Matla ea Lesotho ke Sechaba:
Hlahlobo ea Kokelo ea Bakuli ma Haeng

Lesotho's Strength is its People:
A Rapid Appraisal of Home and Community Based Care

SUMMARY REPORT

Prepared for CARE Lesotho

By

Sara Bowsky, Family Health International
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TABLE OF CONTENTS

Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-retroviral Therapy
CARE	Cooperative for Assistance and Relief Everywhere
CBOs	Community Based Organizations
CF	Community Facilitator
CHAL	Christian Health Association of Lesotho
CHWs	Community Health Workers
CPF	Community Policing Forum
DATF	District AIDS Task Force
DS	District Secretary
FBO	Faith Based Organization
FHI	Family Health International
FXB	Ficksburg, South Africa
HIV	Human Immunodeficiency Virus
HCBC	Home and Community Based Care
LAPCA	Lesotho AIDS Programme Coordinating Authority
LDB	Ladybrand, South Africa
LIW	Low Income Women
MTCT	Mother -To – Child Transmission
MOHSW	Ministry of Health and Social Welfare, Lesotho
NGOs	Non-governmental Organizations
NVP	Nevirapine
OVC	Orphans and other Vulnerable Children
PCV	Peace Corps Volunteer
PEs	Peer Educators
PHN	Public Health Nurse
PM	Project manager
PSCAAL	Private Sector Coalition Against AIDS in Lesotho
PSI	Population Services International
RHAP	Regional HIV/AIDS Program, USAID
SAFE	Sports Health and AIDS Footballers Education project
SA	South Africa
SHARP!	Sexual Health And Rights Promotion program
SC	Site Coordinator
STI	Sexually Transmitted Infection
TB	Tuberculosis
USAID	United States Agency for International Development
VCT	Voluntary Counseling and Testing
WFP	World Food Program
WHR	Women at High Risk

EXECUTIVE SUMMARY

Recognizing the complexity of implementing home and community based care (HCBC) programs and the scarcity of technical expertise in the Lesotho, USAID Regional HIV/AIDS Program (RHAP) and CARE Lesotho requested technical assistance from Family Health International (FHI) to conduct a rapid assessment of current HCBC activities supported by CARE Lesotho. HCBC is internationally defined as "Care and support that ensures meeting the medical, nursing and psychosocial needs of persons with chronic illnesses and their family members in their home environment"[1]. It is in the context of this technical assistance that this first visit was organized. The current report summarizes findings and recommendations from the visit.

Funding for CARE Lesotho's pilot HCBC program is provided by the CORE Initiative, of which CARE International is a primary partner. A total of nine CBOs and FBOs are receiving small grants and support from CARE Lesotho to strengthen their HCBC activities. The HCBC activities are implemented under the umbrella of CARE Lesotho-South Africa's Sexual Health and Rights Promotion (SHARP!) Program, a cross-border initiative.

SHARP!'s primary activities focus on prevention including recruitment and training of peer educators, management of community HIV/AIDS resource and information centers, and condom distribution. The HCBC component consists of a pilot program that provides small grants to nine community-based organizations (CBO) in Maseru and Leribe districts. This program, supported by two SHARP! site coordinators and the CARE Lesotho-South Africa HIV/AIDS Coordinator, was the focus of the appraisal.

OBJECTIVES AND METHODOLOGY:

This rapid appraisal was conducted in collaboration with the CARE site coordinators over a five day period and had the following objectives:

- Rapid assessment of progress made in the implementation of the site activity
- Identify strengths and weaknesses of the program
- Provide feedback to the site
- Provide recommendations including potential technical assistance needs for the site

Specifically the following areas were explored:

- HCBC volunteers capacity (including training)
- HCBC services (scope, type of care and coverage)
- Perception of HCBC by clients, families, and partner services
- Referral systems and linkages for clients and families for other care and support needs
- Sustainability

[1] Family Health International, Comprehensive Care and Support Framework

- Integration with National Palliative Care and HCBC activities

Due to the limited amount of time for the rapid appraisal two HCBC sites, one in Leribe district and one in Maseru district at Ha Thamae, were chosen as by CARE staff as best representing the general status of all sites in each geographic location. Methods of appraisal included direct observation, review of relevant documents, interviews and discussions with the CARE Lesotho-South Africa HIV/AIDS Coordinator and CARE Lesotho-South Africa SHARP! Site Coordinators, informal focus group discussions with the HCBC providers, interviews and discussions with referral clinics, the Ministry of Health and Social Welfare (MOHSW), the Lesotho Senate AIDS Committee and interviews with HCBC clients. A site visit was made to Mekaling, Mohales Hoek where no formal support is being provided for HCBC to explore similarities and differences. A total of 76 people were interviewed through key informant interviews and informal focus group discussions[2]. All work was conducted in the local language Sesotho.

COUNTRY NEEDS FOR HOME AND COMMUNITY BASED CARE

The impact of HIV/AIDS epidemic in Lesotho is one of the most severe worldwide. There are two types of people in Lesotho; those infected and those affected by HIV/AIDS. In 2001 it was estimated that 31% of Basotho[3] adults age 15-49 were living with HIV and 8,200 children were living with the virus[4]. Almost half (49%) of women presenting at ante-natal clinics in Maseru-the capital are living with HIV/AIDS. The average life expectancy in Lesotho has dropped to only 36 years for children born today[5]. Currently 1 in 5 Basotho children under the age of 15 have lost one or both of their parents with close to three quarters of them due to AIDS and the prediction is that by 2010, one in every four children will be an orphan[6].

The primary factors contributing to the high HIV rates in Lesotho include internal and external migration, poverty, lack of HIV/AIDS related services and a lack of the provision of technical assistance and resources to combat the HIV epidemic. Of the limited existing HIV/AIDS services the majority are concentrated in urban areas primarily in Maseru, the capital, followed by other prominent district towns. However, the majority of Basotho, approximately 80% live in rural areas.

NATIONAL AND DISTRICT LEVEL OVERVIEW

The structures charged with delivering HCBC in Lesotho are spread across several sectors and levels of government and NGOs operating in the country. Although Lesotho has several government and multi-stakeholder units coordinating HCBC activities, including the MOHSW and Lesotho AIDS Programme Coordinating Authority (LAPCA), the country does not have a unified coordinating body, strategy or policy on provision of HCBC. Hence there is fragmentation and a lack of coordination at the National level.

[2] See Appendix 2 for breakdown of people interviewed
[3] Basotho is the term used to refer to the people of Lesotho
[4] UNAIDS
[5] UNICEF
[6] Children on the Brink 2002 UNAIDS and USAID

Each district has a District AIDS Task Force (DATF) that is parts of LAPCA structure. DATFs comprise representatives of local government bodies, NGOs, community-based organizations, local chiefs, police and nursing officials. Each DATF is responsible for coordinating all HIV/AIDS activities within their respective districts and have their own work plans and small budgets. HCBC is a primary element of DATF's work. Both DATFs reviewed as part of this rapid appraisal indicated provide limited HCBC kits, assist with HCBC trainings but indicate a strong need for assistance to improve coverage, quality, and monitoring of their work.

CARE site coordinators are members of DATFs in their districts and are considered extremely valuable by the District AIDS Coordinators who are responsible for the DATFs. The task forces also consider CARE's work critical to HCBC through for example its complementary coverage, assistance with trainings, and participation in the DATFs.

COMMUNITY OVERVIEW

Traditional culture and customs in Lesotho are very supportive and sensitive to the need for home and community based care. This tradition is what CARE Lesotho's HCBC pilot is built on. Despite the HCBC workers' limited resources they collectively provide approximately 800 home visits per month and use their own very limited resources to care, feed and support ill people in their communities. Community assistance comes from many informal groups, including traditional savings groups, burial societies, church groups, etc.

The motivation to share comes from traditional values, pride, spiritual beliefs and dependency of one another within communities. The relationship between HCBC workers and clients is that of mutual respect; in fact, for instance all interviewed HCBC workers stated they felt being invited to help was a necessary condition of their assistance, and that they would not offer assistance uninvited. There is also no distinction between AIDS and other illnesses in terms of providing HCBC.

OBSERVATIONS AND RECOMMENDATIONS

Lesotho's culture and values embraced by its communities is undoubtedly an asset in HCBC. CARE Lesotho has made a notable effort in providing trainings, funding and on-going support to the HCBC groups. Support has been provided on an informal basis for more than one year. Financial support to the CBOs and FBOs started approximately 2 months prior to the rapid appraisal. However the community members efforts, commitment and willingness to share and the support provided by CARE cannot provide enough assistance to the sick without an increase in funding, solid technical, logistical and material base. To fully leverage their innate motivation to help, CARE Lesotho needs additional funding and technical up grading to adequately support the HCBC workers. The lack of funding, human capacity and assistance at the district DATF, CBO and NGO level further handicap the outreach and coverage of HCBC in Lesotho.

Although CARE arranged for several training sessions on HCBC, there is a need to implement an on-going support and education strategy for the HCBC workers. Both the HCBC workers and local clinic staff indicate the need for training in areas such as communication skills, care of

children, nutrition and special needs of PLWHA. Additionally, many more village healthcare workers are ready to be trained and to become active providers of HCBC allowing for an increase in coverage of care.

Monitoring and evaluation represent a sizable gap in the HCBC care coverage. There is no systematic approach for assessing and monitoring HCBC care provided in the community. The provision of follow-up and ongoing support to HCBC workers remains a challenge. Some informal systems, like ad hoc record keeping by HCBC workers, do exist, but they need to be upgraded.

On a practical level, there is a need to up-grade the content and supply of the HCBC kits. The HCBC kits are central to the HCBC providers' work providing much-needed materials, confidence and ability to provide better care to their clients. There is also a need for low-literacy education materials that are currently not available in the field.

Lesotho's people and their willingness to help the sick are tremendously important assets in the fight to mitigate the impact of HIV/AIDS and its consequences. Traditional values, customs, and practices secure the foundation needed for the sustainability of HCBC. However, if the care provided is not backed up by considerable technical assistance, funding, training and human capacity-building, the Basotho will not be able to benefit from quality care and provide care to the majority of the population in need.

I. HIV/AIDS IN LESOTHO

Lesotho is a small mountainous kingdom land locked and surrounded by South Africa on all borders. The country is comprised of 10 districts; Berea, Butha-Buthe, Leribe, Mafeteng, Maseru, Mohales Hoek, Mokhotlong, Qacha's Nek, Quthing, and Thaba-Tseka. With a population of 2.1 million people Lesotho is experiencing one of the worst HIV/AIDS epidemics in the world. Currently there are two types of people in Lesotho; those infected and those affected by HIV. HIV/AIDS in Lesotho has spared no one. The most recent HIV sentinel surveillance data indicates that the epidemic in Lesotho is now one of the fourth highest in the world. In 2001, UNAIDS estimated that 31% of Basotho[7] adults age 15-49 were living with HIV and 8,200 children were living with the virus. Almost half (49%) of women presenting at ante-natal clinics in Maseru-the capital are living with HIV/AIDS and a person in Lesotho who turns 15 years old has a 74% chance of becoming infected with HIV by his or her 50th birthday[8].

