spirit (such as Harambee) should be encouraged to help families in great need. Public acknowledgement of these community efforts with the honouring of certain individuals would help promote and support this community endeavour.
- Communities should be encouraged to honour the work of volunteer community health workers.
- Recruitment of additional community health workers should be encouraged.
- Multidisciplinary teamwork should be encouraged to alleviate the work and stress of individual caregivers.
- Informal caregivers should be encouraged to speak out about their needs and to mobilise community support to help address their concerns.
- Community-based support groups should be encouraged to help address the problems of PWAs, and patients with other chronic illnesses and their caregivers. These support groups could be mobilized through community leaders in order to achieve credibility and community acceptance.
- A sustainable system of support for community health workers should be developed. These workers experience considerable stress as they work with people who are ill and dying at home.
- The value of spiritual support and guidance for ill people and their families should be emphasized. Community religious organizations should be encouraged and honoured for this work.
- Emotional, physical and sexual abuse experienced by community members should be highlighted and strategies for alleviation explored. For example, community advocates should be identified to support and guide people to report abuse and to seek legal redress. This advocacy role must be supported by community leaders and given a high status in the community. Community leaders should also provide guidance to promote community values and norms that stress intolerance for abuse.
- Issues of family and community security should be explored. Community leaders should be encouraged and rewarded for developing measures to protect families and communities.

11. Strengthening Complementary Organizations and Services

- Formal partnerships between the national, district, and local governments and religious organizations, NGOs, and the private health sector should be developed.
- Communication between these complementary organizations and the government health care system should be strengthened.
- Complementary organizations should be involved in policy formation and strategic planning for CHBC.
- Complementary organizations should become integral partners in the implementation, administration, and management of CHBC.
Funding for these complementary organizations and services must be sustained over the long term.

12. Providing Orphan Care

- People who work directly with orphans, and orphans themselves, must be integral members of the planning, implementation and evaluation of policies and programmes for orphan care.
- The government should work in collaboration with all partners to ensure the development of effective and responsive policies and practices in orphan care.
- Orphans must have access to a bursary fund that will provide access to schooling, job training and IGA. This bursary fund should cover the cost of school fees, other tuition, uniforms, books and school meals.
- Funds for the provision of bursaries should be made available by the national government and systems for assessment, management and disbursement of bursaries must be the responsibility of district and local authorities.
- Checks and balances must be developed to ensure fair and equal distribution of bursaries.
- Day care centres or other forms of respite from responsibilities should be made available to orphans. That is, orphans caring for other siblings must be relieved of their responsibilities in order to attend school, job training, employment or other IGA.

13. Providing Caregiver Support

- Family caregivers should be provided with emotional support and guidance.
- Caregivers (both young and old) should be given education on caregiving activities that are consistent with their level of education.
- Respite programmes should be developed so that young caregivers can attend school, job training, employment, or other IGA.
- Bursary funds should be made available to youth caregivers to support school attendance, job training or IGA.
- Respite programmes should be developed for elderly caregivers. Such programmes would help provide some relief from caregiving activities, and support the elderly caregiver’s ability to care for a sick family member over the long term.

14. Providing Accessible Care

- CHBC must have a sustained source of funding by the national government. After the external funds have been utilized, sustainable CHBC funding must be a reality.
- If fees are to be charged to patients and families for CHBC, these fees must have a waiver system applied to them, so that families living in poverty and destitution can still access necessary care for ill family members and friends at home.
- A funding scheme for transportation to assist patients and caregivers to visit necessary health care facilities is essential. That is, patients and families that cannot afford transportation should be able to have the transportation fee waived.
- Transportation for health care workers to visit the homes on a regular basis must also be made available. This transportation might include bicycles, motorbikes etc.
The waiver system that allows families in absolute poverty and destitution to access necessary health care free of charge should be applied on an equitable basis. That is, an effective, adequate and transparent process of waivers for destitute families should be instituted. Policy guidelines should be drawn up that address the specific conditions for the allocation of waivers. These guidelines should be followed consistently and transparently by all health and social welfare staff.

The waiver system must cover the cost of health visits, drugs, medical supplies, other treatment regimens, food, soap, water, cooking supplies, and the cost of transportation.
PART II: IMPLEMENTATION OF COMMUNITY HOME-BASED CARE

The Kenyan government is in the process of planning to implement a community home-based care (CHBC) programme throughout the country. In response to this initiative, this second section will provide a conceptual framework which could guide the implementation of a CHBC programme. First, the conceptual framework will be presented with the various categories identified. Next, questions will be posed that address specific issues related to each category within the framework. Initially, we will address general issues and challenges to implementing CHBC. Then, the issues that pertain to the Kenyan reality will be addressed. As the Kenyan government plans and implements CHBC the conceptual framework and the specific lessons from this Kenyan home-care study should give direction to the work.

CONCEPTUAL FRAMEWORK FOR COMMUNITY HOME-BASED CARE

The conceptual framework presented here has been adapted from two WHO documents: *Long-term Care Laws in Five Developed Countries* (WHO/NMH/CCL/00.2) and *Home-based Long-Term Care: Report of a WHO Study Group* (WHO Technical Report Series 898). Each category of the framework will first be identified. This will then be followed by specific questions to be addressed within each conceptual category.

The conceptual framework is divided into eight discrete categories. These categories include: (i) the nature of the programme; (ii) eligibility criteria; (iii) eligibility assessment; (iv) benefits; (v) programme operation; (vi) finance; (vii) coverage; and (viii) cost. Each category of this conceptual framework is discussed and questions are posed relating to the category.

Table 11 provides an overview of this conceptual framework.

---

3 This conceptual framework was first developed by J. Brodsky, J. Habib and I. Mizrahi for the comparison of LTC laws in developed countries (WHO 2000b). It has been adapted by L. Lindsey and the M. Hirschfeld to the reality this study describes.
<table>
<thead>
<tr>
<th>Category</th>
<th>Items to be Addressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>(i) Nature of the Programme</td>
<td>➢ Target population&lt;br ➢ Integrated or separate service&lt;br ➢ Timeline&lt;br ➢ Location of services</td>
</tr>
<tr>
<td>(ii) Eligibility Criteria</td>
<td>➢ Age&lt;br ➢ Disease category&lt;br ➢ Degree of disability&lt;br ➢ Relationship of caregivers&lt;br ➢ Knowledge of diagnosis&lt;br ➢ Number of CHBC hours&lt;br ➢ Ability to pay&lt;br ➢ Degree of family support&lt;br ➢ Provision of physical care&lt;br ➢ Provision of emotional care&lt;br ➢ Provision of housekeeping duties&lt;br ➢ General state of family and home</td>
</tr>
<tr>
<td>(iii) Eligibility Assessment</td>
<td>➢ Assessment tool (universal or location specific)&lt;br ➢ Who will be the assessor?&lt;br ➢ Measurement of the level and type of care</td>
</tr>
<tr>
<td>(iv) Benefits</td>
<td>➢ Cash allowance, service provision or combination&lt;br ➢ Maximum/minimum benefits&lt;br ➢ Waiver system&lt;br ➢ Medications and supplies&lt;br ➢ Food provision&lt;br ➢ Transportation&lt;br ➢ Respite/day care services&lt;br ➢ Counselling&lt;br ➢ Basic nursing care&lt;br ➢ Assistance with housework</td>
</tr>
<tr>
<td>(v) Programme Operation</td>
<td>➢ Government run or joint operation with NGOs etc.&lt;br ➢ Responsibility for service delivery&lt;br ➢ Care planning&lt;br ➢ Education&lt;br ➢ Quality assurance</td>
</tr>
<tr>
<td>(vi) Finance</td>
<td>➢ Funded through general taxation&lt;br ➢ Cost sharing&lt;br ➢ Funding other organizations&lt;br ➢ Cost containment</td>
</tr>
<tr>
<td>(vii) Coverage</td>
<td>➢ Percentage of population&lt;br ➢ Locations&lt;br ➢ Disease categories/target populations&lt;br ➢ Levels of disability</td>
</tr>
<tr>
<td>(viii) Cost</td>
<td>➢ Cost of services&lt;br ➢ Hourly cost&lt;br ➢ Ratio of paid/unpaid workers&lt;br ➢ Education&lt;br ➢ Medicines and supplies&lt;br ➢ Transportation&lt;br ➢ Food supplements</td>
</tr>
</tbody>
</table>

(i) Nature of the Programme

It is important to first identify the exact purpose of the CHBC programme. This purpose has to be clearly identified in order that implementation strategies can be identified that match this precise purpose. Included in the overall purpose statement must be a description of the service, the target population, the locations for CHBC, and a time line. In
order to come to this clear statement of purpose, the following questions should be considered:

➤ Who is the target population? People living with HIV/AIDS only? People with HIV/AIDS and/or other chronic illnesses/disabilities? Will specific chronic illnesses be targeted, or will all chronic illnesses and disabilities be covered? Will the definition of chronic illness include communicable and non-communicable diseases, or only one of these?

