



Hope for African
Children Initiative



Save the Children

“When someone is sick in the house, poverty has already entered”

A research study on home-based care, Morrumbala Centre,
Zambézia Province, Mozambique

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Abbreviations

AMETRAMO	Association of Mozambican Traditional Healers
AIDS	Acquired immune deficiency syndrome
HBC	Home-based care
HIV	Human Immunodeficiency Virus
INAS	National Institute of Social Action/Instituição Nacional de Acção Social
NGO	Non-governmental organisation
OVC	Orphaned and vulnerable children
PHAST	Participatory Hygiene and Sanitation Transformation
PRA	Participatory Rural Appraisal
TB	Tuberculosis
SC UK	Save the Children United Kingdom

Table of Contents

Acknowledgements	1
List of Abbreviations	2
I. Introduction	4
II. Objectives of the Study	4
III. Background on Morrumbala Centre	5
IV. Study Design	6
V. Results	9
A. Difficulties faced by different household members, including children, during various stages of the illness.	9
B. The role of child members of the family in caring for a sick family member	15
C. Coping mechanisms	16
D. Expectations of HBC services	24
VI. Conclusions and Recommendations	27

I. Introduction

Save the Children UK (SC UK) started working in Mozambique in 1984, placing technical advisors in the Ministry of Health. Over the next ten years, SC UK provided technical assistance and financial support in infrastructure, epidemiology, nutrition, immunization, health information systems and information and emergency response.

The current focus of SC UK's long-term development work is improving the quality and quantity of basic health services, reducing food insecurity, advocating for children's rights, responding to the HIV/AIDS epidemic and emergency preparedness.

There are currently an estimated 420 000 orphans living in Mozambique. SC UK, with its Alliance partners SC Norway and US, initiated its first focused intervention on the issues of orphans and vulnerable children (OVC) in the context of the prevalent HIV environment in Mozambique with a 6-month pilot programme in July 2002. The pilot programme addressed various issues in relation to both learning and response to the needs of orphans and vulnerable children in the 4 provinces¹ of Mozambique.

As a component of SC UK's on-going OVC work, home-based care has been identified as a key entry point to access vulnerable children and to provide support to terminally ill parents. It is anticipated that SC UK together with Red Cross-Mozambique (CVM) will launch a home-based care (HBC) project in the District of Morrumbala, Zambézia Province, during 2003. In order to effectively respond to the needs of the family and understand the current coping mechanisms in the community, a home-based care study was conducted in Morrumbala Centre from 1-15 September 2003. The following report elaborates the findings of this study.

II. Objectives of the Study

The study used an intra-household approach to examine family responses to prolonged illnesses. The study also examined community-level responses to families with prolonged illnesses. The study addressed the following 3 general topics:

1. What are the experiences of family members, particularly children, in a household with a chronically ill caretaker?
2. What are the coping mechanisms within the household of a chronically ill family member and what services exist for HBC in the community?
3. What are the expectations of household members and the community from external actors in relation to HBC?

¹ Gaza, Sofala, Manica, Zambezia.

Within these general topics, the study explored the following specific topics:

1. Affects of chronic illness within the household
 - a) What are the difficulties (financial, emotional, and social) faced by different household members, including children, at various stages of a principal caretaker's illness (initial phase, interim phase, death)?
 - b) What is the role of children in caring for sick family members at different phases of the principal caretaker's illness (taking into consideration differences in age and gender among children).
2. Coping mechanisms of illness
 - a) What support mechanisms exist within the family, including support from the extended family, to care for sick family members?
 - b) Are there currently any formal or informal HBC systems in place in the community beyond the immediate or extended family mechanisms? (Including religious leaders, traditional healers, etc.)?
 - c) What are the indicators that households are showing signs of extreme stress (selling of property, pulling children out of school, etc.)?
 - d) What are the differences in coping with long-term illnesses over recent years as opposed to coping with long-term illnesses in the past?
3. What are the expectations of HBC services?
 - a) What do family members (men, women, boys and girls) expect from government, churches, NGOs, CBOs, traditional healers, etc. for home-based care services?
 - b) What are the links being made by households with a chronically ill family member and communities between chronic illness and HIV/AIDS?

III. Background on Morrumbala Centre

Morrumbala Centre is the Administrative and commercial centre of the District of Morrumbala located 220km west of the Zambézia provincial capital of Quelimane. The District of Morrumbala has a population of 331,605 habitants, 51,130 of whom live in Morrumbala Centre. During the civil war, Morrumbala centre was occupied by the Renamo armed forces. During the armed conflict, many of the Morrumbala residents fled to Malawi and stayed there until the end of the civil war. Today a great deal of movement still occurs between Morrumbala and Malawi as local merchants buy their products in Malawi.

In relation to infrastructure, Morrumbala Centre has 6 schools in total, which include 2 primary schools, 2 middle schools, 1 high school, and one trade school. One health centre services all of the barrios and people also seek treatment from traditional healers. Forty (40) health councils exist in the district that is comprised of a total of 565 volunteer community health activists and Morrumbala Centre also has a group of these activists. Morrumbala Centre has one public radio-

based telephone system. The Centre also has radio and television access, and Morrumbala Centre's electricity is currently run by generator for certain hours of the day. The Centre was scheduled to be linked up to the Cora Bassa Dam on 25 September 2003.

Morrumbala has 2 central markets and a private sector cotton factory, Agrimo. Residents produce cotton and chilli peppers as marketable products for income. They also produce maize, beans, sorghum, cassava and vegetables, mostly for subsistence purposes. Morrumbala has a commercial sector as well with merchants buying their products from Malawi and Beira, creating a great deal of movement between countries and provincial borders.