Lesotho is one of the most severely HIV affected countries in the world:

- 31% HIV prevalence
- 49% ANC HIV prevalence in capital
- 36-year life expectancy
- Close to 75% of all orphans are due to AIDS

AIDS case surveillance in Lesotho is hospital based and uses both WHO Bangui clinical case definition with a positive HIV test and the expanded WHO cases definition. It is a vertical system using a special form subdivided into sections on demography, signs and symptoms, risk factors, HIV serology test and the illness outcome. The reporting rate of AIDS cases in Lesotho was estimated at 26-50% in 1997 from AIDS program data[9]. Analysis of the 1999 hospital survey data by occupation showed miners with a high HIV infection rate of 58%, 48% in Ex-miners, 28% in teachers, and 27% among students and among the unemployed a rate of 34%[10]. One of the results of the HIV/AIDS epidemic in Lesotho is the drastic drop in the life expectancy rate which is now one of the lowest in the world whereby a child who is born today is expected to live to only 36 years of age.[11] The toll that AIDS is taking on the situation of children in Lesotho is unimaginable and the percentage of orphans due to AIDS is higher than anywhere in the world.

Today more than 190,000 children in Lesotho under the age of 15—1 in 5 children—have lost one or both of their parents. AIDS has killed nearly three-quarters (73.9%) of these children's parents. By 2010, an estimated 206,000 children—1 in every 4—children under 15 years old will be orphaned, more than 80% of them orphaned by AIDS. These are the highest orphan figures for any one county in the world.[12]

There are many factors that contribute to the high HIV rates in Lesotho including internal and external migration, poverty, lack of HIV/AIDS related services and a lack of the provision of technical assistance and resources to combat the HIV epidemic.

[7] Basotho is the term used to refer to the people of Lesotho
[8] US Global Report, 2002
[9] UNAIDS HIV/AIDS/STD surveillance questionnaire 1997
[10] WHO Lesotho 2003 HIV/AIDS Surveillance
[11] UNICEF The State of the Worlds Children 2004
[12] Children on the Brink 2004 UNICEF, USAID

Rural -urban migration within Lesotho (such as migrating to work in the garment industry wherein 50,000 Basotho primarily women are employed) and migration to workplaces (including men to the mines) in South Africa[13] have resulted in the emergence of oscillatory migration patterns where workers move between urban workplaces and rural homes on a weekly, monthly or annual basis. This has proven to be a major factor in the spread of both HIV and STIs. Dependence on migrant labour also results in patterns of multiple sexual partnerships and family support structures that are more vulnerable to the HIV/AIDS and the economic effects of HIV/AIDS.

HIV/AIDS is one of the greatest factors contributing to the vulnerability of the rural poor. Within this context it is important to note that approximately 80% of the population lives in rural areas yet most services are still centralized within Maseru. People affected and infected by HIV/AIDS are unable to devote the necessary extra effort to agricultural cultivation, and HIV/AIDS is depleting both skilled and unskilled labor. This factor, coupled with ongoing food insecurity due partly to the current drought in the rural areas (primarily in the southern part of the country), is leading to a decline in the nutritional status of people living with HIV/AIDS and affected households.

HIV/AIDS erodes traditional methods of households to cope with food insecurity by reducing capacity to produce and purchase food depleting household assets and by exhausting social safety nets. The food crisis threatens to prolong and intensify the epidemic as women and children are being forced into transactional sex in exchange for food and shelter and children leave school to forage for food.

The position of women and girls has been highlighted as a fundamental contributor to the spread of HIV.[14] In Lesotho, the status of women and girls, in society and within relationships, in particular their economic dependence and the common threat of physical force, makes it difficult for them to protect themselves from HIV infection. In Lesotho women are considered legal minors, and while there are attempts to address the issue of gender discrimination and gender based violence (such as a Marriage Equality Bill) they have not been passed by parliament as some of the provisions of the legislation are controversial in terms of customary law and traditional practices.

However, men in Lesotho are increasingly taking on non-traditional roles such as raising children on their own due to the death of a wife or loved one, the provision of home based care and active involvement in peer education activities which must be recognized and supported. The pressure on men to contribute increasing amounts of resources to their immediate and extended families to care for those who are ill or for children left behind and now living with grandparents is growing. A contributing factor to the situation faced by men in Lesotho is the retrenchment of men working in the mines causing an increased unemployment rate. From 1993 to 1999, the number of Basotho mineworkers employed in the mining industry in South Africa dropped by close to 50% (from 116,129-56,000)[15]. The negative impact of the economic and social effect of this retrenchment is difficult to quantify but will undoubtedly be made worse by the high HIV

[13] Despite retrenchments from the mining sector over the last 10 years, 25% of Basotho work in South Africa.
[14] CARE Lesotho – South Africa, HIV/AIDS Briefing Paper up-dated 2004.
[15] Men and HIV in Lesotho, SAfAIDS/Panos/UNIADS/CARE, 2002

prevalence rate among the returning mineworkers (estimated to be 48%-58%)[16]. These men are forced to come home; many of them are ill and most of them come back to Lesotho without resources or skills to maintain the well being of their families.

II. EFFORTS TO ADDRESS HIV/AIDS IN LESOTHO

The Lesotho health care system embraces curative, preventive and rehabilitative services; Lesotho's health system[17] consists of the following levels:

-A village network of over 5,000 volunteer community health workers.

- Clinics/health centers, where teams serve from 6,000 to 10,000 people.

- Health Service Areas, with teams operating from referral hospitals.

As well as the village health workers, other categories of community based health workers include traditional birth attendants, distribution agents and water minders. This broad-based support for the health sector has been instrumental over the past decade in the decline of certain diseases such as polio. Health centers or local clinics are responsible for immunization of children, ante and postnatal services, family planning consultations and basic curative services. With the shortage of nurse clinicians, it is hoped that in time sufficient numbers of health assistants will reinforce health work at field level. Health centers are staffed by clinicians (doctors and nurse practitioner equivalent) who are able to diagnose and prescribe or by nurses or nursing assistants. Construction of filter (referral) clinics in Maseru has been ongoing to relieve pressure on the outpatient department of the national referral center, Queen Elizabeth II Hospital.

District hospitals are expected to staff all facilities with appropriately qualified staff and the equipment needed to deliver health services. Three district hospitals (in Mokhotlong, Berea and Qacha's Nek) have been rehabilitated and upgraded. There are several district hospitals in Lesotho, as well as two specialist hospitals and a privately run military hospital.

Maseru Private Hospital at Thetsane was established at the end of 1996 and is now overseen by the MOH. The hospital provides medical, nursing and personal care. It has a maternity unit and a casualty and emergency unit. Local medical specialists as well as visiting specialists from Bloemfontein in South Africa consult and operate on a regular basis.

Additionally member churches of the Christian Health Association of Lesotho (CHAL) provide nine general hospitals (each serving a large geographical area), and over 70 health centers, clinics and outposts (mainly in rural areas).

There are an estimated 250 private and public doctors in Lesotho of whom the majority has recently undergone HIV training provided by Life Works a private HIV/AIDS training institution from South Africa. Nurses who comprise more than 85% of the professional health care system in the country provide the majority of professional health care in Lesotho. The Lesotho Nursing Association, a member of the SADC AIDS Network for Nurses and Midwifes (SANNM), have recently revised their HIV/AIDS curriculum however there is great concern about the lack of

[16] Dr. Maw, Lesotho Ministry of Health, HIV/AIDS Situation in Lesotho, 2000
[17] CHAL and Government

support for nurses in HIV care and the retention of nurses in Lesotho due to migration to neighboring countries and the US and UK.[18]

People Living Openly with HIV/AIDS (PLOWH), the national PLHA association of Lesotho, is still at its early stages and has struggled to receive financial and/or technical support; hence its reach and mandate is limited.

The government of Lesotho (GOL) accords high priority to the control of the spread of HIV/AIDS. The national AIDS program is an integrated approach towards the prevention and control of this devastating disease, with countrywide activities involving all government ministries and non- governmental organizations. This multisectoral project is executed by WHO and coordinated by the Ministry of Health, and it involves the oversight of the UN Theme Group on HIV/AIDS.

The three primary players in the GOL are the MOHSW (Ministry of Health and Social Welfare), LAPCA (Lesotho AIDS Programme Coordinating Authority) and the AIDS Unit, which falls under the MOHSW. The Senate (comprised of District Chiefs) also has an AIDS Committee that is trying to work with local chiefs but is experiencing a lack of funding. The Royal Family of Lesotho is also very active in HIV/AIDS work. The office of the First Lady supports PLWHA Support Groups and OVC efforts throughout the country and the Prince of Lesotho is well known for his advocacy work, especially for OVC.

Within Lesotho there is a National AIDS Task Force and each of the 10 districts have District AIDS Task Forces that were established in 2000 to coordinate district activities and provide support to those working in the district. Each DATF reports directly to LAPCA and has representation on the National AIDS Task Force.

The United Nations Theme Group on HIV/AIDS also plays a central role supporting National HIV/AIDS, efforts and initiatives. Most recently the UN Theme Group worked with the Presidents office to strengthen the countries HIV/AIDS Strategic Framework that has now been adopted by the Government. The GOL has also recently procured Global Fund monies for their HIV/AIDS prevention, care and support initiatives. Tenders have been released in the country for four specific areas under the Global Fund initiative. These are Peer Education initiatives, OVC coordination, Laboratory and HIV/AIDS care and support, and community capacity building.

UNICEF Lesotho also plays a primary role in areas including support of OVC efforts, HIV/AIDS prevention focusing primarily on adolescents. Most recently the southern Africa OVC Skills Building workshop supported by USAID through FHI in close collaboration with UNICEF was held in Lesotho to not only build the skills of southern African countries in scaling up National Responses to OVC but to also bring attention to Lesotho within the international arena.

[18] more information on retention and migration of health care professionals can be found in the recent Lesotho Health Sector Reform Report.

Despite the above the majority of the peri-urban and rural populations have very minimal access to basic HIV/AIDS services e.g. VCT, STI management, justice, social services etc. However, it appears that there is some access to HIV/AIDS information through programs such as SHARP!, other NGOs and the MOH and MOE. Yet, no studies have been done to assess the quality and coverage of HIV/AIDS education and information. Most services in Lesotho are centralized and located primarily in Maseru followed by Leribe district in the northern part of the country. VCT is very limited - there is one central laboratory located in Maseru that has two different types of ELIZA machines and two regional laboratories that have one ELIZA machine each. Other District laboratories use only Rapid tests for HIV. Because of shortage of laboratory technicians, nobody is specifically assigned to do HIV testing. Laboratory technicians are required to do all tests including HIV testing. Furthermore, due to long periods of stock outs tests are often not available in many of the districts and samples must be sent to the central laboratory. CARE Lesotho through the CARE managed Private Sector Coalition Against AIDS in Lesotho (PSCAAL)[19] program opened the first stand-alone VCT site in the country, located across the street from Queen II Hospital in Maseru. The VCT site was opened in 2000 as a demonstration VCT initiative for the country to inform policy, protocol development etc. The VCT site currently has a waiting list of over 2,000 people. There are plans for Population Services International (PSI) to open three more VCT sites 2 in Maseru and one in Maputsoe with USAID funding.

The Loss of a Sister –in -Law

"My brother used to work in the mines and just after he lost his job his wife became very ill. We tried to take her to many clinics and traditional healers to help her and spent a lot of money on different medicines and travel. She wanted to have an HIV test but we were not able to find one close by. We tried everything to help her but she just became even sicker. By the end we had spent all of our money and she was so thin and was not able to eat. She had chest pains, was coughing, had white stuff and sores in her mouth, and sore on her body.

She knew she was very sick and when I held her she smiled at me and told me not to hold her too close because she did not want me to get what she had. I know she knew she was dying because of AIDS. Many people in our village helped us to care for her and she was never alone. We all knew what was happening but were not afraid. She did not die in pain but she left us in pain and my mother and brother still cry when they think of her and look at her children. They wished they could have done more but there was nowhere for us to find help it was not their fault we all did everything we could."