➤ Will people with mental illnesses be included in the CHBC programme?

➤ Will people with substance abuse problems be included in the programme?

➤ Will people suffering from “acute” illnesses such as malaria be included in the CHBC programme?

➤ Will the CHBC programme assist caregivers and patients, or is the focus on assisting one of these target groups over another?

➤ Will orphans be included in the CHBC programme?

➤ Will CHBC be a new and separate programme, or will it be integrated into the overall health and social welfare system?

➤ Is the CHBC programme to be delivered throughout the country from the onset, to selected sites or to begin with a pilot project?

➤ When will the programme be initiated? What are the timelines for implementation?

It is very important that the exact nature of the programme be clearly stated and the target population clearly identified. In addition, decisions must be made about whether the CHBC programme should be a separate programme, or one that is integrated into the general health and social welfare programmes of the country. There are advantages and disadvantages to both options. The value of having a separate service is that there is a designated budget for the programme. In addition, a separate programme requires a separate administrative structure that is responsible for the service. However, there is a risk that a separate programme could become vertical in its delivery. That is, CHBC could become isolated from the general health and social welfare programmes of the country. The benefit of an integrated programme is that CHBC would become part of a continuum of care. Moreover, in countries where primary health care (PHC) is a strong component of the health care system, integrating CHBC with PHC could help alleviate duplication of services and provide support for the sustainability of the programme. There is no “right” way to deliver CHBC. Each country must consider the advantages and disadvantages associated with an integrated versus separate programme and choose the process that best suites that country’s structure and delivery of health care.

(ii) Eligibility Criteria

It is not possible to include all people in need into a proposed CHBC programme. Such a strategy would overwhelm the resources of the government. Therefore, it is essential to develop some criteria for eligibility. In order to come to some decisions about eligibility, the following questions should be addressed:

➤ Should CHBC be available to people of all ages? Or, should there be an age restriction on eligibility. If there is an age restriction, what will it be, and how will it be applied?
Should CHBC be available for sick people being cared for at home, regardless of their illness or disability? If restrictions on diagnosis are made, how would these restrictions be assessed and applied?

Will transient families be eligible for the CHBC programme?

Will CHBC be available for people with acute illnesses, or only to those with chronic illnesses/disabilities or terminal illnesses?

Does the caregiver have to be a family member, or can other caregivers (e.g. friends, neighbours) be eligible for assistance in CHBC?

How will the degree of disability be assessed? How will assessment take into account the degree of reduction in activities of daily living (ADL) such as washing, dressing, eating, mobility etc. and instrumental activities of daily living (IADL) such as cleaning, cooking, doing laundry, errands etc.? How will this degree of disability be factored into eligibility assessment for CHBC?

Is it important for the patient’s diagnosis to be known before CHBC will be available? (e.g. issues of stigma might affect people’s willingness to state the diagnosis of HIV/AIDS. Will reluctance to disclose the diagnosis preclude access to CHBC?)

Will there be a maximum and minimum number of hours available for CHBC?

Should the family’s income level be taken into consideration in assessment for eligibility? That is, should a means test be applied? Should families that can afford to pay toward CHBC be required to do so? Or, should CHBC be available, free of charge, to all who qualify for assistance?

Should the amount of family assistance be taken into account? That is, should families that have an adequate number of family members involved in the care of the sick family member be included in the CHBC, or not?

Will people in need of psychological support be eligible for CHBC, or only people who need physical support and care? That is, will people who predominantly require emotional and psychological support and care be assessed for eligibility differently (or the same) as those who require predominantly physical care and support?

Will the state of the home, and the general condition of the family be taken into account for CHBC eligibility? That is, will those in greatest need (due to poor housing or family dysfunction) be given priority?

It is generally agreed that assessment should be performed by either professionals in a single field such as physicians, nurses, social workers etc., or by a multidisciplinary team. A single professional is usually all that is required if the assessment criteria are narrow in focus and if the assessment tools and guidelines are clearly structured. However, if the assessment is multidimensional and leaves room for flexibility and professional judgement, then a team of assessors from different professional groups might be necessary. This decision should be based on the type of assessment done, on the availability of the professionals in question, and on the ability of the national government to afford a team rather than a single assessor.
(iii) Eligibility Assessment

As well as establishing eligibility criteria, it is important to establish procedures for evaluating and assessing eligibility. In order to perform this important function, the following questions should be taken into consideration:

➤ Will a structured assessment tool be established? If so, will this tool be used nationally, or will different tools be used for each district?
➤ Who will be responsible for developing the assessment tool?
➤ How will this assessment tool be used?
➤ How will objectivity of the assessment tool be assured? That is, how will the process of assessment be transparent, egalitarian, and consistent?
➤ Who will be responsible to administer this assessment tool? That is, will a community health or social service professional do the assessment or will a person/team from an outside agency be charged with this responsibility?
➤ How will the level of care and support be measured? That is, how will the assessor identify the number of hours required for the CHBC service? Will the amount of hours be dependent on the severity of the illness, or on the needs of the caregiver and patient?
➤ How will the type of care and support be assessed? That is, who will identify the type of care and support required?

It is important to note that assessment should be uniform and consistent. That is, the process of assessment should be transparent, objective, egalitarian and consistently applied across settings and groups of people. Therefore, although the assessment tool could be adapted to reflect local differences, the main focus of assessment should be universal across CHBC programmes.

(iv) Benefits

It is important to ascertain how the benefits for CHBC will be applied. It is not possible to provide all the benefits that people might require in the provision of CHBC. Therefore, decisions have to be made as to what benefits will be available to the family. The following questions address the allocation of benefits:

➤ Will families be given cash allowances so that they can access CHBC services as they see fit?
➤ Will families be provided with CHBC services, with no cash allowance?
➤ Will the families be provided with a mix of benefits? That is, will families be provided with some cash allowance to access specific services that are necessary for their particular situation, as well as being provided with some general CHBC services?
➤ If cash benefits are provided, will some restrictions apply or will the family be given the responsibility of deciding how the cash allowance should be spent?
➤ If the cash allowance is to have restrictions on use, how will these restrictions be monitored?
➤ What will be the maximum and the minimum limit to benefits?
How will the family caregiver be compensated? Will there be a salary attached to this service, or will there be any other form honorarium?

Will a waiver system be applied to people in absolute poverty? If a waiver system is applied, how will it be administered and monitored to ensure equal access to the system with a transparent process for assessment?

Will CHBC include the provision of medication? If so, what medications will be available through the CHBC programme, and what medications will be restricted?

Will the CHBC programme include the provision of medical supplies? If supplies are part of the service, what supplies will be included?

Will respite care be part of the CHBC programme? That is, will day care, or other forms of respite be available for caregivers?

Will CHBC include physical and emotional care, or will there be some restrictions on the care and support provided? That is, will CHBC incorporate both emotional and physical care and support?

Will counselling be part of the services provided by CHBC?

Will the provision of food or food supplements be included in CHBC?

Will the cost of transportation for the patient and caregiver be included in the CHBC programme?

Will help with housework and other IADL be included in the provision of CHBC?

Will CHBC services involve community care only, or will institutional care also be included in the service? That is, will CHBC also include hospitalization when necessary?

There has been considerable debate about how benefits should be allocated. Unrestricted cash benefits are thought to empower recipients by increasing their autonomy and freedom of choice of services and service providers, facilitate flexible care planning, and enable recipients to directly contact and schedule personal assistance to suite their particular situation. Those who oppose the provision of cash benefits argue that costs will be high due to high participation rates, and the quality of care will be poor due to lack of supervision over service provision. That is, with cash benefits, it is not clear if the cash will go to service provision, or to general family income.

The provision of services in kind allows the family to receive services selected by the CHBC programme, but not to access services outside this programme. A combination of cash allowance and service provision would allow for flexibility whereby families could access services provided by the CHBC programme, and also access other necessary services outside this programme. For example, families might need cash allowances for the purchase of food, and school uniforms, as well as the provision of CHBC services.