Morrumbala Centre is divided into 13 zones (barrios). Each barrio has a hierarchical political structure. The barrios are overseen by a local secretary. A sub-chief is then in charge of blocks of houses, and another sub-chief has responsibility for 10 houses. The secretaries of the barrios receive 15% of taxes they are able to collect. Community courts still operate in the barrios to resolve problems between residents.

Morrumbala Centre is a very Christian area. Forty-five (45) different churches exist in the 13 barrios, and one Catholic Church is located in the Centre itself. One mosque serves the Muslim population.

The Sena are the major ethnic group in Morrumbala Centre. The Sena follow a patriarchal lineage and practice initiation ceremonies for both boys and girls.

The Province of Zambézia has an HIV prevalence rate of 12.5% according to the National Department of Health. Forty-six (46) cases of HIV/AIDS were confirmed between January and August of 2003 in Morrumbala Centre. The health centre staff interviewed stated that they did not have statistics on the number of people with AIDS, but they confirmed that such cases existed.

IV. Study Design

Sample

To meet the objectives of the study of examining the intra household experiences with a chronically ill caretaker, the following target groups were identified to participate in the study:

- Orphaned children whose parents had died of a prolonged illness
- Children whose parents currently have a prolonged illness
- Chronically ill caretakers
- Spouse of chronically caretaker or other adult family member who is caring for the patient

The barrio secretaries and the barrio community workers for the National Institute of Social Action (INAS) assisted in the identification of chronically ill caretakers, their family members and orphaned children whose mother, father or both parents had died of a prolonged illness. A chronically ill person was identified as someone who had been sick for a year or more, with a continuing pattern of falling ill, recuperating for a short period after seeking treatment and falling ill again. Some villagers who had been treated for tuberculosis (TB) but remained ill were also included because of the strong link between TB and HIV. The sample did not include people with leprosy, asthma, or some other type of disability. The specified target groups lived in 10 of the 13 barrios, covering the different geographic areas of Morrumbala Centre. The following table shows the breakdown of the target groups interviewed.

Target group	No. of participants		Total
	Masculine	Feminine	
Orphaned children 8-12 years old	24	21	45
Orphaned children 13-18 years old	13	11	24
Children currently looking after a ill caretaker 8-12 years old	2	2	4
Spouses of chronically ill or other adult family member	7	15	22
Chronically ill caretaker	4	11	15
Total	50	60	110

The sample size of children currently caring for a chronically ill caretaker is quite small, as a majority of the ill caretakers had children too young to be interviewed or did not have any children, and there were no children in 13-18 year old category. Other adult family members were caring for most of the chronically ill patients. Whenever possible, the groups of children were divided into smaller groups based on their ages and sex, and the adults were split into groups according to their sex to promote maximum participation.

In addition to conducting interviews with household members mentioned above, the following community groups were identified to provide information on the care of chronically ill people in Morrumbala Centre.

Target group	No. of participants		Total
	Masculine	Feminine	
Neighbours of the chronically ill	3	1	4
Religious leaders	23	6	29
Volunteer community health activists	10	14	24
Barrio secretaries and INAS staff	13	1	14
Staff of health centre	2	1	3
Traditional healers/birth attendants	5	6	11
Teachers	4	6	10
Total	60	35	95

Individual interviews were conducted with other relevant stakeholders as well. These included:

- The District Administrator of Morrumbala
- The District Director of Health
- The District Director of Social Action
- A representative from the District HIV/AIDS Nucleus
- World Vision-Manager of the Child Sponsorship Programme

Methodologies:

The research study was a qualitative study using 3 qualitative research methodologies.

- Participatory techniques
- Semi-structured focus group discussions
- Semi-structured individual interviews

Family members of a chronically ill person and orphaned children discussed their experiences through the use of participatory techniques adapted from Participatory Rural Appraisal (PRA) tools and PHAST (Participatory Hygiene and Sanitation Transformation)². Children, in addition, drew pictures and performed dramas to provoke discussions around their experiences. The tools provoked discussions around:

- Illnesses in the community
- Prolonged illnesses in their homes

² A set of participatory research techniques using drawings to illustrate a story and understand where people go for treatment.

- The causes of these illnesses
- The difficulties families faced when they had a family member with a prolonged illness
- The type of support they received from within and outside the family
- What other types of assistance and support they needed in caring for a chronically ill family member



1.1 Children in a focus group discussion

The other key community members groups participated in semi-structured focus group discussions to understand their roles in assisting chronically ill patients and to hear their opinions about the particular difficulties families of the chronically ill faced in the community.

When possible, chronically ill patients gave individual interviews about their illnesses, the difficulties they faced, the type of care they have been receiving and other types of assistance they felt they needed to receive in relation to HBC.

The topic of illness in the family was approached with children in a very sensitive manner. Instead of direct interview questions, games and drawings were used to introduce questions of chronic illness in the home. The use of sensitive language was ensured to allow children to feel comfortable in opening up about their experiences.

V. Results

A. Difficulties faced by different household members, including children, during various stages of the illness.

All family members and the chronically ill patients experienced emotional, financial and social difficulties. Children of all ages had difficulty differentiating between the various stages of their parents' illness. These children constantly made comparisons between when their parents were healthy and when they were ill. Adults spoke of the initial phase of the illness and as the illness became prolonged.

Emotional difficulties

The children interviewed between the ages of 8 and 12 expressed a great deal of worry when one of their parents was sick and brought out a great deal of stress and insecurity surrounding their futures. As one child stated, "*When my father became sick, I imagined he would die and we would suffer*". Another child stated when talking about his sick mother, "*I thought my father would marry another woman, and we wouldn't be taken care of well*".

The children also expressed great sadness when talking about their parents' conditions. The mood during the group discussions changed when discussions became more centred around their parents directly. The children became noticeably quieter and the mood in the room more sombre. A group of young boys demonstrated their level of sadness through a drama they performed. The drama showed a boy bringing food to his father in the hospital. The boy brought food twice and during the second visit, his father died, the boy started crying and then went over to the group of boys, representing the family. All of the boys started to hug and cry loudly and they all crowded around the "dead father" and continued to wail loudly.