- Mekaling, Mohale's Hoek

Historically Lesotho benefited from substantial financial and technical international development assistance. However, in the early 1990's many of the primary international donors left the country or drastically reduced their support with the ending of apartheid in South Africa. It is well known that international donors have failed to provide adequate resources and technical assistance to Lesotho for the mitigation of the HIV/AIDS epidemic. Resources that are provided to the country are often in small amounts, with short funding cycles and centralized primarily in the capital and to well-known organizations or institutions. The government capacity to address HIV/AIDS is also challenged by the internal impact of HIV on employees thus decreasing their workforce. For instance, many nurses are leaving the country to seek employment, better wages and working conditions in neighboring countries and abroad in the UK and USA. No study has been conducted to examine the effects of HIV on the health sector of government. The

[19] PSCAAL is a program that grew out of SHARP! and is managed by CARE Lesotho.

government's capacity is challenged by the lack of basic communication technology including no access to email or Internet.

Despite the magnitude of the HIV/AIDS epidemic in Lesotho, the lack of services, resources and support the people of Lesotho are highly committed to and passionate about caring for their families and communities. This stems from the Basotho tradition and culture of taking care of each other and is evident by the commitment of traditional structures (e.g., chiefs and village committees), the lack of people living on the streets, and the ability of communities to mobilize themselves to address their own needs in the best way possible. The people of Lesotho must be commended for their resilience, strength, and courage.

III. CARE LESOTHO

USAID Regional HIV/AIDS Program through FHI is supporting the Sexual Health and Rights Promotion (SHARP!) program a cross border initiative implemented by CARE Lesotho-South Africa. SHARP! is a 3-year program that has had support from three sources; the Bristol-Myers Squibb Foundation, FHI/USAID and CARE Africa Fund. These 3 sources supported specific objectives and areas of the program.

FHI/USAID supports a combination of activities in Maputsoe, Maseru, Ficksburg and Ladybrand. These activities include peer education training for youth (10 – 25 years), Women at High Risk, Low Income Women, Migrant laborers, Long Distance Truck and Taxi Drivers as well as development and support of the Maputsoe and Maseru Resource Centres. The FHI funding is scheduled to come to an end in June 2004 and is currently under review for the possibility of additional funding. The BMS Foundation supported activities in Mafeteng but due to the end of funding from the foundation CARE is no longer providing formal assistance in Mafeteng.

SHARP! is active in two border towns of Lesotho, namely Maputsoe, Maseru[20]. Complementary activities are also implemented in the towns of Ficksburg and Ladybrand in South Africa (bordering Maputsoe and Maseru respectively). Although the SHARP! interventions follow the same guiding strategies, unique features are present at each site. Project components are described below.

The overall goal of SHARP! is to protect and promote the livelihood security of individuals and households affected by HIV/AIDS.

Specifically, the program has five objectives:

1. Reduce HIV/AIDS vulnerability of households by increasing the safety of sex among youth and other priority groups;

[20] SHARP! was until recently also active in Mafeteng/Van Royan's Gate, Lesotho through funding from BMS, not the RHAP program. Although there has been a discontinuation of funding from BMS for the Mafeteng/VR gate border site it has been handed over to Traditional Leaders and the Community Development Committees at both of the border sites and activities are still in progress.

2. Improve the capacity of community based organizations (CBOs) and enhance their ability to provide comprehensive care for people living with HIV/AIDS;
3. Improve the ability of service providers to identify, understand and respond to the reproductive health needs of priority groups;
4. Establish Resource Centers in Maputsoe and Maseru;
5. Pilot home based care activities.

Example of SHARP! Activities
CARE Lesotho-South Africa employs a number of strategies to meet the above objectives. In an effort to reach high-risk groups in the community, peer educators (PEs) are recruited and trained. Training for PEs includes education on HIV transmission, HIV/AIDS prevention, STD symptoms and available treatment options, as well as skills building in condom promotion and negotiation. PEs are also provided basic legal training related to laws, reporting procedures and helping survivors of sexual assault seek legal recourse.

To expand HIV/AIDS prevention and mitigation SHARP! has established community HIV/AIDS resource and information centers in Maputsoe and Maseru. The centers provide community members and CBOs the opportunity to access information and peer education support for HIV/AIDS initiatives and learning. The centers also aim to improve linkages between service providers and community members. Specifically, SHARP! has staff on hand at the resource center to provide referrals, home and community based care (HCBC) CBOs meet at the Center, and a local police officer is available at the center once a week to respond to complains and questions related to sexual assault, violence and other crimes.

Additional efforts to prevent HIV include SHARP!'s activities to increase access to condoms. Free condoms are provided through the resource centers, PEs at both sites distribute condoms and program staff have established a number of free local outlets including at the police station, village chief compounds, boarder posts etc. Through these channels SHARP! has been able to distribute a large number of condoms. For instance in 2003 the Maseru site distributed more than 65,000 condoms.

The pilot community home based care program is funded by the CORE Initiative, of which CARE is a lead partner. The CORE Initiative provided small grants funding to CARE Lesotho-South Africa who in turn are supporting 14 CBO and FBO partners in Lesotho. The funds are intended to contribute to initiatives that decrease HIV stigma and discrimination of which HCBC is one activity. Hence, CARE Lesotho has provided 9 out of the 14 small grants to CBOs and FBOs in Maseru and Leribe districts. The geographical sites are part of the SHARP! focus areas. They were chosen due to the concentration of high-risk populations including mobile populations such as mine workers, women working in factories etc. The total amount allocated to each CBO and FBO is 35,000 Moluti (approximately US $5,000.00). The first portion of funds was provided to the CBOs in early March 2004 and the second portion will be provided in July 2004. The CBOs who are provided support are located in the following places:

Leribe District: Maputsoe, Ha Mathata, Chona Pass, and Ha Maqele

Maseru District: Upper Thame and Lower Thamae, Ha Thetsane, Ho Hloolo, and Tibella

The HCBC pilot is overseen by SHARP! staff consisting of one HIV/AIDS Coordinator and two half time Site Coordinators. All three of the staff have additional responsibilities within SHARP!. The Site Coordinators are Ms. MaMokete Hlaele who started working with CARE Lesotho in 2000 and Ms. MaPoloko Leteka who started in 2003. Both specialize in community capacity building and HIV/AIDS prevention. Although neither has a background in HCBC both have received training from the MOHSW and demonstrate a strong basic knowledge of HCBC.

Recognizing the complexity of implementing programs and the scarcity of technical expertise in the country USAID RHAP and CARE Lesotho requested technical assistance from Family Health International (FHI) to conduct a rapid assessment of current HCBC activities and provide recommendations for improvement. The FHI Sr. Technical Officer has a history of living and working in Lesotho and is fluent in the local language that allowed for in-depth analysis in a short period of time (4 days). HCBC is internationally defined as "Care and support that ensures meeting the medical, nursing and psychosocial needs of persons with chronic illnesses and their family members in their home environment"[21].

It is in the context of this technical assistance that this first visit to the sites was organized. The current report summarizes findings and recommendations from the visit.

IV. OBJECTIVES AND METHODOLOGY

Objectives of the sites visit: This rapid appraisal was conducted in collaboration with the CARE Site Coordinators over a four day period and had the following objectives:

- Rapid assessment of progress made in the implementation of the site activity
- Identify strengths and weaknesses of the program
- Provide feedback to the site
- Provide recommendations including potential technical assistance needs for the site

Specifically the following areas were explored:

- HCBC volunteers capacity (including training)
- HCBC services (scope, type of care and coverage)
- Perception of HCBC by clients, families, and partner services
- Referral systems and linkages for clients and families for other care and support needs
- Sustainability
- Integration with National Palliative Care and HCBC activities

Methodology: Due to the limited amount of time (five days) only a select number of sites and meetings could be held. Two HCBC sites one in Leribe District at Maputsoe and one in Maseru District at Ha Thamae were chosen for the appraisal. It was felt by the CARE Lesotho staff that these sites best represented the general status of all sites in each geographic location.

[21] Family Health International, Comprehensive Care and Support Framework

Methods of appraisal included direct observation of CHBC visits, working sessions, and clinic function, review of relevant documents, interviews and discussions with the CARE Lesotho-South Africa HIV/AIDS Coordinator and CARE Lesotho-South Africa SHARP! Site Coordinators, informal focus group discussions with the HCBC providers, interviews and discussions with referral clinics, the MOHSW and the Lesotho Senate AIDS Committee and interviews with clients. A site visit was made to Mekaling, Mohales Hoek where no formal support is being provided for HCBC to explore similarities and differences. A total of 76 people were interviewed through key informant interviews and informal focus group discussions. All work was conducted in the local language Sesotho[22].

CURRENT STATUS OF HCBC: FINDINGS

I. OVERVIEW OF NATIONAL HCBC:

There are three major HCBC stakeholders within the Government of Lesotho: LAPCA, MOHSW AIDS Unit, and the Department of Social Welfare. However, no official HCBC Task Force exists in the MOHSW or LAPCA to bring together representatives from key stakeholders to coordinate activities and review successes and challenges.

The AIDS Unit under the MOHSW in collaboration with LAPCA coordinates the HCBC implementation efforts in Lesotho. Most HCBC partners are using the Lesotho Community Home Based Care Training Manual developed by the MOHSW. According to the AIDS Unit this manual also provides the framework under which HCBC is implemented while the National HCBC Strategy is developed. Currently there is no HCBC policy or strategy. The MOHSW provides a limited number of HCBC kits to programs. This is not out of a recognition or desire to provide an adequate number of kits but due to the lack of existing resources. They are dependant on donations from various international organizations including occasional donations from pharmaceutical companies. There is no regular supplier of HCBC kits and content and amount of kits vary depending on the donor.

Similar to the HCBC initiatives the Department of Social Welfare provides support to people living with HIV/AIDS support groups. These activities are somewhat similar to the HCBC programs with the primary difference being that HCBC is one element of the overall social welfare focus of the PLHA support groups. The Department of Social Welfare is also working with stakeholders to implement food parcels to those in need.

The Office of the First Lady has been instrumental in supporting OVC and PLHA support groups and works closely with the Department of Social Welfare. Other providers of HCBC and related activities include the Christian Health Association of Lesotho and the Red Cross. Other NGOs such as World Vision are just beginning to mainstream HIV/AIDS into their work.

From the mid 1970's through the 1980s Lesotho enjoyed an active village health care worker program spearheaded and supported by the MOHSW and CHAL. These groups are being revitalized throughout the country and funds are being sought to support their training in

[22] See Appendix 2 for breakdown of people interviewed

HIV/AIDS home based care. Through discussions with government officials and community care providers it is clear that the majority of HCBC is provided by informal groups of villagers or Ba Sebetsi tsa Bophelo Mosteng (village health workers), women's church groups such as Bo Me Ba Saint Annah[23] from the Catholic Church. Other Dioceses such as the Anglican Church are also struggling to find assistance to strengthen informal community care.

At the district level there are District AIDS Task Forces (DATFs) that are part of the LAPCA structure. Each DATF has a designated District AIDS Coordinator who brings together district stakeholders that form the DATF. The role of the DATF is to coordinate all of the HIV/AIDS activities in the district including HCBC.