More empirical evidence is necessary to ascertain the advantages and disadvantages of different forms of benefit allocation (WHO, 2000b). However, without this empirical evidence, governments must make decisions about the kinds of benefits that should be applied to a service, and how these chosen benefit allocations should be monitored.
(v) Programme Operation

It is important to make decisions about who should administer the CHBC programme and how the programme should be operated and managed. In order to make these important decisions, the following questions should be considered:

- Will the government be solely responsible for the CHBC programme, or will the government involve other agencies and organizations in the provision of CHBC? That is, will NGOs, religious organizations, and the private sector be involved in the development, implementation and management of CHBC?
- How will NGOs, religious organizations and the private sector be contracted and/or subcontracted?\(^4\)
- How will guidelines and procedures be developed that outline the responsibilities of the government, NGOs, religious organizations, and the private sector in the provision of CHBC?
- How will the services of these complementary organizations be monitored?
- Who will be responsible for service delivery? Will there be a CHBC team, or will people be drawn from the existing pool of community health workers?
- How will responsibilities be determined so that duplications or gaps in services to CHBC do not occur?
- Who will be responsible for planning care? Will the patient and family be responsible for care planning, or will health workers, a health team, or a case manager develop a plan of care?
- Will there be a case manager to supervise the provision of care?
- Will traditional healers be considered part of the CHBC team?
- How will care providers be (a) educated, (b) supervised, and (c) possibly licensed?
- Will family caregivers be provided with education? If so, how will this education be managed, and who will educate the caregivers?
- What will be the defined criteria upon which the establishment and regulation of quality standards are measured?
- Will there be consumer (or community) input into quality assurance criteria and regulations?
- How will quality assurance be managed?
- How will CHBC be evaluated? Will the process and outcome of CHBC be evaluated? When or at what intervals will this evaluation be undertaken?
- Who will evaluate CHBC?
- What CHBC information systems will be established?

\(^4\) All possible partners need to be made aware of the opportunity to develop contract relations within the context of the National Health Policy. Such contracting requires a legal framework, coherent contractual policies and evaluation mechanisms which will monitor equitable access, and quality of care. In order to avoid fragmentation and ensure the coherence of all health and home-based care within the health system, collaboration should be based on trust, responsiveness and openness, and clearly indicate the objectives sought, the commitment of each party, and the way in which those commitments are to be respected. (WHO – EB107/Conf. Paper No. 5 Rev. 1, Jan. 2001)
Who will monitor these information systems?
Who will monitor the costs of CHBC?
Who will monitor cash allocation to families in CHBC?
If daycare centres or other respite care provisions are part of CHBC, how will these services be monitored, supervised and evaluated?
Based on the evaluation of services, how will necessary changes to the CHBC programme be made?
Who will be responsible for making necessary changes to the CHBC programme?

At the planning stage of the CHBC programme, decisions must be made about what roles the government and other complementary organizations such as NGOs, religious organizations and the private sector should play. There must be general agreement about the specific roles and responsibilities of these various organizations, and plans for communication and partnerships. That is, the roles, responsibilities, types of communication and partnership agreements should be made at the onset of planning a CHBC programme.

It is generally agreed that quality assurance and evaluation are difficult endeavours. However, it is also acknowledged that without these important standards for regulation, programmes might continue unchecked, and over time, cease to meet the needs of the target population. Therefore, at the planning stage of CHBC development, quality assurance criteria and standards should be developed and methods of evaluation agreed upon. It is also important to note that the criteria for quality assurance might change as the programme evolves, however, these changes must be made on sound, empirical evidence.

Managing information systems and the availability of supervision and technical support are important components in CHBC. Data collection and recording of information is important for planning, management and policy-making in CHBC. In addition, it is important to determine the type and level of supervision required for CHBC and the type of technical support that will be necessary.

(vi) Finance

One of the most important challenges facing any programme is to sustain the programme over the long term. Consideration must be given to how the programme will be funded and how these funds will be maintained. Therefore, the following questions should be addressed:

Will CHBC funds be provided through general taxation from the national government?
Will there be a form of prepaid financing for CHBC established? For example, will a social insurance scheme, or other forms of community based insurance mechanisms be put in place?
Will a special premium be applied to employers and employees to contribute to the CHBC programme?
If the national government provides funds for CHBC, will there be a line item for CHBC, or will these funds come from revenue provided to general health care?
Will the costs of CHBC be shared between the national, district and the local governments? If so, what proportion of funds will be available from the national
government, and what proportion will have to be raised by the district and local
governments?

- What percentage of CHBC funds will be invested in service development and
  maintenance, and what percentage of funds will be allocated to running the CHBC
  programme?

- If NGOs, religious organizations and the private sector are involved in the delivery
  of CHBC, how will funds be channelled to these various organizations? Will
government funds be allocated to these various organizations, or will they be
responsible for funding their own part of the CHBC programme?

- If NGOs, religious organizations and the private sector are responsible for obtaining
  their own funding, what mechanisms can be put in place to ensure that funding
  sources can be sustained over the long term?

- If the local community is expected to be responsible for a proportion of the funds,
  how will the community raise these funds?

- Will community-based insurance schemes be introduced and, if so, how will they
  be managed and maintained (Bennet et al, 1998; Ron 1999)

- Will there be a user fee for CHBC? If so, will there be provision made for people
  who are unable to pay?

- What cost containment measures will be put in place?

There is abundant evidence throughout the world of programmes that were initiated
and evaluated as successful and necessary, only to be discontinued due to inadequate, or
complete cessation of funds. Although it is not possible to consider every eventuality when
considering the budget and allocation of funds, there should be mechanisms, checks and
balances in place that address funding sustainability. That is, questions must be raised that
address issues of programme sustainability from the planning stage of CHBC, through to
programme implementation and evaluation. Various initiatives can be undertaken to ensure
the programme can be maintained over the long term, given the heightened awareness of
the need for programme sustainability.

**(vii) Coverage**

In planning and implementing a CHBC programme, it is important to make
decisions about the percentage of the population that could be covered by this service. In
countries where HIV/AIDS is endemic, these calculations might be difficult to make,
however, they are necessary to manage the cost of the service. This does not mean,
however, that certain disease categories, or groups of people should be ineligible for
service, rather that service eligibility must be determined at the onset of the programme.
The section on programme eligibility provides detailed questions to address this item of
coverage. Questions related to the general coverage of CHBC might include:

- To what percentage of the population will CHBC services be provided?

- Will CHBC be delivered to every community in the country? If not, how will
decisions be made about which communities will be served?

- Will the provision of CHBC depend on population density? That is, will urban areas
be serviced before rural areas? How will these decisions be made?

- Will preference be given to certain disease categories or target populations?
Will certain age categories be prioritized for CHBC, or will the service be open to all age groups?

Will levels of disability determine the coverage?

Decisions on CHBC coverage will depend on the financial status of a country, and on the particular needs of the country’s population. There is no agreed upon list of minimum or core services in CHBC. However, it is essential to ensure that the decisions about coverage are made carefully and are well known to caregivers, the community, and those in the health and social welfare sector. Communities may wish to consider alternative ways of meeting needs, taking into account the economy, personal and community preferences, family mobility, and the availability of transportation. However, it should also be noted that access to water, food, sanitation, fuel, shelter and basic income are, while fundamental requirements for all people, absolute prerequisites for quality home care.

**Cost**

The cost of the CHBC programme will depend on the composition of CHBC workers, the cost of salaries, and the cost of supplies, transportation, and other miscellaneous costs. To address the cost of a programme, the following questions should be addressed:

- What services will be provided in CHBC?
- What are the costs of these services?
- What is the ratio of volunteer workers to paid workers?
- How are volunteer workers compensated for their work (e.g. in kind contributions, other)?
- What is the ratio of semi-skilled employees to professional employees?
- What are the salary scales of paid employees?
- What is the cost of educating health and social welfare professionals?
- What is the cost of educating community volunteers?
- What is the cost of educating family caregivers?
- What is the maximum number of hours of service that a family is entitled to?
- How do CHBC workers travel to people’s homes? Are there transportation costs involved? If so, what are these costs?
- Is the cost of transportation for patients and caregivers to visit health care facilities provided in CHBC? If so, what is that cost?
- What are the costs of home-care supplies?
- What are the costs of essential medicines provided in CHBC?
- Does demand warrant local production of supplies, devices and equipment?
- What can be done to encourage local production?
- How can supplies be prioritised?
- What are the costs for food supplements?
- Is the family given a cash allowance, or are services paid within CHBC?
How can health workers be encouraged to share material resources?
How can communities be encouraged to share material resources?
What other miscellaneous costs must be factored into the CHBC programme?