The children between the ages of 13 and 18 also showed a great deal of sadness, as some children had tears in their eyes while talking about how they cared for their ill parent, but they difficulty in verbally expressing these emotions. These older children carried more responsibility in the home when one of their parents was ill; hence they also felt more anxious about how their family would survive. "*I was really worried about my family, and I spent a lot of time thinking to myself, what can I do?*" Older children also felt discriminated against by both their neighbours and their fellow classmates at school. One young girl expressed anger at the lack of help by her neighbours. She stated, "*Neighbours detest people in a chronically ill state.*" Other children stated how they are teased at school for not being clean, lack of clothing, and lack of school material.



1.2 Youth in a focus group discussion

The teachers interviewed also mentioned that they had noticed a difference in some children's behaviour at school. They noticed that the children appeared sad and withdrawn. The teachers then learned that the child has a chronically ill parent in the home when asked what was wrong. The Director of one of the primary schools stated that he thinks it is necessary for these children to receive psychological assistance because they are unable to perform well in school when they have problems at home. He believes that the children are physically present at the school but are not psychologically present.

The adult caretakers of the chronically ill patient in the home experience emotional difficulties as well and struggled to speak openly about their feelings. One woman said that she felt too emotional to explain all the difficulties she has gone through when someone sick doesn't get better. The other women in the group agreed, giving a sense of the despair they felt about the situations they currently face. One female adult caretaker expressed hurt and anger over neighbours speaking badly about her family. Two women stated how neighbours said that their daughters "are whores and contracted AIDS".

The chronically ill patients constantly spoke about how they had been able to provide for their families before they became ill. Now they had to depend on other family members for their livelihoods and survival. Several of the patients appeared demoralized that they could no longer sustain their families and were dependent on others to care for and provide for their families' survival.

Importantly, the chronically ill also spoke of neighbours and extended family members only visiting them or assisting them in the initial phase of the illness, but as the illness has been prolonged they no longer visit or help, leaving the patient not only without assistance but feeling extremely isolated.

Financial difficulties

Having a chronically ill caretaker in the household brings difficult financial consequences for the whole family. As one of the traditional healers stated *“When you have someone sick in the house, poverty has already entered”*. From the various discussions with family members and the chronically ill, the financial safety net is already weak and fragile but often totally collapses if an illness is prolonged. In the initial phase of the illness, families are able to cope with the financial strains of the illness because they may have money saved, a surplus of agricultural products or animals that they can sell. According to the family members, and the community leaders, the initial phase is also the time when the extended family, community members and neighbours contribute financially or in kind.

During the intermediate and final phases of the illness, families struggle to survive. Agricultural production has been reduced or is non-existent because family members are unable to work in their fields, and all of their initial resources have been used up in seeking treatment for the sick family member. These financial problems are reflected in the following statements by the chronically ill and their family members:

“Before I was sick, I went to my fields to produce products to sell; now I don’t produce anything. I can’t do any work. My granddaughter helps me with small work.”

“We have serious problems with our fields; we don’t have food and we don’t have money to buy soap.”

“In the beginning my husband had money but after all the costs we had to sell things in our house and our agricultural products when the situation became worse.”

Several families spoke of how they had sold all of their animals to go to traditional healers for various ceremonies to be healed. One woman said, *“In the beginning we had things to sell (goats) to go to the traditional healer, but now we have nothing, no clothes, no money”*. As a result, families must find other means to survive.

For all of the children interviewed, between 8 to 18 years old, the financial consequences translate into the lack of basic necessities in the home. Children spoke of the lack of money in the home, which then led to the lack of clothing, lack of food, lack of soap, and lack of school materials. Smaller children between 8 and 12 made comparisons before their parent fell sick. *“Before we used to eat well with different kinds of food, rice, bean xima, now we only eat xima. Younger children also mentioned how all the resources go to the sick person leaving them without food and clothes.*

Older children also spoke of the same lack of basic necessities but they also spoke of the lack of school materials, which was a large preoccupation for them.

The chronically ill patients spoke of the lack of basic necessities as well. They stated that they did not have money, clothes, adequate food, or a proper roof over their house. Many of the patients mentioned that they need more nutritious food to help them get better but because they could not work in their fields and did not have any money, they did not have access to more nutritious food. Patients also said that they did not have money to go to the hospital and couldn't buy medicine. However, the District Director of Health, the health centre personnel, and the INAS community workers confirmed that at the health centre, treatment for the chronically ill is free of charge. Importantly, this gap between stated government policy and household level perceptions of health care fees could undermine chronically ill people from getting better.

Social difficulties

Each member of the household experienced different social problems, including isolation from neighbours and friends, having to leave school, no time for rest or play and spousal abandonment. These difficulties occurred mostly during the intermediate and final phases of the prolonged illness.

Many children left school when during the final phase of their parent's illness because they had to care for the patient at home or in the hospital. For example, one 14-year-old girl left school and cared for her mother in the hospital. She took care of all of her mother's needs, including sleeping at the hospital with her, until her mother's death. Those children, able to continue schooling said that other children teased them because of their dirty clothing, lack of shoes and lack of school material.



1.3 Children in a focus group discussion

Children from 10 to 18 years old spoke that they had no time to play anymore because of the amount of work they had at home. Children of 8 and 9 said that they helped with domestic chores but that they still had time to play.

Adult women caring for a chronically ill spouse or other family member spoke about how their daily routines had completely changed. Currently all of their work revolved around caring for their sick family member. In the past, women often had some free time in the afternoon to rest or visit friends. Now, that time no longer exists. One woman stated *“We don’t have time to rest - when you have a sick person in the house, you always have to do something for them”*.

