# Adaptive Strategies and Coping Mechanisms of Families and Communities Affected by HIV/AIDS in Malawi

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"AIDS is clearly a disaster, effectively wiping out developmental gains of the past decades and sabotaging the future", Nelson Mandela, former President of South Africa.

#### Introduction

Ngozi is in her late 30s. She lives in a village in western Rumphi district of northern Malawi. Her husband was in the army and during his career as a soldier he travelled to neighbouring Mozambique several times while his wife stayed at his home village farming. The husband visited her once or twice a year and she received remittances from him. In the early 1990s she started falling sick regularly, became skinny and coughed constantly. Two sons born at this time died at birth. When she gave birth to her last born in 1994 she kept on bleeding for weeks and her condition worsened. In 1993 her husband came back to the village permanently but he fell ill only a few months later and died soon after. Ngozi was pregnant and had four surviving sons. While the wife said that her husband died of drinking bad water and stomach problems, her father in-law believed that his son died of AIDS which he contracted in Mozambique. In the village rumours said that no one would marry a widow suspected of being infected with HIV/AIDS.

For her, life as a widow with five children demanded quite a lot. Her two eldest sons were sent to the capital, Lilongwe, to live with one of her brother in-laws. They visited her once a year during the school holidays. The other three children stayed with her but they often ate with her father in-law or one of her brothers in-law. She continued to cultivate the land but had not been able to harvest sufficient maize for several years due to her illness. Her two remaining sons assist her but they are too young to do all the work and still go to school. The wives of her husband's brothers support her from time to time. Also, she has spent a lot of money seeking help from traditional healers and hospitals. Though her children are being taken care of by her late husband's family, she is forced to keep on working on the land, pounding maize and fetching water for the household. While her father in-law says that she is free to go permanently and stay with her family, she does not want to do that as it means leaving behind her children as they belong to the husband's family (Mastwijk, 1999).

This is one of many stories of the impacts of HIV/AIDS illness and death and of the coping mechanisms of households and families to adopt to the changes caused by the pandemic. Food security is compromised, income is lost, assets are sold, and children are dispersed. During periods of illness, Ngozi (and others like her) get some support from the wives of her late husband's brothers as well as from her own family which has even paid some of her hospital bills. The existence of these kinship relations in Malawian societies tends to cushion the economic and social shocks brought about by HIV/AIDS-related illnesses and death. The HIV/AIDS pandemic places tremendous strains on households and communities to care for those who are chronically ill as well as the orphans and the elderly. This paper looks at some of the coping mechanisms seen within Malawian families and communities as they respond to the HIV/AIDS pandemic.

HIV/AIDS in Malawi is overwhelming. With an HIV prevalence rate of 14 per cent in the economically productive age group of 15-49 years, Malawi is one of the countries most affected by HIV/AIDS in the world<sup>1</sup>. The first case of AIDS was diagnosed in 1985. In the mid-1980s 2 per cent of pregnant women attending antenatal clinics were HIV infected; in less than two decades an estimated 35 per cent of pregnant women were infected (Kalipeni, 2001). According to the National AIDS Control Programme the prevalence of HIV in the economically productive age group is estimated at 26 per cent in the urban areas and 12 per cent in the rural areas. In the same age group, the prevalence of HIV in the northern region is estimated at 9 per cent, 11 per cent in the central region and 18 per cent in the south (Strategic Planning Unit and National AIDS Control Programme, 1999). According to Government of Malawi and World Bank, high rates of urbanisation and labor migration are the most important contributing factors to the high rates of HIV in the Southern Region (Government of Malawi and World Bank, 1998).

Tuberculosis is an opportunistic infection closely associated with HIV infection and in Malawi an estimated 70 per cent of people reported with tuberculosis are also HIV infected (Kumwenda, 2001).

<sup>&</sup>lt;sup>1</sup>Some countries in southern Africa have worse scenarios than Malawi. For example Botswana (35 per cent), Zimbabwe (25 per cent), Lesotho (23 per cent), Zambia (20 per cent) and 19 per cent in Namibia (Refer to Toolis & Mendel, 2000).

Reported tuberculosis cases have risen from 5,000 in 1985 to 24,000 in 2000 (Kumwenda, 2001 and Glynn et al, 1997). These trends in HIV and tuberculosis infections have put a severe strain on the government's health budget because close to 80 per cent of people admitted to hospital wards suffer from HIV/AIDS related problems compared to 20 per cent in 1990.