Most countries have a limited amount of money to spend on CHBC. Therefore, decisions have to be made about what services are affordable. Therefore, some prioritisation of services is necessary. In addition governments should consider how they might cut costs such as bulk buying, reducing import tariffs, sharing supplies with other health care agencies, and manufacturing medicines and supplies within the country.

IMPLEMENTATION OF COMMUNITY HOME-BASED CARE IN KENYA

As the results of the Kenyan home-care study presented in Part I indicate, the burden of caregiving was borne primarily by women who had very little access to, or control of the resources needed to assume this responsibility. Thus, while the need for CHBC was reported to be enormous, families had neither the means nor the knowledge required to care for a sick family member at home. They were left to their own devices to shoulder all the caregiving responsibilities. Moreover, it was noted that caring for family members at home could be used to justify an abdication of public and government responsibility, thus making home-care a “community dumping ground”.

The conceptual framework for implementing CHBC presented in Part II is a tool for the Kenyan government to utilize as they begin to plan, implement and evaluate CHBC. However, based on the results of the Kenyan home-care study, many additional issues require attention. In particular, issues of poverty, stigma, abuse, access to resources, a functioning referral system, education, implementation of VCT, inheritance rights, and orphan care were highlighted as problematic for caregivers in Kenya. Therefore, recommendations from the Kenyan study should be taken into account as the CHBC conceptual framework is applied. That is, both the conceptual framework and the specific issues related to the Kenyan situation should be combined to direct decision making in planning and implementing CHBC. To aid this process, the following questions that pertain to the results from the Kenyan study should be addressed:

How can the stigma of HIV/AIDS be addressed?
How can shared confidentiality be encouraged and supported?
How can VCT be implemented across the country?
What resources and support services must be in place with the implementation of VCT?
How can incidents of abuse be dealt with?
How can community norms and standards be established to confront abuse?
How can people be assured water, fuel, food, sanitation, and a basic income?
How can services be prioritised and rationed, or target groups prioritised?
How can the referral system be improved?
How can a consistent supply and medicines and other medical supplies be ensured?
How can resources for CHBC be allocated in accordance with clearly defined priorities?
Should there be a different CHBC response for people living with chronic illnesses, those with disabilities, and for people living with HIV/AIDS?

How can issues of death and dying be addressed?

How can the provision of wills and other forms of inheritance rights be established?

How can caregivers, patients and health and social service providers be educated and supported in their work?

What can be done to stimulate community and collective responsibility in caring for ill/disabled people and their caregivers at home?

What can be done to further stimulate community and collective responsibility for orphan care?

Will orphan care become part of CHBC?

How can roles and responsibilities be shared among patients, caregivers, families, communities and the government?

What are the roles of NGO’s, religious organizations and the private sector in CHBC in Kenya?

How can the roles and responsibilities of these complementary organizations be strengthened, supported and sustained?

How can partnerships be developed between complementary organizations and the Kenyan government?

Should traditional health providers be involved in CHBC?

What can be done to encourage, and to share responsibility throughout the health and social sector for the development of policy, provision of care, financing, monitoring and evaluation of CHBC?

Kenya has a well functioning PHC system. In addition, the government recently delivered a report on health sector reform. Both these initiatives could be used to advantage in the implementation of CHBC. Combining CHBC with a functioning PHC system allows health and social welfare practitioners already working at the periphery of care to incorporate CHBC within their mandate. However, this incorporation cannot be undertaken without additional staff and proper training. Having dispensaries, health centres, and various primary health programmes in place provides a venue for initiation, administration and evaluation of CHBC. That is, the mechanism of PHC can be utilized to incorporate CHBC. However, additional resources, staff, and education will be essential. These issues will be discussed later in the section on integration of services.

As Kenya begins to plan and implement CHBC, decisions have to be made about the roles and responsibilities of the different levels of government. For ease of description, these levels will be divided into national, district and local levels of the health and social welfare system.

**National-level Responsibilities**

At the national level, policies are needed to guide planning, legislation and regulation of CHBC including the contracting and subcontracting of services. The national government should be responsible for the allocation of resources, financing, and organization and management (including monitoring and evaluation). In addition, the Kenyan government should be responsible for the development of human and material
resources, and the allocation of these resources, based on clearly defined priorities. Finally, if orphan care and VCT are to be incorporated into CHBC, this incorporation should be reflected in the policies, guidelines and regulations developed for CHBC. To that end, the following questions should be addressed:

➢ What can be done to place CHBC visibly on the political agenda of Kenya and ensure adequate political will for implementation?

➢ How will contract relations be firmly placed within the National Health Policy and the ongoing health care reforms?

➢ How will the legal framework for contracting, coherent contractual policies and evaluation mechanisms be developed?

➢ Who will be responsible for the development of guidelines for implementation, monitoring and evaluation of CHBC?

➢ Will orphan care be included in this CHBC development?

➢ Will VCT become part of CHBC, or will it be a separate programme?

➢ Who will be responsible for education and training, and for communication strategies?

➢ Who will be responsible for resource kits, and for the development and maintenance of information systems?

➢ What strategies can be put in place to ensure that CHBC is sustainable, effective and affordable?

➢ How can intersectoral cooperation be encouraged? That is how can the various national ministries such as health, welfare, finance, labour, education etc. collaborate and cooperate with one another in the overall planning and delivery of CHBC?

➢ How can various national government ministries harmonize their policies to facilitate the development of CHBC?

➢ How can the governing bodies of important complimentary organizations (NGOs, donors, religious organizations, and the private sector) be encouraged to partner with the national government in the development and implementation of CHBC?

➢ How can communication between the national, district and local levels of government be established and effectively maintained?

It might not be necessary for the national government to undertake all the initiatives outlined above, but it is the responsibility of the Kenyan government to address each of these issues and make sound judgements about the allocation of responsibilities to the district or local levels. One of the most important factors that the national government must attend to is the need for various ministries to harmonize their policies in relation to CHBC. Most ministries have their own organizational structure, culture and areas of responsibility. They are not used to working across ministries, and to support each other’s work. Therefore, strong leadership will be required to establish a culture of cooperation and collaboration in the development, implementation, and evaluation of CHBC. Table 12 provides an overview of the national-level responsibilities for CHBC.
### Table 12: National-Level Responsibilities for CHBC

<table>
<thead>
<tr>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>➢ Securing political commitment for CHBC</td>
</tr>
<tr>
<td>➢ Promoting intersectoral collaboration</td>
</tr>
<tr>
<td>➢ Planning ongoing financing and sustainability</td>
</tr>
<tr>
<td>➢ Developing policies, guidelines and regulations for CHBC (including contracting and sub-contracting of services), addressing all items described in the conceptual framework</td>
</tr>
<tr>
<td>➢ Planning organization and management strategies for CHBC</td>
</tr>
<tr>
<td>➢ Developing monitoring and evaluation strategies and timelines</td>
</tr>
<tr>
<td>➢ Developing human resources</td>
</tr>
<tr>
<td>➢ Providing material resources</td>
</tr>
<tr>
<td>➢ Allocating resources and funds</td>
</tr>
<tr>
<td>➢ Sustaining partnerships with complementary organizations</td>
</tr>
<tr>
<td>➢ Developing an orphan care programme</td>
</tr>
<tr>
<td>➢ Developing a VCT programme</td>
</tr>
<tr>
<td>➢ Communicating between levels of government</td>
</tr>
</tbody>
</table>

### District-level Responsibilities

In Kenya, the district level will include the provincial governments and district level management. District level management will be responsible for the allocation of resources based upon clearly defined priorities. Monitoring standards of quality for CHBC will also fall to the district level management team. National standards should be adapted to meet local needs, and local guidelines for CHBC should be established. In addition, rewards and incentives for community health volunteers should be considered. Finally, if orphan care and VCT are to be incorporated into CHBC, allocation of resources and monitoring of standards of quality for these programmes will become the responsibility of the district level authorities. In order to meet the responsibilities of the district level management team, the following questions should be addressed:

- How can the capacity of the district level be strengthened in order to effectively administer CHBC?
- How can district level leadership encourage innovation and creativity for the development and management of CHBC?
- What partnerships can be established between various government agencies, health programmes, NGOs, religious organizations and the private sector?
- How will these partnerships be firmly placed within the government’s contractual policies and how will continuity and quality of care be assured and monitored?
- What are the qualifications and numbers of managers required to administer CHBC at the district level?
How can these managers be identified and educated in CHBC?
How can communication between the district, national, and the community (local) level be established and effectively maintained?