Women also spoke of social stigma. Neighbours no longer passed by or only briefly greet them at times. Some of the volunteer community health activists confirmed this lack of support by neighbours. They stated that people stop passing by because they see that the illness is prolonged and they become afraid that if they visit the house they can contract the same illness. These women also stated that friends no longer passed by which created feelings of resentment. As one woman stated *“Friends want you when things are going well, but they don’t show up when you have someone sick at home”*.

Men caring for a chronically ill spouse or other family member did not mention the same social problems. Although they play a large role in caring for the patient, they still have time to themselves and time to do things outside of the home. However, the women’s group and the group of female church leaders felt that a man caring for a chronically ill wife experienced more difficulties than a woman caring for a chronically ill man. The reason is that the man has to do a great deal of domestic work that he is unaccustomed to, which subsequently creates more difficulties.

The chronically ill feel the same isolation from friends and neighbours but also from extended family members who no longer visit and assist the family.

In addition, the illness can cause conflicts within the family. One child gave an example of how his father's illness caused a conflict because the family was trying to figure out "who was trying to kill his father" (witchcraft) and accusing one another.

Their respective spouses had abandoned some of the chronically ill patients interviewed. One woman stated that her husband returned her to her father's home when she became ill. A bride price known as labola is paid for women in Morrumbala which may lead to this abandonment of women because the husband is "not getting his money's worth" if his wife is sick. As one chronically ill young woman stated,

"I started becoming ill after I got married and was living at my husband's home. My husband took me back to my father's home. My father took me to the hospital and after receiving treatment I became better. My husband then came back and took me back to his home. I became pregnant but I had a miscarriage and became weak and thin. My husband took me back to my father's house once again. My father sometimes gives me money to go to the hospital, but he drinks a lot. My sister is taking care of me."

A man said that he could no longer stay with his wife when he was sick because she had been with other men. In other instances, chronically ill women encourage men to find another wife so that he does not have the burden of all the work and also so that her children are looked after in the future.

None of the immediate family members are immune to the difficulties a prolonged illness brings into the family. Each member experiences a lack of basic necessities and the isolation from their wider community. Financial worries and isolation lead to emotions of feeling extremely worried, frustrated, sad and angry from the lack of support.

B. The role of child members of the family in caring for a sick family member

Children play a significant role in caring for a sick family member as well as assuming responsibility for the domestic work in the house. The roles and responsibilities of the child depend on the circumstances in the home, whether there is another adult caretaker, or an older or female sibling. Children of 8 and 9 years old spoke of assisting in some household activities like fetching water. These younger children said they still had time to play and do very little

caretaking of the sick family member because they had an older sibling who took on these responsibilities.

Children from the age of 12 and older spoke about the increase in their responsibilities in the home. These responsibilities included taking care of the chronically ill person, domestic work and if necessary looking after younger siblings. Older children assumed greater responsibility if no other adult caretaker existed in the home, or if this other caretaker was quite elderly. If both male and female siblings live in the household, their responsibilities are divided along gender roles. Girls generally take on the following domestic chores:

- Fetching water
- Cooking
- Washing clothes
- Caring for younger siblings
- Cleaning the house
- Pounding maize or taking it to the mill
- Fetching wood

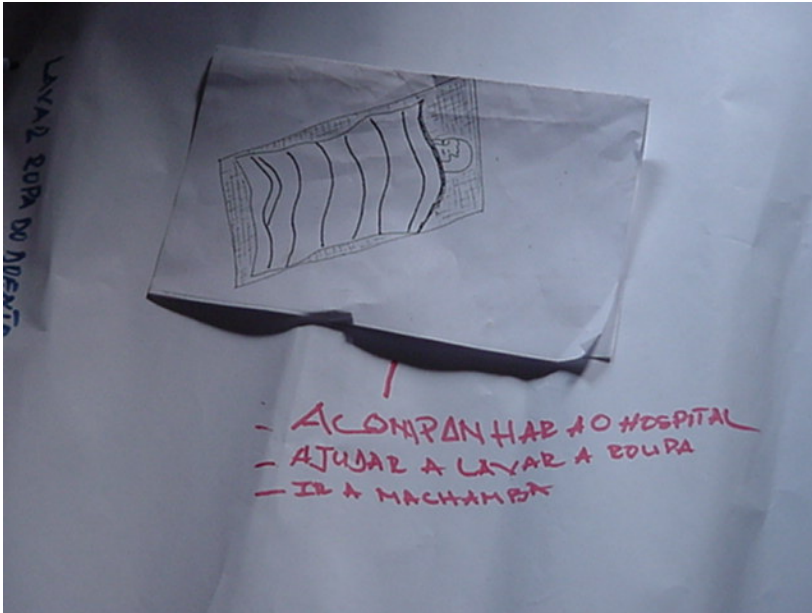
Boys generally take on other responsibilities such as:

- Going to the fields
- Taking food to the hospital
- Piecework to earn money
- Fetching wood

Boys do all of the domestic chores that have been more stereotypically done by girls if no female siblings live in the home. In addition to the necessary domestic work that must be completed on a daily basis, older children (both male and female depending on the circumstances in the home as mentioned above) assist the chronically ill patient in the following ways.

- Cook and feed them porridge
- Change and wash their clothes
- Wash sheets
- Give them a bath
- Sit by them and attend to any need they have
- Sleep close to them
- Take food and water to them in the hospital
- Give them medicine
- Attend to their needs while admitted in the hospital

The impact of these increased responsibilities on the children as mentioned earlier is that they no longer had time to play, they often abandoned school to care for their family member in the home or in the hospital, and according to the community health workers working for the district directorate of health, these children become very tired, do not have enough to eat and as a result eventually do not have the strength to work in the home.