II. DISTRICT LEVEL

The District AIDS Task Forces in Maseru and Leribe are responsible to LAPCA as are all DATFs throughout the country. Each has a designated District AIDS Coordinator who is often the Chairperson of the task force, and the district representative on the National AIDS Task Force as is the case with the Leribe District AIDS Coordinator. The District AIDS coordinators ideally should work closely with the District Secretary. Within all major areas of the districts there are also AIDS Development Programs with designated local coordinators (also members of the DATF) who assist with carrying out plans and coordination of services.

The DATFs comprise representatives from district government bodies, NGOs (such as CARE, PSI, WV, Red Cross etc), CBOs (such as those conducting HBC, Peer Education etc), Chiefs, local police and district nursing officials. Each DATF is provided with small funds from and controlled by LAPCA and has developed its own annual work plans[24]. Funds are used to provide HIV/AIDS trainings and to supplement NGO and CBO activities.

The role of the DATFs is to coordinate all HIV/AIDS activities within their district. DATFs also provide trainings, HIV/AIDS sensitization, provision of HCBC and HCBC kits, support for funerals and PLHA support groups. The District AIDS Coordinators also reported that they often "top up" NGO programs for instance, through transportation to Population Services International (PSI) for their condom distribution activities. The DATFs meet monthly to review progress, report on new programs, review challenges, and share funds. Additionally, each member on the committee goes back to work within his/her own groups on issues related to HIV. For instance, representatives from the police department have started working internally on issues related to rape and HIV. According to the Leribe District AIDS Coordinator the DATFs are run on the *"belief of complete transparency - working together allows for easy identification of problems, people in need and provision of support."*

Both CARE Site Coordinators are members of the DATFs in the districts they work. The District AIDS Coordinators and DATFs consider their contribution and CARE's support to HCBC highly valuable. For instance in Leribe the District AIDS Coordinator made it clear that although they have a budget and a work plan they cannot support the entire district and that by having CARE

[23] BoMe Ba Saint Annah is the traditional women's Catholic Church group who conducts community services such as visiting the ill as part of their religious commitment.
[24] See attached example of Leribe DATF annual workplan.

support the 5 HBC programs and closely collaborating with the DATF they are able to share their experiences and have better coverage thus reaching more people. *"SHARP! is the anchor in Maputsoe and considered extremely important to the DATF. If SHARP! were to end it would set us back in many ways."*

The DATFs in Leribe work closely with the HBC programs through joint provision of HCBC trainings, sharing experiences and challenges and cross fertilization of lessons.

HCBC is considered a primary element of the DATFs work. They do not have an HCBC strategy or work plan but perceived this as an area for which they would like technical assistance. Currently some issues related to HCBC are covered in their general work plan but again this was felt to be insufficient.

Both sites have DATFs supported village health care worker programs run out of the district hospitals and referral clinics. It was reported that most village health care workers have not been trained per the HCBC model due to a lack of resources. For example, there are currently 50 village health care workers in Maputsoe identified for HCBC training and eager to start. The DATFs also supply the CBOs and other HCBC initiatives with HCBC Kits provided by the GOL (see appendix for list of supplies included in HCBC Kits). Kits are requested annually and very rarely re-supplied during the year. It was found that the Maseru HCBC CBOs supported by CARE were provided with enough kits for all workers at the beginning of the pilot yet there is no mechanism to consistently re-supply or replenish the kits. In Leribe the DATF reported that they requested 500 kits last year and ran out very quickly. The HCBC workers in Leribe are currently sharing kits and there is no support mechanism to re-supply or replenish the kits.

The DATFs identified two major areas of concern related to the HCBC activities: a) the ability to serve all in need of HCBC and b) the challenge of providing on-going support and monitoring of the HCBC workers. *"We have trained hundreds of people but have lots of problems providing on-going support.. we do not know what many of them are doing and have trouble keeping basic monitoring and evaluation records."* The Leribe District AIDS Coordinator was not sure how many support groups and HCBC groups there are but estimated approximately 160 in the district with roughly 30 members each and the total number of clients served as being between 600-800 of which a small percent includes children with HIV.

It was clear that a contributing factor to these challenges is a lack of human resources at district level. The District AIDS Coordinator is the only full time person. CBO, FBOs and NGOs are reported to have little funding for HCBC and also lack human capacity and assistance.

The DATFs feel the most satisfaction from working with a family who has a member living with HIV to help them understand the illness, accept the situation and the positive family member and, when they are able, to link the family with care services such as the HCBC provided by CBOs supported by CARE Lesotho. Aside from assistance to develop a HCBC strategy and action plan, they also feel assistance is needed in the following areas: to scale up HCBC activities to reach more people, address the provision of palliative and hospice care, enable identification of and collaboration with HIV positive children and their families, improve family

counseling, increase quality and supply of HBC kits, and enable provision and linkages of basic clinical services and in resource mobilization.

III. HCBC SITES

Due to the short time allocation for the rapid assessment only two HCBC sites (one in each district) were visited. The first was in Maputsoe, Leribe and the second in Ha Thamae, Maseru. Both are considered peri-urban sites. The Ha Thamae site is home to one of the largest garment factories in Lesotho with a large migrant population coming from rural areas in the country.

Both sites have one district government hospital where VCT and PMTCT are provided. CARE Lesotho supports one VCT center in Maseru and PSI through RHAP USAID support is expected to open two more in the capital and one in Maputsoe in the near future.

PMTCT is not available at any of the referral clinics but the Maluti Adventist Hospital in Berea (which serves part of the Leribe population) started PMTCT in 2001. Due to a lack of clarity and relationship building between the referral clinic and district hospital staff are reluctant to refer pregnant women to the PMTCT site. An example is that of the referral clinic in Maputsoe. The clinic's brief is to refer 1st time ANC positive women to the Maluti Hospital for PMTCT. But it was indicated during informal discussion that referral clinic staff are still in negotiations regarding place of birth i.e. either at the district hospital or at the referral hospital and what access to NVP is available for mom and infant.

Basic HIV/AIDS clinical care is provided at each of the district hospitals. It is estimated that more than 50% of patients in the male and female wards have AIDS related illnesses. There is no access to anti-retroviral therapy (ART) other than through private doctors, which is too expensive for the vast majority of the population. It is reported that ART can be bought in select local markets.

Each of the sites' referral clinics provides HIV pre and post-test counseling and blood draw. The blood sample is sent to the district hospital for testing. Results take at least one week to return to the clinic. The waiting time for results is considered a primary factor for loss of follow up of those who are tested by clinic staff.

The traditional structure of each site consists of a District Chief who also sits on the Lesotho Senate and the Lesotho Senate HIV/AIDS Committee. Within each major section of the district there are also local area chiefs who are responsible for the well being of their communities, oversight of village committees, registration of births, deaths and liaising with other government officials. The involvement of local area chiefs in HIV/AIDS activities varies from site to site but it is anticipated that as part of the new Lesotho Global Fund initiative there will be an increased focus on capacity building of the traditional structures in HIV/AIDS.

Traditional healers also play a primary role in the care of people living with HIV/AIDS both formally and informally. It is estimated that at least 85% of people will consult a traditional healer sometime during their illness[25]. Additionally, traditional birth attendants play a vital role

[25] Mom Why Don't You Take Your Child to the Clinic, PhD Dissertation, Mokhotlong, 2000.

in the care of women and children and there is large number of formally trained and lay traditional birth attendants in Lesotho. It is estimated that approximately 45% of women still deliver at home[26].

In addition to the government and traditional structures there are several traditional groups and activities such as stock fel's (traditional savings groups), burial societies, women's church groups who often visit households with ill family members, and groups of village members who organize themselves to assist chronically and terminally ill people. These structures are the frontline response to social and community problems. Furthermore the church plays a vital role in assisting people in need through the provision of spiritual support, minimal material support and some organized activities such as the women's groups mentioned above.

NGOs and CBOs are also active in each of the sites and these include PSI, World Vision (WV), Red Cross and CBOs supported by the Office of the First Lady. However, their ability to contribute to the scale needed is also hampered by a lack of resources and technical assistance.

In addition to supporting the HCBC CBOs and FBOs within the site CARE Lesotho also supports HIV/AIDS Resource Centers, PLHA Support groups and Peer Educators.

In summary there are multiple activities taking place in the two CARE supported sites. The traditional structures have been in existence for generations. However, the HCBC activities still remain fragmented, are not well coordinated, do not have a clear referral system and are in desperate need of support.

Mekaling is a local area comprised of approximately 8 villages and is located in Mohale's Hoek district southern part of the country. There is roughly the same proportion of men working in the mines from Mohale's Hoek as there are in Mapotsoe[27]. Mekaling is located approximately 35 kilometers from the district camp town where at least 5 garment factories are due to open within the next 3 months. These factories will be the most concentrated in any one district in the country. It is expected that numerous women and young girls will be recruited from the Mohale's Hoesk district including Mekaling and surrounding areas to work in the garment factories. Unless HIV prevention and care services are introduced there will be an exponential growth in the already high (approximately 22%) HIV prevalence rate.

There are similar traditional structures and clinical services in Mekaling as Maputsoe and Ha Thamae but there are no NGOs supporting HCBC and the primary referral clinic located at Holy Cross is only now beginning to revamp its village health care program. WFP and UNICEF have provided some food assistance to those most in need yet; there are concerns that food distribution will end. According to the Chief of Mekaling, MeMasante Lerotholi, there is a critical need for assistance to the people living in her constituency. She has heard of some activities taking place in the district camp town and has tried to solicit assistance but has been told that there is no funding for her area. The most recent development in her area has been a mortuary approximately 300 meters from her home, opened by a private doctor from the camp town in

[26] UNAIDS Epidemiological Fact Sheet, 2000
[27] TEBA Mine Population Database, 2001

2000. She stated that when she looks at the mortuary she is reminded of the numbers of deaths and wishes that instead of a mortuary there were programs to assist her people.

During discussions with a number of women and men at the chief's compound it became apparent that they too are doing what they can to help their own and surrounding family members. But unlike the Northern part of the country they have not been able to plant for two years so there is often not enough food to share with others let alone to provide a balanced diet within their own homes. During the month of November at Ha Mohlakana (the chief's village) people went without water for one week. The stories of death and illness are never ending and each home has been affected.

II. HCBC CBO – MOTHO KE MOTHO KA BATHO – A PERSON IS A PERSON THROUGH PEOPLE.[28]

The Basotho have a long history of caring for each other at the community level. It is well known that when someone in the community is ill they will not be alone. A common response when this is discussed with Basotho summarizes the situation "Ha re na kheto. Ke batho ba rona - re tla esta joang" We have no choice. These are our people what will we do?

The majority of the HCBC CBOs and FBOs supported by CARE Lesotho stemmed from the Basotho tradition of helping people in their communities who are ill. ***Hence, the formation of the HCBC groups*** was not done by CARE but was built upon the existing traditional structures. Those involved in the traditional care of people who are ill recognized an increasing need for people who were ill among their communities' members. They then solicited the support of other people in their communities to form a Makhatlo[29]. A few of the groups were developed by concerned chiefs and local development committees who called upon community members to volunteer help ill people in their communities. Workers in this instance were identified on a voluntary basis and the chief and development committee made the final selection. Most of these HCBC groups were formed around 2000 and all of them worked with no external assistance until CARE Lesotho began funding and supporting them in March 2004. However, CARE did have a relationship with the existing site Chiefs and village development committees through their PE initiatives. Using the traditional structures CARE worked through the development committees and chiefs to identify the HCBC groups/Makhatlo, which are now the CBOs, and FBOs supported by CARE.

Leribe CBO Meeting Profile

There were 12 HCBC workers comprised of 4 men and 8 women. Eight of the 12 workers currently have chronically or terminally ill family members living with them.