It is important to note that decisions have to be made about the level of administration and governance provided at the district level, and the amount of responsibility afforded to the community or local level. These decisions must be made in the planning stage of CHBC, and guidelines developed and adhered to so that each level of government is aware of their areas of responsibility for CHBC. Such guidelines should help avoid the problems of duplication or gaps in service. Table 13 provides an overview of the district-level responsibilities for CHBC.

Table 13: District-Level Responsibilities for CHBC

<table>
<thead>
<tr>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>Defining priorities</td>
</tr>
<tr>
<td>Monitoring standards</td>
</tr>
<tr>
<td>Promoting capacity building</td>
</tr>
<tr>
<td>Offering rewards and incentives</td>
</tr>
<tr>
<td>Developing partnerships with complementary organizations within established contractual policies</td>
</tr>
<tr>
<td>Allocating resources</td>
</tr>
<tr>
<td>Training CHBC managers</td>
</tr>
<tr>
<td>Managing orphan care</td>
</tr>
<tr>
<td>Implementing VCT</td>
</tr>
<tr>
<td>Communicating between levels of government</td>
</tr>
</tbody>
</table>

Local-level Responsibilities

It is at the community level that the practical application and implications of CHBC are experienced. The culture of the community, its norms, standards and leadership will play an important role in the CHBC programme. The results of the Kenya home-care study indicate that some communities are better at mobilizing the community spirit, initiating community Harambee, and providing effective leadership than others. Therefore, some communities will be in a better position to incorporate CHBC. However, it is essential that strategies are developed that promote effective leadership and mobilize the community action in all communities where CHBC will be implemented. This community involvement includes the involvement of caregivers, patients, health and social service workers, community volunteers, and community leaders. That is, all community members who are in some way associated with the needs of orphans, caregivers, patients, and those associated with VCT should be involved in the initiation, responsiveness and sustainability of the CHBC programme. In order to achieve this community mobilization and commitment, the following questions should be addressed:

How can effective community leadership be encouraged and promoted?
How can innovation and creativity within the community be encouraged?
How can all the people associated with CHBC be active participants in the development and management of the local CHBC programme?
How can existing structures be used to speed up the implementation of CHBC?
How can available resources and accumulated experience be identified and used as a starting point for further development.
How can local communities ensure that policy makers and professionals listen and learn?
How can cooperation and collaboration be encouraged between the community, NGOs, religious organizations, the private sector, and health and social service practitioners?
How can VCT be implemented and maintained at the local level?
How can communication between the local, district and national levels of government be established and effectively maintained?

The impact of CHBC will be experienced at the local level, especially in the homes of patients and caregivers. However, regulations, policy guidelines, administration and management decisions will probably be undertaken at the district or national levels. Therefore, effective communication between all levels of government and within different government agencies will be essential if effective and responsive CHBC is to be established and maintained. Table 14 provides an overview of the salient features of local or community level responsibilities for CHBC.

Table 14: Local-Level Responsibilities for CHBC

<table>
<thead>
<tr>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>Promoting effective leadership</td>
</tr>
<tr>
<td>Developing norms and standards for CHBC</td>
</tr>
<tr>
<td>Promoting community spirit</td>
</tr>
<tr>
<td>Promoting community advocacy for CHBC</td>
</tr>
<tr>
<td>Creating effective community action</td>
</tr>
<tr>
<td>Promoting innovation and creativity</td>
</tr>
<tr>
<td>Building on existing community experience</td>
</tr>
<tr>
<td>Accessing available resources</td>
</tr>
<tr>
<td>Incorporating existing structures into CHBC (integration)</td>
</tr>
<tr>
<td>Collaborating between complementary organizations</td>
</tr>
<tr>
<td>Providing VCT</td>
</tr>
<tr>
<td>Providing orphan care</td>
</tr>
<tr>
<td>Communicating between different levels of government</td>
</tr>
</tbody>
</table>
The section that follows attends to the different levels responsibility required at the national, district and local levels of government in order to secure and sustain funding and quality delivery for CHBC services.

Integration of Services

In the conceptual framework outlined in the first part of Part II, there was general discussion about whether CHBC should be integrated into the health and social welfare system, or be a separate programme of care. In light of the results of the Kenyan home-care study, it would appear that CHBC should be integrated into the general health and social system of Kenya. As the WHO technical report on home-based long-term care (WHO, 2000c) states:

The case for integration is more compelling in countries in which there is a strong primary health care system. Here, integration means that home-based long-term care services are provided within a comprehensive primary health care approach. It also means that such care is part of the organizational structure of primary health care, has an identified budget for which it is accountable, and may share facilities, equipment and transportation with other parts of the structure (p. 16).

This same report also suggest that integration is important when the health services infrastructure is weak, and the ability to make staff available in the home is limited. In such cases, integration of CHBC with PHC can take advantage of existing resources and use those resources more effectively. However, PHC services in Kenya are weak. The structure of PHC is in place, but the ability of this structure to provide the necessary care, services and resources is severely compromised. Access to essential drugs, medical supplies, referral, and transportation at the periphery of care is poor to non-existent. Therefore, although it is recommended that implementation of CHBC should be done through the existing PHC structure, resources to sustain the structure require considerable improvement. It is therefore recommended that the Kenyan Government draw on the capacity of a wide range of partners (NGOs and the private sector) who will be guided and monitored by coherent contractual policies anchored within the national health policy and reforms.

One positive element documented in Part I of the study is the ability of the community to mobilize resources when needed. That is, the Harambee spirit was still an important function of community life. Therefore, as the national and district governments improve the resource base of PHC, the community can also be mobilized to attract more volunteer community workers to help support CHBC. In fact, without this volunteer workforce and community spirit, CHBC would be very expensive, and beyond the financial means of the national government.

Another important factor identified in Part I was the need for education and training. This education was necessary at all levels of the health and social service sector, as well as for community volunteers, caregivers and patients. Integrating CHBC into PHC would provide access to a pool of workers who could receive adequate training in CHBC required for diseases and conditions with widely different etiologies, as well as for VCT and orphan care. These paid and volunteer workers could then be responsible for training the patient and caregivers at home.

In order to integrate CHBC with PHC, there must be integration of the organizational structure, planning and budgetary integration, functional integration as well as integration of facilities, equipment and transportation (WHO, 2000c). Organizational
integration requires that administrative structures be designed such that a single administrative unit, or several agency administrations are combined with adequate coordination between these units. Budgetary and planning integration means that CHBC would fall under the umbrella of PHC, but would have its own budget and planning structure. Functional integration refers to combining otherwise independent services into a functional whole whereby management, with different organizational cultures, become part of one overall service. It is at the level of functional integration that decisions about orphan care and the VCT programme should be made. That is, VCT and orphan care could become part of PHC and be parallel services with CHBC, or they could be incorporated into CHBC. Based on the problems identified in the Kenya home-based care report (Part I), vertical programmes such as TB DOTS and family planning could also be integrated under one PHC umbrella. Regardless of how these functional decisions are made, the important factor is that all programmes at the periphery of care should be integrated to provide a holistic service to the community.

There are two specific reasons for integrating CHBC into PHC. First, integration makes it possible to provide a comprehensive set of continuous services, while also respecting the patient and family's particular needs, preferences and values. Second, integrating CHBC with PHC can be achieved at lower costs than developing a separate service. However, coordination will be crucial, and the types of services available must be defined and provided for, according to need and budget allocation. That is, integration of CHBC with PHC will require an adequate infrastructure, a consistent source of supplies and resources (both human and instrumental), and a defined programme of services that are flexible enough to meet the specific needs of the target population.

In order to promote the incorporation of CHBC within the PHC system, the following issues should be considered:

- Respect and encourage grassroots initiatives;
- Use local structures and programmes to ensure sustainability;
- Ensure that all partners in CHBC work together (public health, NGOs, religious organizations and the private sector);
- Place CHBC into the ongoing system of health reform taking place in Kenya;
- Decide which levels of government (national, district and local) are responsible for policy formation, and service delivery.