1.4 Children's drawing: Children's role in caretaking

C. Coping mechanisms

Immediate and extended family

The family of the chronically ill patient engage in several coping strategies necessary for the family to survive and to care for their sick family member. These strategies include piecework, smaller scale agricultural production, and selling household products

According to children, they often find piecework, known as "ganho-ganho" to earn money or to be paid in kind to sustain their sick family member and to meet the basic needs for themselves and their family members. Boys stated that they sold diesel at the end of the day to earn money, while girls sold tomatoes. "Ganho-ganho" was not limited to children. Some other adult family members cut and sold wood or grass to earn money. One chronically ill young woman, in an intermediate phase of her illness, also does odd jobs for her neighbours when she has enough strength to earn food or money to help sustain her family.



1.5 Adults in focus group discussions

Other adult family member also stated that as the illness became prolonged, they had to sell their animals and all of the maize from their silo to take care of their chronically ill family member. Some families had the human and material resources to continue working on their fields. However, all these families mentioned that their agricultural production had been reduced due to the lack of manpower and time they could spend in their fields. Other families spoke about having small fields in their homes to produce vegetables, which also contribute to the families' survival.

Some families had accessed the government services that can also assist them. These included receiving free treatment at the hospital and accessing the small subsidy (32.000 Mt/month=\$1.30 USD)³ available through INAS for the elderly and the chronically ill, although this is in fact rare. Only one chronically ill young woman and two chronically ill elderly women had accessed the INAS subsidy out of the 15 people interviewed. A majority of the chronically ill also mentioned that they did not have money to go to the hospital, indicating once again that people had very little access to the information that they could receive free treatment at the hospital and apply to receive funds from INAS.

Extended family members played a role in supporting the chronically ill patient according to the group discussions with the children. Family members who offer help depend upon the relationship to the ill person. In the case of women, sisters usually aid the ill person. In the case of men, brothers are usually the caretakers. However, aunts, uncles, mothers, and other family members were said to help. The type of assistance from extended family members included:

- Washing the sick person's clothes
- Preparing food

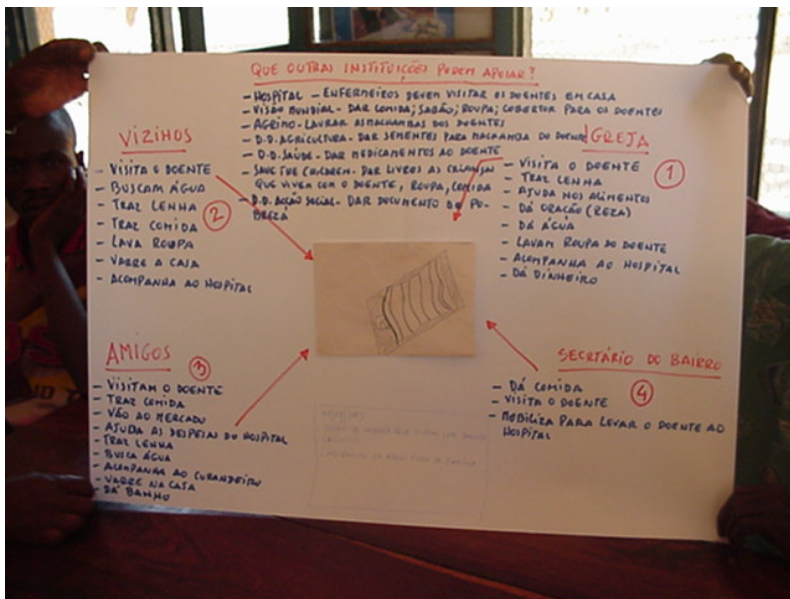
³ Although this amount is available, the process to receive the subsidy is extremely complicated and inaccessible to the most poor.

- Fetching water
- Looking after the person while in the hospital
- Bringing maize flour to the family
- Bringing money to the family
- Taking the sick person to the traditional healer or the hospital

However, this extended family support only occurred in the beginning of the illness according to the other adult caretakers and the chronically ill patients themselves. Barrio secretaries, INAS community workers and neighbours confirmed this information stating that family members become tired of helping when they do not see the ill person improving at all and, after they reduce support they soon do not come to visit at all. In contrast, the children's groups said that the extended family provided more support to the ill person than other community groups such as neighbours and church members.

External support mechanism

Beyond the immediate and extended family, no formal HBC systems exist in Morrumbala Centre. Neighbours, churches and the local barrio leadership provide informal support. Patients may receive treatment from traditional healers or have been initially visited by volunteer community health activists.



1.6 Identification of support mechanisms by adults

Neighbours

Support from neighbours is a contested issue and depends on the relationship between neighbours. Simply being a neighbour to a chronically ill person does not necessarily guarantee support. On the afternoon scheduled to hold focus group discussions with neighbours of the chronically ill patient, only 4 neighbours arrived to participate in the discussion, demonstrating a lack of interest by the neighbours. Yet children always mentioned neighbours as providing assistance

to ill family members. They said that neighbours assisted with domestic chores such as washing clothes, washing dishes, fetching water, cooking, and sweeping the yard. One young girl, in disagreement, stated that the neighbours did not help and stated “neighbours detest sick people in a chronic state”.

The women’s group of adult caretakers supported this idea that neighbours did not help them at all. Instead, neighbours spoke badly about the household and the sick family member. Several of the chronically ill patients said that the neighbours helped in the beginning but as the illness progressed they no longer supported or assisted them. Several others stated that the neighbours did not help them at all.

This information conflicts with the information from the children. This contradictory information can be explained in a number of ways. To begin, the children had trouble differentiating between phases of the illness, so the neighbours may have only assisted in the beginning, but the children remembered their support. On the other hand, the chronically ill and their adult caretakers are in a desperate situation, so they felt the need to portray their situation in as dire a manner as possible. The chronically ill possibly feared that if they said neighbours were assisting them they would not receive further support from an outside source.