"We work in teams of 2-3 and visit an average 3-4 households a day, 4 days a week. In some places we are the only ones providing care. There is no other village health worker, community nurses or things of this sort. We re-supply our own care Kits with our own money and give our food and anything else we can to those who are in need and suffering.

CARE [Lesotho] helps us a lot and we want more help but even if they ran out of money and had to stop we will keep moving forward because these are our people."

There are an average of 4-5 trained HCBC workers per CBO who visit an average of 3-4 households per day. None of the

[28] One of the most common Sesotho Proverbs meaning that a Person is not a person without other people.
[29] Makhatlo is a traditional group of people who are working towards a common goal.

HCBC workers are formally employed and the majority of them have completed primary education. The age of HCBC workers ranges from 28-60 years of age.

The HCBC workers do not receive any ***remuneration***, ***payment, incentive or subsidies*** in cash or kind but to the contrary use their own resources to help the families they are working with. This is viewed as a major challenge for the workers as they find it very difficult to *"go to someone's home who is hungry, sick and has nothing and not give something to help them."* Many instances were cited of giving food from their own gardens or supplies, blankets, transport money for the clinic, soap etc. In extreme cases this has caused problems for a few of the workers with their spouses who become upset that "the little they have is being given away". The workers expressed a strong desire that even if they are not "paid for what they do" that they are given assistance to find ways of providing for the families they work with.

The workers are motivated by spiritual belief, pride in working for their people stemming from Basotho values, meeting together, the support of the Site Coordinators and occasional workshops provided by SHARP!. Some workers have grouped together to start small IGA activities to raise money for their HCBC activities but even these do not adequately fulfill the need.

In Maseru the HCBC workers visit households either on their own or in pairs. The client in the household has the opportunity to decide who works best with them. In Maputsoe the HCBC workers conduct home visits in teams of 2-3. This was stated to be due to the shortage of HCBC Kits whereby there are not enough for each HCBC worker to have their own kit. Each of the groups estimate that they work a minimum of 3 days per week and some 7 days per week depending on the situation in the household. For instance, if the client lives alone and is bed-ridden the HCBC worker will visit every day. The total number of households cared for in Leribe in February 2004 was 33 and the total in Maseru was 34. Although difficult to be precise it was estimated that the total number of visits during February 2004 was more than 400 in Maputsoe and more than 400 Ha Thamae.

CARE or the HCBC workers in the two sites visited do not do ***client selection.*** A pitso[30] was held in both sites by the local chief to introduce the HCBC workers to the villages and community members were encouraged to call upon them as needed. Hence, the vast majority of clients come from community referral, followed by chiefs and a small percent from clinics. All clients with any illness are provided HCBC – there is no selection based on HIV status, age, religion etc. Most HCBC workers expressed a fear of going to a household where they know someone is ill if they have not been requested by a family member to do so or have not been referred by the chief or clinic. It was felt that they must be invited or referred to a home. To show up without an introduction is something that is not felt to be appropriate in their culture. The referrals and that no client would be turned away were principles that both groups felt very strongly about.

Although the first financial support provided to the CBOs was given in March 2004 the first ***HCBC training*** took place in May 2003 and was provided by both SHARP! staff (the Site Coordinators) and the MOH. The MOH and CARE Lesotho worked together to conduct the training. The training manual and technical assistance was provided by the MOH. CARE adapted

[30] Pitso is a traditional public gathering or meeting most often called by the Chief.

the training material to a more participatory training methodology. The training lasted two weeks the goal and objectives of the training were as follows:

HCBC Training Goals:

- To provide caregivers with sufficient information, skills and support to enable them to protect and promote the health of people living with terminal illnesses including AIDS.
- To enable the caregivers to provide compassionate care to those who are terminally ill
- To protect and promote the health of the caregiver
- To enable a sick person to live his/her life with the dignity and respect that he/she deserves

Overall Objectives of HCBC Training:
Participants will

- Have been introduced to the idea of community home based care and related this to their own or others previous experience of involvement in care
- Have acquired information on STDs/HIV/AIDS/TB
- Have developed an understanding that people hold differing attitudes towards HIV/AIDS/STDs
- Have learned about the importance of listening and being non - judgmental
- Have identified typical problems which a care giver may face
- Be able to recognize and take care of the common physical problems that can be caused by a terminal illness
- Be able to recognize the emotional problems that can be caused by a terminal illness and have identified support which may be needed by the terminally ill person
- Be able to recognize when it is important to seek additional help and where to go for this
- Have identified some of the practical issues which may face a person who is dying of a terminal illness and discussed ways of responding to these issues

Additional training for the HCBC workers has included a one-week counseling training from PSCAAL and a one-week nutrition training from LAPCA. A number of the HCBC workers had also taken part in the PE trainings and sensitization activities in their communities providing a foundation for HIV/AIDS prevention knowledge. Due to time limitations it was not possible to conduct a quality of training assessment. However, it was reported by former trainees that the training helped to form a stronger base of knowledge and skills and that there is a need to continue trainings for on-going learning and support.

HCBC workers interviewed report that they conduct the following activities:

Respite care e.g., house keeping and washing of clothes, blankets and linen.	This is done on a daily basis for bedridden clients who are living on their own. For clients with other household members it is done approximately once/week and on an as needed basis.
Cooking	Daily basis for bedridden clients, as needed for those with other household members
Bathing client	Daily basis for bedridden clients who are

	living alone and as needed for those with other members in household
Assessment of general condition on day of the visit	Per visit but there is no checklist, monitoring tool for clients or guide for consistency.
Monitoring of medication	Observation only for clients on medication – HCBC workers not trained in any aspect of medication use.
Provision of panado, paracetamol, Nystatin (from HCBC Kits)	As needed per opinion of client and HCBC worker. Clear that Panado and Paracetamol are given for just about any symptom. Use of Nystatin not clearly articulated.
Counseling and prayer	Much of the support is in the area of counseling and prayer. Clients as well as HCBC workers belong to different churches. An interdenominational approach is used.
Referrals primarily to clinic and other care and support services	As needed basis by HCBC worker yet no clear guidelines or resource guide. Clinic relationships vary according to which nurse is on staff. HCBC worker often accompanies client to clinic and at times will use own money to pay for the visit and/or medications
Provision of traditional remedies	Basotho commonly uses traditional remedies. The most often cited within the context of HIV/AIDS is Soso a drink made from boiling a mixture of peach tree branch, pine tree bark, grape leaf, African potato (moli), algae (bolele), aloe (moriri oa matlpa) and mofeefee[31] which is sipped throughout the day. Soso is believed to clean ones blood, provide strength, and to help with ulcers but is *not* believed to cure AIDS or other illnesses. . Other types of traditional remedies were cited and include those for headache, vomiting, diarrhea, and bad luck.
Pain Management	No access to pain medication or systematic way of assessing and managing pain. Heavy reliance on Panado and Paracetamol without clear understanding of the difference..
Material Support	HCBC workers provide as much as they can from their own homes. Some of the CBOs have started their own gardens to provide fresh vegetables to clients and a few are starting IGA activities with the hope of raising money to support their clients.
Nutritional Support	Donations from HCBC workers. Inconsistent and loosely targeted food assistance from

[31] No translation is available for mofeefee.

	WFP and UNICEF. Monitoring of food intake – including asking client what they will eat that day and checking in the home to see if the food is there.
Family Centered Care	HCBC report that they focus not only on the client but also on other household members. But indicate need for better communication skills in this area.
Children who are chronically ill or living with a life threatening illness.	Report small number of children suspected to have AIDS and difficulties identifying and working with children with HIV and working with other children who are chronically ill or living with a life threatening illness.
Prevention	Report small discussions on prevention and some condom distribution.

Access to supplies by the HCBC workers is extremely limited. For each HCBC kit supplied to the Maputsoe group one had to be shared between 2-3 workers. The Ha Thamae group were supplied with enough for each HCBC worker. These kits are provided one time per year, are not calculated according to client need, and there is no provision for restocking. HCBC workers report that once the supplies are finished they use their own money or the group collects funds to procure supplies. The HCBC workers also use their own money to provide transportation money and funds for clinic appointments and medications of their clients.

It is the perception of the HCBC workers that HCBC kits are central to their work; providing them with much needed materials, confidence, and ability to provide better services to their clients. The HCBC workers felt it was important to have enough kits for each client and to add the following to the kits: thermometers, basic pain and curative management medication (they have no other means of accessing medication), more bandages/dressings, more gloves and chucks. Both HCBC CBOs also reported the need for on-going education on how to use the supplies to maximize their benefit and for other means of procuring the contents in the kits.

WFP and UNICEF both supply food parcels to selected geographic areas. However distribution is reported to be inconsistent and occasionally those most in need do not benefit. The GOL is preparing an initiative through the Global Fund to provide food parcels to orphans and other vulnerable children but the content of the parcels and distribution strategy have not been finalized. Most clients have support from family members but there are cases of people who have no family and are not well enough to procure any food for themselves and cases of families who are in dire need. Hence, the HCBC workers often find themselves sharing whatever they have with their clients for the fear that if they do not the client will not survive. It is also a long tradition of Basotho to help each other when in need even if it is the help may seem small. There is no access to bed linen or blankets at either site. Given that the weather in Lesotho drops below freezing in the winter this is a major concern of the HCBC workers for their clients who do not have resources to stay warm.

Bana ba monna ba arolelana hloho ea tsie.
Children of a man share the head of a grasshopper.

Those who are related will share their food, no matter how little it is. -Sesotho Proverb

During the site visits there were no ***patient education and resource materials*** (pamphlets, check lists, client education material etc). HCBC workers indicated a need for simple low-lit material that could be used not only when communicating with the clients but also as a referral for themselves.

Each site uses the ***referral clinic*** within their area as the primary means of professional clinical care for their clients. The clinics are aware of the HCBC program and on occasion will allow clients referred from the HCBC program to skip the queue and be seen right away. It was reported that the nurse in charge participates in case management reviews together with the HCBC teams yet upon discussion with the nurse at the Maputsoe clinic she has only done this once and attributes it to a lack of time. It was however reported by some of the HCBC workers that the nurses are relatively accessible to the HCBC workers if they have questions related to their work.

The HCBC CBOs felt that the relationship with the clinics could be stronger and that one barrier is that the relationship is primarily dependant on one nurse. Given that there is a high amount of staff turnover at the clinics (due to the rotation schedule of nurses in Lesotho) there is a lack of consistent relationships between the clinic and HCBC workers and Site Coordinators. Hence, the Site Coordinators and HCBC workers must reorient the new nurse in charge each time there is turnover. An average of 2-3 referrals are made to the clinic per month.

The referral clinics are responsible for immunization of children, ante and postnatal services, family planning consultations and basic curative services for children and adults. For instance the Maputsoe referral clinic is an outpatient clinic. The precise size of the population served by the clinic is unknown but estimated at more than 7,000. Services provided at the Maputsoe clinic include:

- Pediatric services: preventive, curative, and chronic care including a well-baby clinic.
- Adult services: curative care (STD, and TB), HIV pre and post test counseling and specimen collection (specimen is sent to referral hospital and results return to the clinic in approximately one week), emergency care, and limited social services.
- Reproductive Health services: antenatal care, 24-hour delivery ward, and family planning.
- Other services: X-ray for children and adults.

The clinic does not provide mental health services, sexual abuse services, or standardized HIV/OI care and treatment.