In Malawi in 1987 the dependency ratio was at 1.01; by 1998 when the last census was conducted this had risen to 1.3 (National Economic Council, 2000). The increase has mainly been attributed to the HIV/AIDS pandemic as it is causing the death of productive men and women. In addition to this, HIV/AIDS has led to the decrease in life expectancy. In Malawi, for example, life expectancy in 1985 was estimated at 45.2 years and expected to rise to 57.4 years by the year 2000. Now, however, it is estimated that the life expectancy rate for Malawi is around 36 years of age.

## The impacts of HIV/AIDS on communities

One of the outcomes of the HIV/AIDS pandemic in Malawi is that the general demise of the young and economically productive men and women leaves behind children and their grandparents with limited social and economic support. HIV/AIDS impacts negatively on AIDS affected family members' capacity to generate income and produce adequate food. The reduction in yields of food crops and income is made worse because members of the family spend most of the time and resources on providing care and support for the patient (Munthali and Ali, 2000). A study conducted in Blantyre shows that persistent illness or death of proprietors resulted in the closure of small scale businesses and abandonment or reduction in size of gardens being cultivated. Families reported declines in food availability since the onset of illness (Munthali, 1998)<sup>2</sup>. In other instances, people in households affected by HIV/AIDS will seek casual labor on other people's farms to earn money so that they can meet the needs of the patient and the household, but at the expense of working on their own plots of land (see Munthali & Ali, 2000). Thus, while poverty contributes to HIV/AIDS, at the same time AIDS creates poverty as resources are spent on caring for the patient and maintaining the household.

Children and their grandparents suffer greatly because of the loss of social and economic support. Even though the parents may leave behind some economic resources for their children, in some instances relatives of the husband may grab the property, leaving the children destitute. For grandparents, the AIDS pandemic has ushered in the responsibility of looking after orphaned grandchildren and they are bringing up a whole new generation.

The Malawi government defines an orphan as any child aged between 0 and 18 years who has been deprived of one or both parents. However, in most African societies the definition of orphanhood is mainly the loss of the mother because women are the primary caregivers (Jacques, 1998). When a mother dies and children are left in the care of their father, there is generally a feeling that the fathers are not responsible enough as indicated in the following remarks by orphaned children in Mzimba District during focus group discussions:

Most of the male parents drink beer. When your mother dies, the father spends all the time drinking beer and that means that whatever money comes his way is spent on beer. There is nothing left for his children to buy food and other needs. We are also deprived of the love which was there when both parents were alive.

According to the Ministry of Youth, Community Services and Social Welfare, at the end of December 2000 there were approximately 1.2 million orphans (see Munthali & Ali, 2000). A number of studies (see Foppena, 1996; Cook et al, 1999 and Munthali & Ali, 2000) have identified the problems faced by children orphaned by HIV/AIDS. They may be HIV positive themselves and will likely suffer and die before they reach the age of five years. Economic deprivation, and its consequences, is likely to

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<sup>&</sup>lt;sup>2</sup>Studies in urban households of Cote d'Ivoire, for example, show that when a family member has AIDS, income falls by 52 to 67 per cent while expenditures on health care quadruple (Unicef, 1999). Savings are depleted and people often get into debt to care for their sick. Food consumption has been found to drop by 41 per cent (op. cit). The Malawi NACP has projected that a minimum of 25 per cent and as much as 50 per cent of people currently employed in the urban based sectors will have died of AIDS related illnesses by the year 2005 (SITAN, 2001).

occur. Children orphaned by AIDS—and orphaned for other reasons—may have lost many of their parents' assets during the period of illness and to relatives. In addition, the general lack of food and income are real worries for orphaned children (Munthali, 1998). Some orphans also lack shelter because of the inability of their frail grandparents to repair or build houses. Access to education may be denied, if school costs cannot be met. The government introduced free primary school education in 1994, but orphans will drop out of school if they do not have school uniform, soap for bathing and washing their clothes, exercise books and writing materials. In the case of older orphans who are in secondary school they may lack school fees hence they may decide not to go on with their studies. Even though school fees might be available from well-wishers, older orphans may make a decision to drop out of school because there is nobody else in the home to care for their younger siblings. Attendance at school can be a problem because sometimes guardians tell them not to go to school but instead to work in the house. A young girl is quoted as saying: "I do not go to school. I would like to go but I have to find firewood or help in the field when there is a lot of weeding to do." (Mastwijk, 2000).

Education for all children suffers, as teachers and administrators become ill, experience absences from classroom teaching and supervision, and eventually die. AIDS is the leading cause of death among teachers and it is estimated that approximately 10 per cent of the country's teachers have already died of AIDS.