One example demonstrates this clearly. A chronically ill woman who was interviewed stated that the neighbours did not help her or her children at all. At that same moment, the interviewer noticed her child returning from the neighbour’s house with a full plate of cooked cassava to eat.

The 4 neighbours who showed up for the focus group discussion stated that they are helping their chronically ill neighbours with domestic chores, some money and counselling them at times about their illness and how to manage the resources that still existed in the household. The neighbours say that it is they who are helping the chronically ill because the extended family has reduced their support.

Neighbour support, therefore, is most likely variable depending on the relationship between neighbours, and the neighbours’ willingness and ability to help.

Churches

As mentioned earlier, Morrumbala Centre is a very Christian area. Forty-five (45) churches exist in the 13 barrios and the Catholic Church is in the Centre. One mosque serves the Muslim population.

Church leaders/pastors stated that their church policies include helping the chronically ill, but in practice the churches have difficulty in assisting the

chronically ill because of a lack of resources. Their congregations are also poor and church members can offer only small amounts of money and maize flour as their donation to the church. Individual members of the church offer families' support by bringing wood, fetching water, washing clothes and praying together according to church leaders. The pastor will take the sick person into his house and take care of him in cases where the family has completely abandoned a chronically ill person. Each church also has women's Bible study groups who have weekly meetings to study together and talk about their lives. They also have responsibilities to visit the chronically ill in their homes or in the hospital.



1.7 Meeting with community leaders

Church leaders also stated that their church members have the right to go to any house to offer assistance, although the chronically ill patients interviewed stated that church assistance is only going to church members at this time.

The Catholic Church does not have a specific programme for assisting the chronically ill either. However, Catholic Church members do go to the hospital and give poorer patients 200,000 MT. The priest feels that people need to be trained in HBC to assist the chronically ill and their families both materially and spiritually. He stated that the Catholic Church could indirectly help with food, clothing and other things.

The research team was unable to speak with the Imam of the local mosque to find out what type of assistance they give the chronically ill.

The various churches could be a good resource for a formal HBC programme. The church leaders stated that they have a Pastor Nucleus where the pastors gather and discuss problems in their churches. They said that they have never discussed the issue of the chronically ill in their community, but now feel that it is

something they need to consider. Both the pastors and the women interviewed from the from the women's Bible study groups said that churches could hold a meeting with all of the church representatives to debate the issue about assisting the chronically ill in their homes, and these representatives could then identify people from within their congregations who would like to be involved in this work. However, these women stated that each group of church members would have to work in separate groups because each church has its own principles, policies and ways of working which would make it difficult for them to work in one large group. They said that if money is involved, it always creates more problems.

Local barrio structures

The local barrio structures as well provide informal support to the chronically ill in their areas. The local chiefs responsible for certain blocks of houses have monthly meetings with community members to discuss which houses are experiencing difficulties. People from the community then give the chief food or money to help the family, and the chief gives this to the family experiencing difficulty on behalf of the community. The secretaries confirmed that a majority of this assistance occurs in the beginning of an illness but later on people are tired of assisting because they themselves also do not have a great deal of money.

The barrio secretaries also help with documentation for families to give to the Department of Social Action so that they can receive free treatment at the hospital. Secretaries also go to the hospital and organize an ambulance when needed.

Traditional healers

A majority of the chronically ill patients interviewed stated that they had sought treatment from traditional healers at some point during their illness. The cost of treatment by traditional healers varies, with some charging cash payment while others charging nothing in the hopes that the family will repay through other means as thanks for their services. Two chronically ill patients spoke about selling all of their animals to pay for ceremonies performed by traditional healers. Although traditional healers provide a great deal of treatment to the chronically ill, they rarely provide care in the home. The traditional healers said they were unable to provide care in the home because they do not personally know a majority of their patients. Patients that they do personally know they will treat in their homes, and other times they ask patients to change houses while they are receiving treatment so that the traditional healer can ensure that the person is complying with the treatment prescribed. For example, if a patient has been instructed not to have sexual relations for a month, it is difficult for this person to comply if they are living in the same house with their spouse.

The traditional healers stated that they couldn't leave a person without some form of treatment when they serviced a chronically ill person but did not have a

cure for their particular disease. In these circumstances the traditional healers experiment with different types of medicine in the hopes that they will either find a cure or reduce the pain the patient is encountering.

In other circumstances, traditional healers who cannot cure a patient will refer that patient to another traditional healer who he thinks may be able to help. The patient is then advised to go to the hospital if that traditional healer does not succeed.

When asked about treating people who cannot afford to pay, the traditional healers stated that they never turn a person away who cannot pay because they “work through the spirits and within each person exists spirits”. The traditional healers also said that if a person who was unable to pay becomes better, they would remember the traditional healer and bring him something to thank him later on.

Other traditional healers said that sometimes they do charge in advance of providing treatment because often patients receive treatment from themselves and from the hospital at the same time. When the patient improves, he says that the “hospital cured him” and the traditional healer is forgotten and receives nothing.

The traditional healers said that to improve care for the chronically ill in their homes, the Department of Health needs to collaborate with AMETRAMO (Association of Traditional Healers) to reduce illnesses. AMETRAMO also needs help from the Department of Health with providing transport and a house to treat patients. These requests appear to have more to do with assisting the traditional healers themselves than the chronically ill.

Community health activists

The health council has several community health activists in the barrios and outlying villages. These activists do weekly visits in the barrios. Each activist is responsible for 10 houses. When they find that someone is ill, they initially provide basic first aid and if needed, they advise that person to seek treatment at the hospital, or they take them to the hospital themselves. The activists also provide education to the households regarding hygiene involving water and sanitation, malaria, prenatal consults, and nutrition for pregnant women. Although these community health workers do not provide any formal care to the chronically ill, they are a useful resource in the community who could inform a HBC team about the chronically ill in their areas and the difficulties they are facing. Some of these activists could also be recruited to perform home-based care because of their previous training in first-aid and hygiene practices.