There are observation beds used to determine if a client needs to be transferred to the referral hospital and labor and delivery beds. The bed capacity is 4 pediatric beds, four beds for men, four for women and six for labor, delivery and postpartum care. On average the bed occupancy is 2-3 patients per day with 8 on busy days. The clinic has one ambulance, primarily used for transferring patients to the referral hospital.

"We have too many people coming here with HIV/AIDS. It is overwhelming. I see more wasting, diarrhea, TB, and coughing, then I ever have. I also see too much herpes and "mokhopo" (common word for rash but now associated with HIV/AIDS).

I have 50 village health workers waiting for training in HIV HBC but we do not have the money… We also need to do more men to men work. They have these in the mines and when the men come back to Lesotho they are the ones who most often take condoms from the clinic."

- Referral Clinic Nurse

The clinic opens at 8 am (although people queue around 6:30-7am) and the last patient is seen at 4-4:30pm when the clinic closes. There is one physician on site yet according to staff there are some difficulties due to the language barrier, as the physician speaks very limited English and does not speak Sesotho.

Each clinic has village health care workers per the government program who have not been trained in HCBC. However the nursing staff, HCBC workers and the Site Coordinators expressed a strong desire to have them trained. The CARE supported sites cover geographic areas that are not covered by the village health care workers.

The nurse in charge at the Maputsoe clinic has received two HIV related trainings. The first was a one-week training that covered basic HIV/AIDS and care and support of people living with HIV/AIDS. This training took place in July 2003 in Swaziland and was supported by International Development Africa. Anglo American conducted the second training where she was taught how to conduct rapid HIV test. Although it was reported to be useful to know how the tests work she has not been able to put the training into practice, as there are no test kits available at the site where she is working.

It is the perception of the nurse in charge that the support CARE Lesotho is providing to the HCBC CBOs is very important to the community but that it would be better if they were able to also help the village health workers. She felt that the basic essentials needed to provide appropriate home care are the following:

- Enough HCBC Kits for everyone.
- Would like eventually to see the following included in the kits: mouth care, morphine, acyclovir, anti-diarrhea and vomiting, and vitamins.
- Would like to have nurses or someone with clinical training supervise and be directly linked to HCBC workers.
- Ability of HCBC worker to talk/listen– provide comfort and confidence
- Bathing of clients
- Nutrition monitoring e.g. what did you eat, what will you eat what do you have etc. Food rations should only be provided to those most in need.
- Timely referrals e.g. when care is beyond the ability of the HCBC provider e.g., persistent vomiting, or dehydration.
- If the care is for someone with AIDS they should be treated like all others.

None of the HCBC workers or Site Coordinators has a professional background in health or clinical practice and no systematic back up support from clinical staff. ***Education and on-going support*** as indicated above has been provided through the three specific workshops (HCBC, Nutrition, and Counseling), the weekly and monthly meetings and through the support of the SHARP! Site coordinators. SHARP! Site coordinators although only employed 50% of the time, spend the majority of time at the sites they serve. Their functions not only include assisting the HCBC CBOs but also coordination and supervision of the Peer Education program and resource centers and activities, service provision coordination of other NGOs and Ministries (e.g. through

representation on the DATFs and their daily work with the CARE-Lesotho formal and informal partners).

The HCBC CBOs meet once a week at the Maputsoe Resource Center with the Site Coordinator to review their cases, lessons, and challenges and to up-date each other on areas of special interest. The FHI Technical Advisor had the opportunity to sit in on each of the Maputsoe and Ha Thamae weekly meeting. The Maputsoe meeting consisted of the teams of HCBC workers taking turns describing the situation of the clients they are working with. The rest of the group including the Site Coordinator provided assistance, and support for challenging situations. It was also observed that each of the HCBC workers was very committed to their work as they spoke with passion, emotion and sincere concern and that they gained a tremendous amount of support from each other. It was also clear that there were many questions that they had related to the well being of their clients and how they can better help them.

Case Review

"We went back to visit our client who is a 35 year old woman. She has been sick for a long time. She went to the clinic a couple of weeks ago and is now suffering from chest pain. She is not feeling better and has chest pain. I think she might have TB but she does not have the R20.00 for transport to the clinic [TB services are free in Lesotho].

I used my gloves and apron when I bathed her and rubbed body cream on her. I washed her clothes and linen in bleach, soap and hot water. I also gave her some panado. She did not have any food in her home so we [HCBC team] gathered food, cooked, and left her with a hot meal.

There is no other community health worker in her area to help her and her 13 year old is not in school so she does most of the care. "

At this particular site there is also a Peace Corps Volunteer (PCV) who until recently was working solely with the adolescent HIV prevention program out of the resource center. She is a registered nurse from the United States and has started to provide basic lessons to the HCBC group on anatomy and "how the body works". She is also reviewing the purpose of the HCBC kit contents with the HCBC workers. This was felt to be of considerable value by the HCBC workers and the only constraint was that she does not speak Sesotho. However, HCBC workers who speak English translate for others. The PCV is scheduled to finish her assignment in June 2004 and there are no plans for a replacement.

The Ha Thamae group conducts a similar type of session to that of Maputsoe at one of the HCBC workers homes. However, in addition to their internal HCBC CBO workers weekly meeting they immediately follow with a meeting with their clients who are able to leave their homes. This is held in the classroom of a neighboring school. Here they review their work with their clients, provide them with a hot meal (put together from donations from the HCBC workers and from vegetables from their small garden located at one of the HCBC workers homes); this is followed by singing and prayer.

In addition to the weekly meetings the HCBC CBOs meet monthly with the Site Coordinator, the DATF, and the district nurse. During the monthly meeting the HCBC workers provide a general verbal report on their achievements, case reviews, and challenges and a written report to both the SHARP! Site Coordinator and the DATF. It is reported that they are also provided with a restocking of material for their HBC Kits if additional materials are available. This restocking is reported to be very inconsistent and limited.

The ongoing support also feeds into the ***monitoring of the HCBC activities*** as both HCBC workers and the Site Coordinators use the information to strengthen activities. There are occasional supervised HCBC visits made whereby the Site Coordinator will accompany the HCBC worker to observe their work. It is reported that the HCBC CBOs will occasionally have nurses from the referral clinics accompany them during these visits, however this has been done only once at each site. Although it is reported that one nurse at each site does on occasion attend the weekly meeting.

There are no formal reporting documents, guides, or instruments for tracking clients and overall work of the HCBC program. HCBC workers use composition notebooks to record client information and these are turned over to the Site Coordinators for monthly review. There is also no reporting format to inform communities on the progress of their work or to solicit feedback from the communities on their perception of the program. Both the HCBC workers and the Site Coordinators expressed a strong desire to know how well they are doing both in terms of coverage and quality of work. The program does not have a monitoring and evaluation strategy and no special studies are taking place in relation to the program.

Why Won't He Tell Me?

"I feel bad. I have been working very hard with one person, a man who has been sick for a long time.

I go to his house every day to see him, bath him, clean, cook and check on his health.

I have heard from someone else that he told them he has AIDS. But he will not tell me. I do not understand why he will not tell me when I do so much for him."

- HCBC worker

There is no ***logistical support*** for the HCBC workers and very little support for the HCBC Site Coordinators. The HCBC workers travel by foot at times up to 4 kilometers per day and the Site Coordinators primarily rely on public transport. For the Leribe Site Coordinator this means traveling close to 4 hours per day round trip.

The ***needs*** perceived by the HCBC workers can be summarized as follows:

- Communication skills in three areas a) with the client b) with the client and family and c) with the clinical staff at referral sites.
- Self confidence
- Training and ongoing education in general issues related to HIV/AIDS, HIV/AIDS care and support.
- Better ability to care for children with HIV
- More skills on addressing needs of children who have terminally ill parent/s
- How to decrease people's fears of HIV specifically of someone who is very ill with HIV
- Up-grading of care skills especially related to clinical care of PLHA and long term care of bed ridden clients e.g. to prevent and treat bed sores
- "Home management" e.g. how to keep a hygienic home for someone with HIV/AIDS, respite care.
- Better understanding of nutritional needs of PLHA by age
- Skills for resource mobilization and monetary support to better help those they serve and to decrease amount of own money spent.
- First AID skills

- Epilepsy - a better understanding of epilepsy in general (both traditional and western treatment) and how to care for someone with both epilepsy and HIV)
- Clinical support/backup
- How to increase effectiveness of referrals
- Adequate supply of HCBC Kits and inclusion of thermometers, pain medication, basic curative medicines, and bandages.
- Community sensitization on HIV/AIDS
- Better relationships and support with referral clinic staff (one suggestion was to have a type of ID that the HCBC worker would show when taking a client to the clinic).

V. HOUSEHOLD LEVEL: CLIENT, FAMILY AND HCBC WORKER

The HCBC workers are very sensitive to the privacy of their clients. Before entering the small tin home of a middle aged man we waited outside for the HCBC worker to confirm that the client would allow a visitor. Upon entering the home the HCBC worker had already finished bathing the client, cleaning his home and was preparing porridge for his morning meal (made from corn meal brought by the HCBC worker). The house is spotless and the man, in his early 40's, is lying in bed. His sister and brother in-law who used to live in the same compound died the previous year. He is now bed ridden and has no family.

The HCBC worker explained that she comes to his home every day to check how he slept, clean, cook and see that he has something to eat and has taken his medication. It is clear that they have a good relationship as they frequently make eye contact and chat with each other. They both explain that this is a difficult situation for him. As we observe her working with her client with the utmost respect and attention he turns to us and says, "*If I did not have her [the HCBC] I do not know what I would do*." He then goes on to explain that he is feeling better and is now able to eat. He had apparently been very sick the week before but the HCBC worker was able to arrange transport to the clinic where they went together. They tell how they both go to the clinic and the man has given consent for the nurse to speak with the HCBC worker about his condition so that the HCBC worker can better assist him at home.

The HCBC worker then explains that she is concerned about him as the winter is coming. He has only one thin blanket and she is worried that he is too weak to fight off any type of illness that may come with the cold. The other concern is that they are trying to figure out a plan for him to easily reach her in the night if needed. There are no phones in this area and he lives alone. When we leave the home the HCBC worker looks at us and simply says, "*When his time comes I do not want him to die alone*. *I have seen many like him and they just do not get better.*

Three houses away we enter the next home with an additional HCBC worker who lives only a few houses away from the client. Here is a young woman who also is bed ridden and lives with her father in a small one room tin house. Similar activities as outlined above had already taken place earlier in the morning. The difference here is that she had been diagnosed with TB and is currently taking medication. During discussions with the client and the HCBC worker it was revealed that the clients father had been coughing for some time but he had not yet been referred to the clinic.

Another two homes away a young woman was resting in bed along side her 6-year-old nephew. During this visit the HCBC worker asked the client how she was that day – she was much better than before but still very tired. However, her nephew was not doing well, had a rash that was prominent on his extremities and face and his right arm was wrapped in a cloth. He had apparently fallen the day before.

The above briefly outlines three different scenarios and the main CBHC activities held at the household level that can be summarized as following:

- All of the clients visited and spoken with through home visits and one informal group discussion are concerned about their HCBC worker. They clearly express the desire for the HCBC worker to have more support. They know that the food, time and energy provided by their HCBC worker is not compensated in any way. One client expressed concern that the HCBC workers will get "tired" of her one day and may not come again.

- Basic care is provided in a respectful and resourceful manner.

- While pain is clearly recognized by the HCBC worker both s/he and their client expressed the need for a systematic way of addressing pain including pain medication.

- HCBC workers stated that they only bring the materials they need from the kit to the home and do not carry the whole kit. During these site visits and discussions most HCBC workers were buying or supplementing materials through their own means.