In addition to physical deprivation, orphaned children experience psychosocial problems which include the general lack of parental care, stigmatization, and untold grief (see Cook et al 1999). Most programs in Malawi are addressing the physical needs but not much has been done on the psychosocial needs. Indeed, the difficulties faced by orphaned children have sometimes been denied by policy makers who refer to the presence of traditional relations and the extended family<sup>3</sup>.

Early marriage, at the expense of schooling, is a coping strategy for some girls and their families (Foppena, 1996; Cook et al, 1999 and Munthali & Ali, 2001; see also Mastwijk, 2000). Sexual relations are another way some young women seek to cope with the economic pressures caused by HIV/AIDS. One young women said:

"I was made pregnant in 1998 just after sitting for my Primary School Leaving Certificate<sup>4</sup> (PSLC) examinations. At that time my mother was very sick so I had to find someone who could give me money to help my mother as my father had died two years earlier. I am the eldest in the family of five, three girls and two boys. So I met this boy who was working in town on my way from school and this is why I fell into a trap. The child's father ran away as soon as I told him that I was pregnant. Unfortunately my mother died a month later without knowing that I was in such a condition." (Munthali & Ali, 2000).

<sup>4</sup> PSLC are examinations that pupils take at the end of their primary school education and after this they can go to secondary school.

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<sup>&</sup>lt;sup>3</sup> In 1997 a very high ranking Government of Malawi district official brushed aside the issue of orphans suffering, arguing that the Malawi culture does not permit such a thing to happen (personal communication).

## The Extended Family System

Both patrilineal and matrilineal kinship systems exist in Malawi and these have implications on how households cope with death, illness, orphanhood, and inheritance.

Patrilineal systems of descent are practised in the northern region of Malawi and in the lower Shire River valley in the far south. When a woman marries, she goes to stay with her husband in his home village. When she dies she is buried there. Marriage in patrilineal systems also involves the transfer of bride wealth from the husband's family to the woman's family. A number of reasons have been given for the payment of bride wealth: compensation of the bride's family for the loss of her companionship and labour; making the children born out of that marriage to be full members of the husband's family and his clan (only if bride wealth is paid in full); and recognition of the man as the legitimate husband of their daughter (see Munthali, 2001b). Sons inherit their father's property, and women are denied any property rights to land and livestock, creating a women's economic dependency on men in the family (Mastwijk, 1999).

This type of arrangement has implications on coping mechanisms and strategies. If the husband dies the woman may choose to remain in her husband's home village where she, together with her children, will be taken care of by the relatives of her late husband as exemplified by the case at the beginning of the paper. Though the assistance provided might be inadequate as the late husband's relatives might also be providing for their families, this is nevertheless a coping strategy for not only those families affected by HIV/AIDS but for other families as well.

In the past when the husband died one of his relatives (especially the younger brother or cousin) was supposed to inherit the widow and cater for her and her children's needs and he could also bear children with her in the name of the deceased brother. Among the Tumbuka in northern Malawi, wife inheritance has been a form of social security for the woman and her children. The Tumbuka society is, however, changing and wife inheritance, though still being practised, is on the decline and one of the reasons for this change is that the practise enhances the transmission of HIV/AIDS and surviving widows are suspected of being infected (Cook et al, 1999).

In certain circumstances brothers may inherit their late brother's wife just because of interest in property or money left behind by the relative; once that money is finished then it marks the end of marriage leaving the woman and her children with nothing at all<sup>5</sup>. In some cases when the widow is not inherited she goes back to her home village where she re-marries. Re-marrying especially for women is also a form of coping.

In matrilineal systems<sup>6</sup> of descent as is practised among the Chewa, Yao and Lomwe of central and southern Malawi, upon marriage, the husband goes to live in the wife's home village. Domestic authority is exercised by the wife's brother who has control over his sister's children. In this context kinship and inheritance is traced through the maternal line and in general children belong to the mother and her clan. Though descent is matrilineal, control over resources is still in the hands of the men. In a matrilineal system, unlike in patriliny, the woman is in a better position because she stays with her kin in her own village and she can always call on them in times of illness or death. She also farms her own land (see SITAN, 2001).

In recent decades, with the monetization of economies and the introduction of wage labour, it is evident that many women from matrilineal societies migrate with their husbands to urban areas for employment. After the death of the husband, there are increasing tendencies that members of his family claim children as is the case in patrilineal systems. Such changes in family social structures were evident by the early 1980s and probably earlier (Phiri, 1982). The migration into urban areas distances the women from their kin groups who provide care and support in cases of illness. The removal of children by the

<sup>&</sup>lt;sup>5</sup> Focus group discussion with community members from Kayithazi Village near Ekwendeni in Mzimba District.