Currently, unconnected and informal systems exist within the community that could be utilised in providing or assisting with a formal HBC system.

Collaboration with churches is required to look into the different type of assistance/support they could provide either as a holistic group or as separate entities. Volunteer community health activists could be part of a formal HBC team due to their former training and experience in first aid and basic hygiene promotion.

Signs of extreme stress in the household

As mentioned earlier, families receive assistance from their extended family and community members during the initial phases of the illness. As the illness continues, support falls away and families are left to cope on their own. Their agricultural production is down and all resources are going into the care of the chronically ill family member. These conditions can lead to extreme stress in the household, and the families and community group interviewed identified the signs of this stress. The following signs were identified:

- Selling household goods and agricultural products
- Children do not go to school
- Lack of clothing or dirty clothing on children
- Malnutrition in children
- Children living in the street asking for money
- Young children of 6 or 7 trying to find work
- Reduction in meals, 1 meal per day
- “No smoke from the house” meaning they are not cooking due to lack of food
- Weight loss in the other adult caretaker (not the patient)
- Grain storage silo is empty
- House “without a door” seen as a poor, weak house
- Yard and veranda are dirty

The condition of the children appear to be a large indicator of the household difficulties, and at an extreme level, traditional healers mentioned that young girls are driven into prostitution and young boys into theft. The other indicators can be noted in the state of the household, which is dirty and no signs of cooking indicating a lack of food. These indicators are most likely noted during the intermediate and final phases of the illness and it is during this time that the families need the most support instead of the least.

Differences in coping with long-term illnesses now and in the past

All of the community groups interviewed stated that the current response to coping with a prolonged illness is the same as in the past in relation to the immediate family providing care for the chronically ill family member. However, other differences do exist between the situations now and in the past. Firstly, the religious leaders, and professors spoke about how life is much more expensive now and agricultural production is lower than in the past due to floods and

droughts and infertile land. This statement implies that people had more resources in the past to assist a chronically ill person.

Traditional healers, the barrio local leaders, and the community health activists also spoke how life had changed and that people no longer respect the norms, traditions and morals of the past. These include listening to their parents, caring for the ill, and not engaging in the sexual activity that can bring illness into the home. They feel that people no longer look out for one another but only “look out for themselves”. This lack of caring for others sometimes reaches extreme points where a chronically ill person is completely abandoned.

The barrio secretaries also mentioned that in the past people lived in the same yard or compound with their extended family. Now people live in a dispersed manner, which results in a lack of pooling of human and material resources to support the chronically ill person. The secretaries also stated that these prolonged illnesses were very rare in the past but are much more common now.

Finally, barrio secretaries and community health activists argued that, in the past, people received proper and effective medical treatment for illnesses from the hospital where as now they do not receive proper treatment.

Dispersed settlements, reduced resources and a more selfish attitude have translated into a situation where the chronically ill are left with very little support outside of the immediate family.

D. Expectations of HBC services

The chronically ill patients and their family members identified various needs they deemed important for HBC services. The chronically ill stated they need nutritious food to help them recuperate. In addition, they requested other basic necessities such as clothes, soap, and a roof for their house or a covered area where they can sleep outside. They also want help with their children’s education, registration and school materials. The chronically ill also requested for the Department of Health to grant them free treatment at the health centre, and to receive improved treatment.



A majority of the chronically ill patients had difficulty identifying who could provide this type of assistance. Several said that they had been sick for so long and no one had ever visited them or asked what they had needed. Therefore, a majority of the chronically ill stated that “the people doing this research” could provide this assistance.

Adult male caretakers also spoke of the need for the basic necessities of food, clothes, soap and that the NGOs working in the area such as World Vision and SC UK could provide these necessities. These men also want assistance from various government departments. They would like the Department of Health to provide nurses from the health centre to visit the ill in their homes and to provide free treatment. In addition, they would like the Department of Agriculture to provide them with seeds for their fields, and the Department of Social Action to give them “poverty status” so that they are eligible to receive a subsidy from the Department. They would also like the private sector company, AGRIMO, to assist them by clearing their fields so that they can plant food.

The female adult caretakers also spoke of churches and NGOs providing the same basic necessities mentioned above, as well as spending time visiting the chronically ill. These women also mentioned the health centre providing free treatment and the Department of Social Action providing money for the patient.

All of the groups of children had difficulties defining additional support for chronically ill caretakers. The children mentioned that the traditional healers and the nurses need to give better types of medicine to the patient. The tone in which the children spoke about this implied that orphaned children felt their parents could have survived if the right medicine had been given to them.

One of the community health activists, who are also a Village Headman in the area, wanted to know what would be done for the orphaned children whose parent died of a prolonged illness. He also stated that “we have given you a lot of information; you can’t just take it and throw it in a drawer or go or burn it and do nothing”.

Now that the research has been completed, people in the community and with chronically ill family members are hoping for something to come out of this process that will help the chronically ill and their families.

The link between chronic illness and HIV/AIDS

Throughout the research process, community members and the chronically ill and their family members spoke very little about HIV/AIDS. When speaking about general illnesses in the community, all the groups of children and family members mentioned AIDS. Yet when speaking about the causes of the illnesses that their respective family members suffered from, the responses always included a list of the signs and symptoms, and people stating that they did not know the cause of these signs and symptoms. Many of the signs and symptoms were similar to AIDS such as weight loss, diarrhoea and vomiting, swollen legs, herpes and abscesses all over the body. Some of the adolescents spoke about HIV/AIDS when they described general illnesses in their communities, and one young girl wrote on a piece of paper that her mother had died of AIDS.