- Clients expressed high appreciation for the HCBC work and felt that they could call upon the worker any time. However workers are concerned that clients who are living alone and bed ridden will not be able to contact them if they need help at night.

- HCBC workers shared stories of some clients who are getting better and those who had died. They display a great deal of support for one another.

- The client is the center of the HCBC workers attention.

Similar to the two sites in the north, people in Mekaling will also tell you stories of how they continue to mobilize themselves, provide home visits and try to care for those they love. AIDS was spoken of openly during the discussions and it was clear that people here are aware that the disease is killing many of their people. They say that they are not afraid to care for people with HIV/AIDS as they have become used to the illness and can easily identify a person who is dying of AIDS. It was reported that only a few were trained in the village health care worker program in the 1970s and no one in the area has received any training in HCBC related to HIV/AIDS. People say that they feel comfortable caring for sick people but that AIDS is a disease that is not like the others they are used to.

PROGRESS STATUS

The following statistics from the Leribe and Maseru sites are inclusive of the month of February 2004. The progress was as follows:

- 9 of HCBC CBOs (Leribe and Maseru)
- 33 clients served in the 4 Leribe sites (21 men and 12 women, ages 10-64 years old with majority of clients between mid 30s and early 40s)
- 34 clients served in the 5 Maseru sites (25 women and 9 men, ages 5-60 years old with the majority of clients between mid late 20s and late 30s)
- Life of project: 54 people trained in HCBC, counseling and nutrition

OBSERVATIONS: The following is an interpretation and summary of the findings from the technical assistant's perspective.

There is an urgent need to support HCBC programs in Lesotho as the current support and coverage is not meeting the demand for care. If support is not provided those in need today will not receive the much needed support and models will not be identified that can be scaled up to reach the expected increase in demand throughout the county.

The CARE Lesotho program most specifically the SHARP! staff have integrated the HCBC into their current work despite the overwhelming workload that they currently face. This initiative is building on a sustainable indigenous care model and providing much needed support. The groundwork of building a trusting relationship between district and community level partners has been accomplished, training provided and a level of ongoing support is being provided. With continued and increased funding, technical support, integration of lessons learned, and continued collaboration at the district and community level and other organizations providing HCBC and related services this can become a sound model for the provision of HCBC. It is also foreseeable that with relatively minor changes and expansion of services the model can be expanded to other sites that are in need of support.

Following are some observations that have to be considered for the improvement of the HCBC pilot. In order to achieve the SOW for this assignment it was important to look at the larger context in which the CARE HCBC pilot is functioning. Therefore, some of the observations outlined here are not specific to CARE Lesotho but are critical to strengthening the overall HCBC response in Lesotho.

The following are intended as suggestions for taking the program to the next step. It is recognized that the primary limiting factor to addressing these issues in the pilot has been a lack of technical and financial support and that some of these observations are not within the current mandate of the CARE Lesotho HCBC pilot.

National Policy and Coordinating Structures

- There is currently no HCBC Policy or strategy in the country and no specific national level coordinating structure for HCBC.
- There is no readily available information on the national coverage and status of HCBC activities in the country for instance through a HCBC database or resource guide.
- A National HCBC training guide exists and is being used but there is no accreditation process for HCBC programs or workers.

District Level Support

- The critical role of the DATF cannot be underestimated. The District AIDS Coordinators are under a tremendous amount of pressure and carry a heavy workload. The DATFs have no HCBC district level strategy, are very concerned about the HCBC coverage, quality and their need for technical support.

CARE Lesotho Staffing:

- Despite the commitment and sound basic HCBC knowledge of the current SHARP! staff supporting the HCBC CBOs they are currently not receiving any technical support for HCBC, do not have a designated HCBC care technical staff member, have not had any exposure to model HCBC programs and have competing responsibilities.

Sustainability

- Given that CARE Lesotho is working with traditional care mechanisms these community and household level activities will continue even if support is discontinued. However, given the magnitude and complexity of the provision of care at the community and household level if technical and programmatic assistance to CARE Lesotho and their CBO partners is not provided the current provision of care will not reach its full potential and an opportunity for developing a model for expansion will be missed.

Collaboration

- Collaboration at the district and community level appears to be strong. Contributing factors include participation on the District AIDS Committees, the strong relationship that the Site Coordinators have with the HCBC CBOs and the District AIDS Task Force and District AIDS Coordinators. Due to a lack of time it was difficult to assess the relationship between the HCBC CBOs and Site Coordinators with other NGOs providing HIV/AIDS related services. Although the primary focus of the CARE related activities is at the District and community level it was noted that the relationship of the CARE Team with National level HCBC partners was not as strong as it could be for both CARE and the National level stakeholders to benefit from each other's initiatives.

Coverage:

- There is a clear discrepancy between the number of clients and households receiving HCBC and those in need of HCBC. This appears to be due to a lack of trained HCBC workers and

resources including HCBC kits. Lack of HCBC kits was a primary factor for the Maseru HCBC CBO working in teams of 2-3 so that they could share the kits.

- Within Maseru and Leribe CARE Lesotho is supporting HCBC in areas that are not being covered by the District AIDS Task Force yet it is not clear as to how many other areas within these districts are in need of support.

- Most HIV/AIDS funded activities are concentrated in the urban and peri-urban areas of Maseru and Leribe. Hence, one questions what is happening in the rural parts of the country where close to 80% of the population resides. The southern part of Lesotho is of particular concern given the HIV rates, incoming factories, and high-risk populations.

HCBC Knowledge, Skills and Support:

- From the interview, observation, and discussion with Site Coordinators and HCBC workers, they clearly had good knowledge about HIV prevention and basic care. However, there is room for improvement in care skills specifically related to working with someone (adults and children) with HIV/AIDS including early identification of possible problems (physical and emotional) and case management.

- Currently there is no formal clinical or technical HCBC support being provided to the Site Coordinators or the HCBC CBOs. Nurses must be called on from the referral clinics to answer HIV/HCBC related questions of HCBC workers and their clients. The relationships with the referral clinic staff vary and are challenged by clinic staff turnover and a lack of capacity within the clinics. This increases the risk that clients will not receive the most appropriate and timely HCBC.

- At each level of care (Site Coordinators, HCBC CBO, and clinic staff at referral clinics) indicated a strong need for skills building in areas such as HIV, HCBC, palliative and hospice care, pain management, community care for children with HIV, communication skills and client progress monitoring.

- HCBC Kits are being used by the CBOs but there is no system to replenish or restock the kits during the year and essential elements to the provision of HCBC are missing from the kits.

- In Lesotho clients expect a pill or injection when they are ill and if they receive one of these it is considered a sign of “good care”. For the HCBC workers aspirin (panado) paracetamol and nystatin are the only medications available to them, they have no alternatives. Both panado and paracetamol are used interchangeably with panado used more frequently than paracetamol (primarily due to its wide availability in cafes and shops). HCBC workers do not have the level of skill needed to identify and manage some of the problems faced by their clients. Hence, panado and paracetamol appear to be used for almost all physical complaints including head aches from “thinking too much”, side aches, stomach pain etc.

  The heavy reliance on panado (aspirin) increases the risk of gastric irritation (especially for people who are unable to eat). Misuse of paracetamol can lead to liver failure. The current

use of panado and paracetamol masks underlying issues, not allowing for appropriate investigation of, for example, emotional pain, mental illness or physical ailments such as neuropathic pain.

- While pain is clearly recognized by HCBC workers there is no systematic way of assessing pain or addressing pain management (including access to medication).

- HCBC workers are faced with many issues related to orphans and other vulnerable children within the context of HCBC including children with HIV. However they have not received any specific training or skills building in this area.

- Although the primary focus of the HCBC workers is their client, their ability to provide care and support is sometimes compromised by complicated family and household issues of their clients such as communication around illness the early identification of other family members who may be ill especially children.

- Although mostly informal there are an increasing number of PLHA support groups and PLHA who are becoming publicly open about their sero-status in the country, of which CARE Lesotho supports some. However the involvement of PLHA directly or indirectly in HCBC appears to be limited.

Education, Care and On-going Support for HCBC Workers:

- There is no system in place for continuing education for the HCBC workers. Although they have undergone three trainings to date there is no in-service training or continuing educational opportunities.

- At one site it was found that 8 out of 12 of the HCBC workers were caring for terminally ill family members within their own home. This coupled with their workload and the high HIV prevalence and increasing poverty contributes to a great deal of emotional and physical stress.

- HCBC workers are clearly expending their own resources (money, food and material goods) to provide care for their clients, work at least 4 days per week, and most have no means of consistent income. There is an urgent need to develop a strategy to provide financial support or remuneration to the HCBC workers**.**

Information Education and Communication:

- Currently there are various IEC materials for HCBC including pamphlets, HCBC check lists or other case management tools, reporting forms, or low-lit client information available throughout the region. CARE Lesotho also has the expertise needed to develop and adapt culturally competent material. However no IEC related material is currently being used in the HCBC program.

Referral System and Entry Points to HCBC

- Relationships with referral clinics and hospitals have been established but are an area of great concern for Site Coordinators and HCBC CBOs. There is no formal referral system or strategy for referrals to and from these sites and hence there is a lack of understanding of the level of care to be provided at the community and home level and possibly delayed referral and compromised follow up.

- Referral to and from other care and support systems and activities such as NGOs, feeding programs and social assistance are not regularly carried out.

- Current entry points primarily include those from community members and chiefs. Entry points stemming from clinics, hospitals and other related programs have not been fully maximized.

- Family centered care whereby the primary client is used as an index case for possible assistance to other family members who may be in need of care is not maximized, for example in relation to TB identification, referral and management.

Monitoring and Evaluation:

- Although very basic data exists the current CARE Lesotho supported HCBC pilot program has relatively little baseline data on the provision and use of HCBC. Such information is important for monitoring the intervention, especially the impact of the introduction of the HCBC intervention on pre-existing traditional services. The following was not available:

- There are no existing tools to easily capture data needed by the HCBC worker, communities and the program to monitor their progress. The HCBC workers use school composition notebooks to record their home visits but these are not used systematically as a tool for data collection.

- There is no evaluation strategy for the HCBC program.

- Traditional remedies and culture play an important part in the provision of HCBC yet there is no mechanism for documenting these factors.
- There is no mechanism for reporting back to and soliciting feedback from the communities in which the HCBC workers provide services.

RECOMMENDATIONS

Based on discussions, review of documents, and observation the following recommendations are made. It is understood that the prioritization of some of these recommendations will be contingent on funding and mandate of CARE Lesotho. Given the nature of the assessment the following recommendations cover both general recommendations for the overall strengthening of HCBC in the country and specific recommendations for CARE Lesotho. There are many opportunities to gain from neighboring country experiences, trainings and expertise. Hence, an

overall recommendation is that opportunities for local or regional technical assistance, training, mentoring etc be explored. Regardless of the origin of technical assistance it is imperative that the TA has sound knowledge and understanding of the social and cultural context of the country.

General Recommendations

Immediate Priorities

- National mapping exercise to identify current HCBC coverage and efforts, levels of HCBC being provided, gaps (geographic and provision of services), and funding and technical assistance needs.

- National HCBC consultative workshop to scale up national HCBC response.

- Development of specific HCBC coordinating structure that involves representatives from all key stakeholders.

- Development of National HCBC Policy and strategic action plan to include essential elements of care at home and community level, content of HCBC kits and mechanism for restocking and re-supplying, goals, objectives and roles and responsibilities of key stakeholders.