**Quality Assurance**

As noted in the CHBC conceptual framework, quality assurance, monitoring and evaluation are essential features of an effective and responsive CHBC programme. Therefore, it is very important that the Kenyan government address these issues at the outset of planning CHBC. Overall policy guidelines, regulations and monitoring systems must be developed by the national government. Decisions will then have to be made as to how these quality assurance mechanisms will be adapted and implemented at the district and local levels. Therefore, an effective quality assurance programme should address the following issues:

- What legal framework, policy guidelines and monitoring systems should be developed by the national government to regulate services provided by the government health care system as well as those provided by contractual partners
How should these monitoring mechanisms be adapted and implemented at the district level and local level?

Are there additional quality assurance mechanisms that should be developed at the district and local level?

Will these quality assurance mechanisms address all aspect of CHBC (including orphan care and VCT if these programmes are combined with CHBC)?

Who will be responsible for monitoring quality assurance at the national, district and local levels of government?

How will results from these quality assurance programmes be communicated throughout the system?

Based on the results of quality assurance monitoring, how will necessary programme changes be implemented?

Who will be responsible for changes to service delivery in CHBC.

How will these changes then be monitored, who will be responsible for the monitoring process, and how will results of the monitored changes be communicated to the target population?

Financing CHBC

Financing and the costs associated with CHBC were addressed in the conceptual framework presented at the beginning of Part II. As Kenya begins to develop and implement CHBC, these financing and costing issues should be taken into consideration. However, based on the results of the Kenya home care study (Part I), certain financing and costing issues are highlighted.

As stated in Part I, Kenya has been awarded a USD 50 million loan from the World Bank to be used over a five-year period for prevention and care of HIV/AIDS across the continuum. In addition, other funding agencies, in particular UK DFID, have contributed considerable funds to this initiative. The Kenyan government has decided that CHBC, orphan care and implementation of VCT should be essential components of this HIV/AIDS continuum of care. Therefore, for the next five years, funding for CHBC seems assured. However, during this time period, considerable efforts must be made to ensure sustainability of this programme. Issues of sustainability must be addressed from the onset. It would be unconscionable for a programme of this scope and magnitude to be funded, only to later become vulnerable to changing political will and finances. Therefore, efforts for sustainability must be developed and implemented from the onset of the CHBC programme. Responsibility for financing CHBC will predominantly fall to the national government. However, district and local governments will also be responsible for instituting and funding sustainability. These issues will be discussed as they pertain to each level of government.

(a) National-level government

The national government must consider whether funding CHBC should come out of general tax revenue, be taken as a proportion of the GNP, or be based on a proportion of the health care budget. The national government should also consider cost sharing agreements between employers and employees, development of social insurance schemes, and agreements with private insurance. Moreover, a system of user fees could be considered. However, given the level of poverty and unemployment (52%) this would not
seem to be an effective measure. Finally, cost-sharing agreements might be possible between NGOs, religious organizations and the private health sector. However, these complementary organizations are often vulnerable to changes in funding levels. The important element to note is that issues of sustained funding must be decided upon and implemented before the loan agreements expire. Innovative ways of using the loans to establish a mechanism for continuity and sustainability of CHBC must be explored and set into motion.

(b) District-level government

The district level governments will also have to make decisions about funding allocation to CHBC. Funds from the national government should be specifically designated to CHBC. In addition, district governments will have to be responsible for securing additional funds. These funds might come from community based insurance schemes, or from partnerships with NGOs, religious organizations, or the private sector. These partnerships must be nurtured, and supported throughout the initiation of CHBC, in order for them to continue after external funding comes to an end. Because NGOs, religious organizations and the private sector are also vulnerable to sustained funding, partnerships must involve creative and innovative strategies that promote sustainable funding and cost containment.

The district level government must also consider staffing ratios for CHBC. An appropriate mix of paid and unpaid staff must be developed. That is, there must be adequate professional staff to supervise and educate CHBC workers, while at the same time promoting and supporting volunteer community workers. In this way, staffing costs can be contained.

As prior detailed, poverty is a huge problem in Kenya, particularly for people caring for sick family members or orphans at home. The ability of these caregivers to pay for CHBC is severely compromised. Therefore, including a user fee component in strategies for sustainable funding does not make sense. It is very likely that this source of funding could not be realized. In fact, CHBC will probably have to finance the programmes’ services while also providing subsistence funds to very needy families.

(c) Local-level government

Local communities should also be required to develop creative and innovative programmes to promote sustained funding for CHBC. Although a large proportion of CHBC funds should come from the national government and be administered through district level management, communities should also be expected to contribute to the sustainability of the programme. One possible alternative is the development of community based insurance scheme (Carrin et al, 1999). Strategies such as promotion of the community spirit and community mobilization are important factors to consider. In addition, promoting community empowerment and creating effective partnerships with complementary organizations should be encouraged. If communities are given the responsibility for contributing funds to CHBC, and provided the freedom to make choices about how these funds are raised, it is likely they can contribute to the sustainability of CHBC. However, a note of caution is necessary. Many of the communities (see Part I) were already overwhelmed with the problems of caring for sick family members and orphans within the home. Therefore, decisions to make communities responsible for some of the CHBC funding should be approached with sensitivity to their current situation. That
is, there is a fine line between encouraging community participation in the creation of funds, and overwhelming these community resources.

Cost containment issues are also very important. No government can provide all the services people might need at home. Therefore, the Kenyan government will have to set priorities, and make difficult decisions about resource allocation to CHBC. For example, will there be a cap on the amount of services a family can access? Will people with more severe illnesses/disabilities be given priority over those in less need? Will a quota system on CHBC be established? That is, will only a certain number of people in each community be eligible for CHBC? These cost containment issues also relate to making choices about eligibility for accessing CHBC.

**Eligibility for CHBC**

Issues concerning eligibility for CHBC were addressed in the presentation of the conceptual framework, and the Kenyan government must consider these issues as they plan and implement CHBC. However, based on the results of this study, specific issues relating to eligibility should also be considered.

Kenya has a large and growing problem of people returning home to be cared for as they become ill and die from HIV/AIDS. As the HIV/AIDS epidemic continues, more people will start to become sick and die. For many people infected with HIV early in the epidemic, the latent period is now past and the severe problems associated with opportunistic infections are becoming evident. Therefore, the problems associated with caring for sick family members with HIV/AIDS are growing and will continue to grow into the foreseeable future. The Kenyan government will be required to make some important decisions about who will be eligible for CHBC. As noted earlier, the initiation of CHBC has come about through funds from the World Bank. This loan is targeted to providing HIV/AIDS prevention and care across a continuum. Therefore, PWAs and their caregivers must be granted eligibility for CHBC. However, questions must be raised about how this eligibility will be assessed, and what other diseases/disabilities should also be incorporated into CHBC.

As the Botswana study (WHO, 2000a) identified, specifically focusing CHBC on HIV/AIDS causes the programme to be stigmatised. As a result, some people are reluctant to access services. Although the Botswana government made eligibility for CHBC to then include people with chronic illnesses and disabilities, as well as those with HIV/AIDS, the stigma to CHBC remained. Therefore, the Kenyan government should carefully consider how CHBC will be marketed, and what kind of perception the general public will have of this programme. Issues of stigma were already noted to be very problematic in Kenya. Therefore, it would be counterproductive to develop a CHBC programme that carries this HIV/AIDS stigma.

Of the 53 caregivers interviewed for the Kenya home-based care study, 22 were caring for a family member with chronic illnesses and/or disabilities other than HIV/AIDS. It is possible that this illness ratio would be consistent in the overall population. Therefore, it would be essential that eligibility for CHBC include not only HIV/AIDS infected and affected patients and caregivers, but those people with other chronic illnesses/disabilities. It should also be noted that 24 caregivers interviewed were caring for a person with HIV/AIDS, but another diagnosis was given. A conspiracy of silence surrounded the patient’s diagnosis due to the stigma of HIV/AIDS. Based on the results of this study, the following specific considerations for eligibility for CHBC should be addressed:
Will a diagnosis of HIV/AIDS be essential before CHBC will be provided? That is, can a family access CHBC without divulging the patient’s diagnosis? The conspiracy of silence and stigma associated with HIV/AIDS makes this question of eligibility particularly important.

Will people with other chronic illnesses/disabilities other than HIV/AIDS be eligible for CHBC?

Who will assess eligibility?

These questions are identified in light of the results of the Kenyan home-care study. Other issues of eligibility identified in the conceptual framework should also be addressed.

**Supplies and Equipment**

The initiative to implement CHBC in Kenya came about, in large part, as a response to the growing problems of caring for family members with HIV/AIDS at home. Therefore, a CHBC programme must ensure that supplies and equipment be available to provide the necessary care for PWAs at home. Home-based care kits should be available for community health workers to take to the home. These kits should include the necessary drugs to treat common symptoms and opportunistic infections, and equipment such as gloves, mackintoshes, aprons, soap, detergent and condoms. In addition, these supplies and equipment should be constantly available at the dispensaries and health centres.