Church leaders, women's religious groups, neighbours, and community health activists stated that the causes of these illnesses was due to sexual relations with several people, mostly by people who travelled a great deal between the different provinces and into other countries. None of these groups mentioned HIV/AIDS directly.

The traditional healers stated that people no longer performing ceremonies nor following traditions caused these illnesses.

One illness that all groups spoke about was "M'pepo". M'pepo is an illness that is caused when a young girl has an abortion and does not inform her family. She then infects her parents by putting salt in their food or sharing a plate of food with them. She infects any man she has sexual relations with who then in turn can infect others through sexual relations. M'pepo carries the same symptoms as AIDS, carries some stigma because people are afraid to enter the house because they think they can catch M'pepo, and people blame young women for this disease. One female traditional healer stated that women provoke these illnesses because of their sexual behaviour. When asked what difference existed between M'pepo and AIDS, one of the female caretakers said it is the same thing. However another woman said the M'pepo has a cure and AIDS does not. Several other participants in various discussions stated that M'pepe has a cure. One traditional healer stated that M'pepo could be treated only if the young girl admits to having an abortion immediately, and a ceremony is performed. If this does not happen immediately after the abortion, M'pepo cannot be cured. Despite the clarification that M'pepo can only be cured if the young woman admits to an abortion immediately by one of the traditional healers, a majority of

the people we spoke with stated that M'pepo has a cure whereas people stated that AIDS does not have a cure.

M'pepo may be easier for people to speak about for several reasons. Firstly, the responsibility for contracting M'pepo falls on a young girl having an abortion whereas a person (man or woman) has to take personal responsibility for contracting HIV.

Hence, the chronically ill and their family members do not want to admit they have AIDS, because that means they are admitting that the person will die. M'pepo is also a cultural way to prevent youth in engaging in sexual relations or for young girls to seek abortions.

With very few people speaking about HIV/AIDS directly beyond stating it as an illness in the community and that it does not have a cure, it is difficult to analyse whether the silence around HIV/AIDS is due to fear, stigma, or lack of complete information about the disease or all of the above.

VI. Conclusions and Recommendations

The results of this qualitative study demonstrate that home-based care services occur at an informal level in the community of Morrumbala Centre. The immediate family carries the main responsibility in caring for a chronically ill family member. Most families have sufficient resources to treat the illness in the initial stages. During these initial stages of the illness, families often receive support from extended family members, church groups, neighbours, and from community donations. This support includes basic necessities such as food, soap and money and assistance with domestic work in the home. However, as the illness progresses, this support falls away. The families' fragile resource safety net is used up and the family experiences difficulties in trying to sustain themselves and their chronically ill family member. During the intermediate and final phases of an illness, agricultural production drops considerably or is non-existent, prior resources in the household have all been used up in caring for the patient, basic necessities become scarce, the family often becomes isolated from the rest of community and extended family members totally abandon the family out of fear, stigma, or exhaustion from helping and seeing no improvement.

Children between the ages of 10 and 18 take on greater domestic responsibilities to assist in the household, including responsibilities in caring for the chronically ill person. Children of these ages also engage in piecework to earn money to sustain the ill family member, the family or for their own necessities such as clothing or schooling material. Children often abandon school during this period because they have too many responsibilities in the home, do not have school materials, or are ridiculed by fellow students for their lack of proper clothing, poor hygiene and lack of school material. These children no longer have time to play,

and are emotionally upset and worried about the situations in their homes and what the future will bring.

Other informal systems of support systems exist in the community, which included the churches, community leaders, and some neighbours. These community members also have limited resources in terms of the amount of support they can give, but they do demonstrate a willingness to support the chronically ill person in the initial phases, but greater work needs to be done in educating community members that a chronically ill person needs support through all the phases of their illness both materially and psychologically.

People with a chronically ill family member can access certain government services. Families can apply for a subsidy through the Department of Social Action. Chronically ill patients have the right to receive free treatment at the health centre. However, the patients and their family members do not have this information, demonstrating the need for better communication about services available and how to access them.

The gaps that exist at the moment include distribution of basic necessities such as nutritious food, clothing, soap, school material for children, a covering for the roof, accessing and receiving medical treatment in the home, and friendly visits to make the chronically ill person and their family feel less isolated within the community. These gaps are consistent with the expectations of the chronically ill patients and their families.

After holding the various focus group discussions with church leaders, community leaders, community volunteer health activists and the various family members, everyone agreed that the chronically ill need more support and they said, "their minds had been opened". Therefore, an environment potentially exists to create a formal HBC system in Morrumbala Centre but it will need to be developed and supported. To create such a system requires a great deal of collaboration between the various actors in the community including government institutions, churches, NGOs, community leaders, community health activists, families of the chronically ill and interested community members.

Based on the findings of the study, the research team makes the following recommendations for HBC programme:

1. It needs to be decided which chronically ill people will be included in HBC services and chronic illness is defined. For example, will these services include the elderly whose illnesses may be related to old age than HIV/AIDS, people with TB, etc.?
2. Assistance for children of the chronically ill need to be included in relation to school registration and material, clothing and psychological counselling.

3. The chronically ill need improved, nutritious food to help them recuperate, basic necessities to maintain good hygiene including soap, water sheets and mats.
4. Assistance with domestic chores to alleviate the pressure on immediate family members so that children can have time to play and adult caretakers time to rest and visit with friends.
5. Free medical treatment in the home.
6. Psychological counselling and support for the chronically ill patient and their family members.
7. HBC needs to be accompanied by an educational programme about STI-HIV/AIDS to better inform the community about HIV/AIDS to and try to end the silence around the issue and tackle stigma.
8. Capacity building training for traditional healers precautions in treating chronically ill patients and in STI-HIV/AIDS.
9. Prepare families for the death of the family members and organizing inheritance in collaboration with the Notary Public and the Department of Social Action.