- Training of village health care workers in HCBC (per GOL training manual).

- Assistance to DATF to develop HCBC strategy and implementation plan including monitoring and evaluation process.

- Donors to increase funding to Lesotho and to increase current geographic target areas to include rural areas and southern part of the country.

Midlevel Priorities

- Development of a national HCBC database and resource guide for increasing access.

- Development of National accreditation process for HCBC workers and HCBC organizations.

  Although not specifically related to HCBC - Explore contributing factors to the reported high demand for VCT as this may have important implications not only for Lesotho but also for neighboring countries and the region

CARE Lesotho HCBC Specific Recommendations:

Immediate Priorities

Funding and increase of human capacity:

- Provision of funding and technical support to CARE Lesotho for the continuation and strengthening of the HCBC pilot. Given the nature of this type of work long-term funding is recommended.

- SHARP! is working with very few staff. There is a need to increase the Site Coordinators to full time, increase their HCBC technical capacity, and either have a HCBC specialist or contract TA for on-going support.

- Increase number of trained HCBC workers.

Strategy and implementation plan:

- Based on lessons from pilot and consolidation of recommendations CARE Lesotho will need to develop a HCBC strategy and implementation plan for the next phase of activities.

- It is essential that a referral strategy be developed as part of the HCBC strategy and within each HCBC site. At the site this should be done not only with the existing health care facilities but also with other care and support services and activities. This should be developed in collaboration with the DATFs.

Training effectiveness, and support:

- Communication skills training on aspects of dealing with difficult issues such as eliciting client's concerns, physical condition of client, emotional and mental distress and illness, differing concerns of household members, physical limitations due to illness, anticipatory grief, impending death this type of training has been provided in many regions in palliative care and training will soon take place in Malawi. One consideration is to deliver a similar training in Lesotho.

- Various technical areas were identified for further training and on-going education and support such as pain management, palliative care, children with HIV, psychological and emotion support, dealing with mental health issues, OVC within HBC etc. These should be prioritized within a strategy for ongoing education and support. Additionally it would be beneficial to identify available trainings within the country and region. There are various training institutions and resources available that can be easily provided and tapped into.

- Encouragement of PLHA support groups to identify one or more representatives to be actively involved in the HCBC. The level of involvement can be decided between the PLHA and CBOs but at a minimum it is suggested that the representative is actively involved in the planning and monitoring activities. This can be done both at the CARE level and CBO level, for instance through participation in the weekly and monthly meeting and random spot checks.

- There is a need to develop (within the HCBC strategy and implementation plan and the the monitoring system) a mechanism to provide the needed technical support and supervision to the Site Coordinators and the HCBC workers. This could include strengthening the monthly

and weekly meetings, active involvement of nursing staff from referral clinics, supervision check lists etc.

Resources and supplies:

- Development of simple resource guides for HCBC workers outlining existing services and activities that their clients can benefit from – i.e. a simple resource directory. Again this is something that can be developed through the DATF structure.

- Review content of HCBC kits and explore options of improving the content and supply including funding possibilities for provision and replenishing and accessing information on "model kits" in the region. For instance South Africa has a comprehensive HCBC kit and Mary Crewe in Pretoria SA has just finished a study on feasibility and effectiveness of HCBC kits the findings of which may benefit the pilot program.

Monitoring and evaluation: Develop a monitoring and evaluation framework that takes into account the HCBC workers monitoring needs and traditional monitoring methods.

- Develop simple strategy for reporting back to and soliciting feedback from traditional leaders and village development committees on the status of HCBC activities. This can be easily incorporated into the traditional structures and meetings that take place and will enhance not only community awareness and possibly involvement but will increase the motivation of the HCBC workers.

- Drawing on existing monitoring tools from HCBC programs in the region develop simple monitoring tools with HCBC workers to streamline not only data collection but also to improve case management.

Care and support of HCBC workers:

- There is a need to strengthen the care and support interventions for HCBC workers to address issues related to working and living in an environment with high HIV prevalence including the emotional and physical stress related to their professional and personal lives. Possibilities for this type of support should be sought and worked through with the HCBC workers themselves and a strategy developed.

- Explore mechanisms to support HCBC workers not only to decrease the amount of money and resources they are putting into their work but also strongly consider remuneration for HCBC workers. For example, in South Africa HCBC workers are provided with R500.00 per month (with discussions currently taking place to increase this amount).

<u>Midterm priorities</u>

- To increase coverage of HCBC explore possibilities of increasing the number of HCBC workers and entry points for identifying clients such as through existing care and support

activities and health care facilities and using client as a case index for other family members in need of care.

- To increase coverage of HCBC and target geographic of great need it is recommended that following consolidations and rapid strengthening of current HCBC sites CARE Lesotho consider replication in the southern part of the country.

- Although the focus of the HCBC pilot is at the district and household level strengthening the relationship with National HCBC stakeholders will benefit both the pilot and other initiatives.

- Advocate for and participate in National level efforts suggested in general recommendations above.

Appendix A

Scope of Work for Technical Assistance in Home Based Care (Lesotho)

Background:
The Sexual Health And Rights Promotion program (SHARP!) is a cross border initiative implemented by CARE Lesotho-South Africa. This initiative is being implemented in two border towns of Lesotho, namely Maputsoe and Maseru (in addition to South African sites). In the recent past, SHARP! has introduced a home based care component to activities in Lesotho sites. In South Africa sites, SHARP! peer educators are referring to existing hospice care programs and following-up to ensure appropriate care.

Currently, forty CBO members from the Maputsoe site have undergone a two-week training workshop on home based care by the facilitators from the Ministry of Health. At the end of the workshop, the Ministry provided the program with 15 HBC kits freely. This is part of the incentive/tool kit given to the participants on graduation from the HBC training. Further negotiations have been entered into by the Maseru Site staff with the Ministry's staff for further trainings in Maseru.

Activities:
The consultant will visit SHARP! activities in Maseru and Maputsoe over three (3) days in March. She will meet with SHARP! staff coordinating care and support activities in the two sites. She will meet with trained home based care providers, relevant Ministry of Health and Social Services staff, and staff at clinics that serve as referral points for the home based care activity.

She will do a rapid assessment the activities and make recommendations for improvement, if necessary. Some considerations will include: training for HBC providers; quality assurance and supervision; linkages to peer education & prevention programs; linkages to clinical services such as opportunistic infection and TB treatment; linkages to other services such as OVC and psychosocial support; and sustainability and integration with national palliative & HBC activities.

The consultant will be paired with SHARP! staff throughout her visit to promote capacity building.

Deliverables:
The consultant will produce a report of findings, which will describe how HBC is being implemented, its strengths, weaknesses, and suggestions for strengthening the program. The report will also identify appropriate local resources for strengthening the program, if needed. Future technical assistance by FHI to the program is not foreseen by USAID.

The Consultant:

The consultant is a senior technical officer, with experience in care and support programs. She is fluent in Sesotho, and has experience working as a community-based nurse in Lesotho.

Appendix B
Home and Community Based Care Kits

The following are the basics that are provided in the HCBC kits used by the HCBC workers in Lesotho. It was difficult to itemize the volume and quantity of each item because there is no consistent supplier and items and quantity often changed based on the donor.

- Savlon
- Methylated Spirits
- Gentian Violet
- Nystatin
- Paracetamol
- Panado (aspirin)
- PVC Washable apron with neck band
- Gauze swabs
- Gauze bandage
- Skin antiseptic: Salvon
- Surgical gloves
- Aqueous cream
- Soap cake
- Bleach bottle

The following are the contents of the Home and Community Based Care Kits provided by the South Africa government. This is also the recommendation for all HCBC providers within the country. This information is intended as a consideration for improving the HCBC kits currently used in Lesotho. Use of pain management medication such as opiods within a home setting is only provided through registered institutions. Hence, HCBC programs that are part of palliative or hospice care program have access.

HCBC programs that are not officially affiliated with registered institutions do not have access to pain management medications such as opiods for use with their clients. These clients only receive pain management medication upon admission to district hospital.

<u>Professional Home Care Kit</u>:

* Description. Volume and Qty each
Gentian Violet 20ml 1
Paracetamol 500 mg tabs, 20's 10
Paracetamol Suspension 100ml 1
Acetylsalicylic acid tabs 300mg, 30's 10
Ferrous Salt 30's 1

Folic acid 5 mg 30's 1
Ascorbic Acid (Vit C) tabs 100mg 28's 5
Multivitamin syrup 100ml 1
Calamine lotion 100ml 1
PVC Washable apron 90 x 112 with neck band
Gauze swabs 100 x 100 100's 1
Cotton wool, 500 g 1
Gauze bandage 100mm 10
Skin antiseptic w dispenser Cetrimide & irrigation bottle 1
Surgical gloves 100's 2
Aqueous cream 100 g 5
Clinical thermometer. oral/rectal 1, rectal 2, oral 3
Daktarin oral gel tube 5
Rehydrate, 2 x 20 2
Povodine lodine cream Tube 6
Plaster adhesive 25 mm x 3 m 2
Plastic soap box with lid 110 x 70 x 35 1
Ball pens, Blue with cap 2
Umbrella, Foldable 1
Ensure 500 ml can 1
Soap cake, 100 g 2
Bleach bottle, 500ml 1
Linen savers, 510 x 650 100
Surgical scissors, 12 cm straight 1
Hand torch, Use 2 x D sz batteries 1
Paper towel, 120's 10
Kidney dish, Small 1
Razor disposable, 5 per pack 1

One month supply at a total of R 1 800.00 per kit

Home Care Kit: Lay Caregivers

* Description. Vol & Qty each
Gentian Violet 20ml 1
Multivitamin syrup 100ml 1
Calamine lotion 100ml 1
PVC Washable apron 90x112 with neck band 1
Gauze swabs 100 x 100 100's 1
Cotton wool 500g 1
Gauze bandage 100 mm 1
Skin antiseptic w dispenser Cetrimide & irrigation bottle 1
Surgical gloves 100's 2
Aqueous cream 100 g 5
Clinical therm oral/rectal 1, 2 rectal, 3 oral
Rehydrate 2 x 20 2

Povodine lodine cream Tube 6
Plaster adhesive 25 mmx 3 m 2
Plastic soap box with lid 110 x 70 x 35 1
Ball pens Blue with cap 2
Umbrella Foldable 1
Ensure 500 ml can 1
Soap cake 100g 2
Bleach bottle 500ml 1
Linen savers 510 x 650 100
Surgical scissors 12 cm straight 1
Hand torch Use 2 x D size batteries 1
Paper towel 120's 10
Kidney dish Small 1
Razor disposable 5 per pack 1

One month supply at a total of R 1 600.00 per kit

Appendix C

A total of 76 people were interviewed through key informant interviews and informal focus group discussions in Ha Thamae - Maseru, Maputsoe - Leribe, and Mekaling – Mohale's Hoek.

The break down is as follows:

Four informal focus group discussions:

- Maputsoe HCBC team 12 people (8 women four men)
- Ha Thamae HBCB team and clients 28 people (HCBC workers: 15 women and 1 man clients 9 women and 3 men)
- Mekaling Chief compound 12 people (8 women and 4 men)
- Lesotho Senate AIDS Committee 6 people (3 women and 3 men)

Key informant interviews:

- Department of Social Welfare – 2 people
- Ministry of Health AIDS Unit 2 people
- 2 District AIDS Coordinators
- 2 Clinics - 3 female nurses
- 2 traditional healers
- 1 Peace Corps Volunteer
- 2 People Living Openly with HIV
- 6 HCBC clients