The government will also have to make decisions about what other medicines and equipment would be considered essential for patient care at home. Obviously, the care of people with other chronic illnesses/disabilities would require a wide variety of supplies and equipment, and the government will not be able to provide all that is necessary for different patient needs. However, the Kenyan government will have to make decisions regarding what they consider essential to the provision of CHBC, and ensure that these provisions are available on a consistent basis. Questions in the cost section (viii) of the CHBC conceptual framework raise important issues for the Kenyan government to consider when making decisions about providing and allocating equipment and supplies.

**Human Resources**

In Kenya, there is a mix of health and social service workers working at the district and community (local) levels. There are nurses, physicians, midwives, clinical officers, and social workers with professional training. These workers are paid by the national or district government, depending on the location and mandate of their work. In addition, community health workers (CHW), community based distributors (CBD) and traditional birth attendants (TBA) provide volunteer care to people at the periphery of services. These volunteer workers are paid “in kind” and do not receive a salary. In the implementation of CHBC, it will be very important to retain this complement of workers. That is, nurses, clinical officers, social workers and physicians should take a supervisory and educative role and the community volunteers should be responsible for much of the direct care. At this time, Kenya is not in a position to pay all the workers that will be required to initiate and maintain CHBC. Therefore, this volunteer workforce will be essential. These volunteers can perform a number of tasks such as providing advice to families, distributing certain drugs and supplies, performing basic nursing care, and referring patients to health facilities. However, in order for these volunteers to perform these vital services, they must receive appropriate training and support. It should be noted that initiation of CHBC does not necessarily mean that additional workers must be added to the work force. It is possible for
existing workers to be retrained to undertake the important work of CHBC. The numbers and kinds of workers required will, however, need ongoing evaluation.

According to the technical report on home-based long-term care (WHO, 2000c), CHBC should be kept as simple as possible to ensure long-term sustainability. Over-medicalization and over-professionalization of CHBC should be avoided, particularly where strong family and community networks are already providing care. In Kenya, this community support is still evident, however, it is being severely strained by the overwhelming needs of patients and caregivers. The problems associated with care of HIV/AIDS have greatly exacerbated this problem. As the results of this Kenyan home-care study attest, caregivers often provided care to their family members to the detriment of their own personal, social and economic well-being. Therefore, these informal networks need considerable support and education in order to continue their vital work. Mechanisms must be put in place whereby health and social service professionals provide supervisory support, guidance and education to community workers, caregivers and patients. In addition, a system of rewards should be put in place whereby volunteer workers and caregivers are acknowledged and rewarded (in some appropriate fashion) for their work. Without this support, efforts to implement and maintain CHBC will be stalled.

CONCLUSION

In Part II, a conceptual framework for the implementation of CHBC was presented. This conceptual framework identified issues, and posed questions that the Kenyan government should consider as they plan, implement and evaluate CHBC. Following the presentation of the CHBC conceptual framework, specific issues identified in Part I of the Kenyan home-care study were related to this framework. That is, the issues, problems and recommendations identified in the study were applied to the CHBC conceptual framework. In particular the responsibility of the national, district and local levels of government for the initiation of CHBC were addressed. This was followed by a discussion on integration of services in Kenya, quality assurance, financing, CHBC eligibility, procurement and allocation of equipment and supplies, and the development and maintenance of human resources. The overall purpose of highlighting these specific issues was to assist the Kenyan government in planning, implementing and evaluating CHBC that is relevant and responsive to the particular needs of the Kenyan population.

Implementing effective, responsive and sustainable CHBC in Kenya is a priority initiative. However, the important contribution of family caregivers to the success of the CHBC programme cannot be over emphasized. Without the family caregivers continued commitment to provide care to sick family members at home, CHBC could not be actualised. In addition, the contribution of volunteer workers is vitally important. These caregivers and volunteer workers must be sufficiently acknowledged for their efforts and a reward system must be established to give respect to these vitally important and valued members of the CHBC team.

The results and recommendations of this intervention study, together with a suggested framework for implementation of CHBC, comes at a critical time as responsible partners begin to plan and implement CHBC in Kenya. It is hoped that this study will provide guidance and support to the Kenyan government in the initiation of CHBC.
REFERENCES


APPENDIX A: CAREGIVER QUESTIONNAIRE

Thank you for agreeing to be part of this exploratory study investigating the experiences of home-based family caregiving on children, youth and elderly people. The information we collect will not identify you in any way, and there will be no adverse consequences to you from your participation in this study. The information we collect will become part of a report that will be shared through the World Health Organization and distributed to people who are interested in family caregivers experiences of home-based caregiving. The purposes of this study are to:

- explore and describe the phenomenon of home-based caregiving to family members living with HIV/AIDS and other chronic illnesses by children, and youth and elderly women.
- raise awareness of home-based family caregiving, particularly in relation to forgone opportunities for a satisfactory quality of life for children, youth and elderly women
- develop sustainable effective strategies/interventions to improve the quality of life for these home-based family caregivers
- develop sustainable effective strategies/interventions to improve the quality of care

Community: ____________________ District: _______________ Date: _______________

Name of Researcher: __________________________________________________________

Is the community (a) Urban (b) Rural? (Circle one)

In your opinion, what is the socio-economic status of this family? (a) poor, (b) middle class, (c) wealthy? Please circle one.

Please describe the dwelling, type of sanitation, water supply, heating, lighting etc.

__________________________

Gender of caregiver M      F (please circle one)
What is the caregiver’s age?
What is the caregiver’s occupation?
Caregiver’s years of education (including basic schooling and advanced education)?

Is there any form of income coming into this family? Yes  No (Please circle one)
If there is any income coming into this family, please state what it is, and from whom

__________________________

Demographic Characteristics of the Family and Family Caregivers
1. Please include all the family members living in this household.

__________________________

5 While the questions are asked directly to the family caregiver, the answers are noted down by the interviewer
Circle all the members in the family and state their age:

<table>
<thead>
<tr>
<th>Family Member</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Father</td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td></td>
</tr>
<tr>
<td>Brothers (state how many, including age)</td>
<td></td>
</tr>
<tr>
<td>Sisters (state how many, including age)</td>
<td></td>
</tr>
<tr>
<td>Grandmothers (state relation to father or mother, including their age)</td>
<td></td>
</tr>
<tr>
<td>Grandfathers (state relation to father or mother, including their age)</td>
<td></td>
</tr>
<tr>
<td>Aunts (state relation to father or Mother, including age)</td>
<td></td>
</tr>
<tr>
<td>Uncles (state relation to father or Mother, including age)</td>
<td></td>
</tr>
</tbody>
</table>

Are there orphans in this family? How many? What age?

Are there other family members in this home? Please state who they are and how many.

2. What is your relationship to the person living with HIV/AIDS or other chronic illness?

3. Do you have other activities outside the home, e.g. Work, school etc. Please state:

---

**Illness Related Variables**

4. What illness does this patient have: (a) HIV/AIDS, or (b) other chronic illness. Please circle one.

5. (If this illness is not AIDS) what is the diagnosis? ______________________

6. How long has the patient had this illness? When was it first diagnosed?

7. How ill is the person with HIV/AIDS or other chronic illness?
   (a) very ill, (b) moderately ill, (c) fairly well? Please circle one.

8. Is the illness getting: (a) worse, (b) better, (c) remaining the same? Please circle one.
9. What are the main symptoms of the illness?


10. What do you believe caused the illness?


11. Has the patient and/or family been isolated or stigmatized as a result of this illness?  
   Yes  No  Please circle one, if yes, give an example:


12. What kinds of crises happen in this family? When and where do crises happen? Please give an example:


13. Which family member takes charge if a crisis happens? Please provide the name and their relationship to the family.


14. Where do family members go to seek advice/treatment in providing care for the person living with HIV/AIDS or other chronic illness? Who gives the advice?


   **Treatment/Procedure Variables**

15. How many hours of home-based family caregiving do you do each day?  

16. How long has the patient needed this home-based family caregiving?  

17. What treatments have to be given?


18. Can you carry out the treatments that are required?  
   Please circle one:  Yes  No  Please explain:


76
Support Resources

19. Does anyone outside the home and family help with giving treatments? Please state how many, and give details about their role (eg. Volunteer, neighbour, health worker etc)

20. Do other family members play a role in patient care? Please describe:

21. Are NGOs involved? If so, which ones, and what services do they provide?

22. Are formal health care workers involved in patient care? Yes No

23. Is the formal health care worker involvement adequate? Yes No
Please describe with an example.

24. What health supplies (medicines, dressings, equipment, gloves, etc.) are needed?

25. What health supplies do the patient and family receive (eg. Medicines, equipment, soap, gloves, dressings etc.)?

26. What other important life events are happening in the family (besides the illness) that impacts on care? (eg. People moving into the family, orphan care, other injuries, illnesses, births, deaths, changing family constellation, drought, retrenchment, etc.)

Actual Caregiving Involvement

This section provides information about the level of care that is required for the family member. Please answer by circling the words ‘none’, ‘minimal’, ‘moderate’ or ‘complete’ that best describe this level of care. Please circle one word only.
27. Activities of daily living (ADL)

(a) How much help does the patient need with feeding?
   None    minimal  moderate  complete

(b) How much help does the patient need with washing?
   None    minimal  moderate  complete

(c) How much help does the patient need with dressing?
   None    minimal  moderate  complete

(d) How much help does the patient need with mobilisation?
   None    minimal  moderate  complete

(e) How much help does the patient need with elimination?
   None    minimal  moderate  complete

28. How much help does the patient need with instrumental activities of daily living (IADL)? Please answer by circling the most appropriate word(descriptor).

(a) How much help does the patient need to get water?
   None    minimal  moderate  complete

(b) How much help does the patient need with cleaning/sanitation?
   None    minimal  moderate  complete

(c) How much help does the patient need with getting supplies?
   None    minimal  moderate  complete

(d) How much help does the patient need with shopping?
   None    minimal  moderate  complete

(e) How much help does the patient need in dealing with money/finances?
   None    minimal  moderate  complete

(f) How much help does the patient need with getting health care supplies?
   None    minimal  moderate  complete

(g) How much help does the patient need with cooking?
   None    minimal  moderate  complete

(h) How much help does the patient need with collecting firewood?
   None    minimal  moderate  complete

29. What do you do when you provide care to the patient? Please give an example.
30. What kind of emotional support do you give to the patient? Describe with specific examples.

31. What other roles do you perform? (eg. parenting role, orphan care, working outside the home etc.) Provide details with specific examples:

32. What are the treatments prescribed by outside authorities? (eg. Diet, medications, exercise, physiotherapy, other physical treatments etc.)

33. What care do you do that is prescribed by outside authorities (eg. Health care workers, doctors, traditional healers, etc.)?

34. What do you do with your free time (if any)?

35. What symptom management is required? Please circle the symptoms that need care. You may circle as many symptoms that the patient has, and please add others if they are not on the list.

Pain management
Tuberculosis
Caring for confusion
Diarrhoea
Immobility
Skin lesions
Other symptoms: ________________________________
36. How do you manage these symptoms?

__________________________________________________________________________

37. How do health workers (nurses, doctors) manage the symptoms?

__________________________________________________________________________

38. Are these symptoms managed well? (a) Yes, (b) No. Please explain:

__________________________________________________________________________

39. How much do you know about how to carry out the treatments? What form of
instruction have you received?

__________________________________________________________________________

40. What support mechanisms/resources are there? (e.g. Gloves, water, disinfectants,
medical supplies, medications, disposal of waste etc).

__________________________________________________________________________

41. What do you know about maintaining personal health and preventing physical harm
to yourself?

__________________________________________________________________________

42. In your opinion, what word would you use to describe the level of satisfaction you
think the patient feels with the family caregiving he/she receives? Circle one:
Very satisfactory Somewhat satisfactory Unsatisfactory

Please explain:

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

80
**Impact on Family Caregivers**

43. How would you rate your quality of life? Please circle one:
- Very poor
- Poor
- Neither poor nor good
- Good
- Very good

44. Circle the word that best describes the impact that caregiving has had on you:
- High
- Medium
- Low

Please provide an example:

45. Circle the word that best describes your level of satisfaction at being a home-based family caregiver? Circle one:
- High
- Medium
- Low

Please provide an example:

46. (If the caregiver is a young person) What is the impact of caring on their schooling or ability to seek employment? Please explain:

47. (If the caregiver is an older person) What has been the impact of family caregiving on your financial, physical, and/or social well being? Please explain:

48. What kind of support do you need for yourself?

49. Who do you turn to for support for yourself? Do you receive the support you need?

50. Some people get depressed when they have to care for others in the home. Has this happened to you? Please explain:
51. Caregivers often find that providing care to a family member impacts on their ability to have friends, join in social events outside the home, or continue with income generating activities. Has this happened to you? Please explain:

52. What is the attitude of other people toward you as a caregiver? Please explain:

53. Some people say that the role of family caregiving affects their feeling of spirituality. Has this happened to you? If so, please provide an example:

54. Some people say that the role of family caregiving affects how they worship. Has this happened to you? If so, please explain:

55. Some people start to abuse substances such as food, alcohol, drugs (legal and illegal), and tobacco etc. Has this happened to you? If so, please explain:

Strategies for Action (all respondents)

56. In your opinion, what strategies need to be in place to provide support to family caregivers in home-based care?
57. How can we begin to put these strategies into action?

58. Do you think voluntary counselling and testing for HIV should be available in your community? Yes No Please explain.

59. If voluntary counselling and testing were available to you in your community, would you volunteer to be tested for HIV? Yes No Please explain.
APPENDIX B: KEY INFORMANT INTERVIEWS

Thank you for agreeing to be part of this exploratory study investigating the experiences of providing home-based family caregiving on children, youth and elderly people. The information we collect will not identify you in any way, and there will be no adverse consequences to you from your participation in this study. The information we collect will become part of a report that will be shared with the World Health Organization and distributed to people who are interested in family caregivers experiences of home-based caregiving. The purposes of this study are to:

- explore and describe the phenomenon of home-based caregiving to family members living with HIV/AIDS and other chronic illnesses by children, and youth and elderly women
- raise awareness of home-based family caregiving, particularly in relation to forgone opportunities for a satisfactory quality of life for children, youth and elderly women
- develop sustainable effective strategies/interventions to improve the quality of life for these home-based family caregivers
- develop sustainable effective strategies/interventions to improve the quality of care

**Position/Role:**

**How long have you been in this position:**

1. Please explain the work you do in home-based care?
2. Are there many orphans in this community? Approximately, how many and how are they cared for?
3. In your opinion, what are the major problems encountered by older women as family caregivers?
4. In your opinion, what are the major problems encountered by young girls as family caregivers?
5. What resources are there in the community related to family caregiving? Are there other NGO’s, hospice, hostels, etc and other home based care agencies?
6. Are these other resources well used? Please explain.
7. Is there a referral system in place to support home based care? Please explain.
8. Does the referral and support for family caregivers in home-based care need improving? If so, how might those improvements be made?
9. What other resources/strategies need to be in place to support home-based care?
10. How do you think these strategies can be put into action?
11. Do you think voluntary counselling and testing (VCT) for HIV should be available in the community? Yes No Please explain.
12. If VCT were available in the community, do you think community members would volunteer to be tested for HIV? Yes No Please explain.
13. Is there anything else you would like to add about the issues of family caregiving by children, youth and elderly women in home-based care?
APPENDIX C: FOCUS GROUP INTERVIEWS

Date of FGD: ____________
Venue: ____________
No. Recruited for FGD: ____________
Time FGD started: ____________
Time FGD ended: ____________

1. What are the common health problems in this community?
   What is the magnitude of HIV/AIDS?
   What are the sources of care?

2. What are your views about taking care of someone who is sick?
   • Are you comfortable in providing care?
   • Are you willing to provide care?
   • Is caring for the family member difficult?
   • What are your major concerns?

3. Sometimes it is necessary to help a sick person with daily activities. What do you do to help you sick family member?
   • Help in feeding/bathing
   • Washing clothes
   • Financial assistance

4. What constraints do you encounter as you provide care for the sick family member?

5. Do you think you need more information about how to care for someone who has AIDS? What kind of information? What are your most urgent needs?

6. What are the advantages of taking care of a sick person at home?

7. What are the disadvantages?
   • How has care giving affected social relationships?
   • What precautions do you take?
   • What strategies should be put in place to alleviate the burden of caregiving?

8. Are there any other comments that anyone of you would like to make about taking care of someone who has AIDS or other chronic illness? Does anyone have any questions they would like to ask?