<sup>&</sup>lt;sup>6</sup>There are matrilineal systems where the wife goes to live with the husbands family in his village. In this paper I refer to situations of uxorilocal residence only

husband's kin also robs these women in matrilineal descent groups of an important old age insurance (Mastwijk, 2000).

#### **Care in Extended Families**

Despite rapid social change, the extended family remains the most important social safety net in Malawi. In times of illness, the next of kin are responsible for the provision of care; and the role of people who are not relations is usually minimal. People count on support from their families. Thus, in a study conducted by Munthali & Ali (2000), informants stressed the importance of keeping good relations with relatives to assure that they would provide care if a person were sick. If necessary, the extended family system can alter household composition, either through sending away some dependents to live with relatives or inviting the sick to join a household (see the opening story).

Despite the strength of family relations, HIV/AIDS has stimulated change and combined with other factors to create more complex and fluid forms of social relations and responses, to be discussed below. These responses are necessary, because the burden of caring for the sick can be overwhelming for both families and communities. The dwindling of community support for those who are chronically ill, as well as for the aged, has been attributed to the loss of values that are an important part of Tumbuka customs, as well as to the Europeanization of life styles, which emphasise individualism, and the general monetization of economies. The importance of monetization is underlined by an old grandmother who was looking after 15 grandchildren in Mzimba District:

At present, everything must be bought and this brings problems when there is need to assist your relatives. You need to buy everything while, in the past, for example meat was never bought because everyone had cattle.

Still, while the monetization of the economy is one of the contributing explanations of declining capacity to cope with the epidemic, the demise of productive young men and women with HIV/AIDS, as well as the large number of chronically ill people, also negatively affect community support. Coupled with this is the high prevalence of abject poverty in Malawi, where an estimated 60 per cent of the people in the rural areas and 65 per cent of those in the urban areas live below the poverty line (GoM and UNDP, 1993). Thus, even where members of the extended family may want to assist relatives affected by HIV/AIDS, they themselves are struggling to make ends meet. Such families suffer even more "when a member falls ill or dies, when they take in orphans or when a sick member returns home. They are further impoverished when the adult labour is reduced by death or illness" (Hunter & Williamson, 1998).

Two quotes (from Mastwijk, 2000:20) illustrate the difficulties faced by extended family care givers who have neither the resources nor the ability to care adequately for sick relatives and orphaned grandchildren:

Last year my brother died and left four children that are now living in my house. I have five children and I have to feed them all but this is giving problems as there is not enough nsima for all of them. (poor middle-aged man, Rumphi).

I am a 70 year old woman and I had 8 children. Four of them died and left me with 18 orphans to take care of. They do help me in the field. I get some support from the church and my other children but that is not enough. Every morning I am struggling to get some food for them so they don't get to school or to the field on an empty stomach. (elder widow, Mchinji District).

# Sibling-headed Families

While the extended family system seeks to meet the needs of orphans and those who are sick, then, this is not always possible. Some orphaned children, though of an age when they have to be at school, are forced to care for themselves and their siblings. These orphans survive by engaging in small-scale businesses such as selling prepared food, doing ganyu (casual labor), or selling land

<sup>&</sup>lt;sup>7</sup>"There is nothing free these days. Everything costs money," is how one person put it. (Mastwijk, 1999).

inherited from their parents. Thus HIV/AIDS has forced many children to grow up overnight and start heading families. Older orphans tend to leave school to take care of their fellow siblings. This situation also arises when the remaining parent is too sick to care for his or her children. An older woman said, "These older children are a source of good support when their parents are sick. They go out and do ganyu and the money is used to buy some of the things needed for caring for their parents."

Orphans also carry sand, mould bricks, sell firewood, produce and sell charcoal (Munthali & Ali, 2000). They are paid very low wages and are vulnerable to maltreatment. In some instances, children are forced onto the streets to beg, or into prostitution, early marriages and sometimes crime in order to survive. A priest in south Nkhata Bay in northern Malawi noted:

Some of the orphans, knowing that their grandparents are too old to control them, refuse to listen to whatever they say. They even refuse to work in the gardens and, as a result, the yields are

Coping with the Impact of HIV/AIDS

A family of nine sisters (eldest being 21 years old) along the Chileka Road in Blantyre lost both parents in 1996<sup>1</sup> and were taking care of an ailing elder brother who had dropped out of paid employment. There was no one in employment and the household relied on casual work (ganyu) for survival. None of the older members had gone beyond standard 6 and seven children were at school and were distributed from classes 1 to 3. They once were selling mandasi (doughnuts) but failed to sustain the business. They had also been selling their land around their home to other people who were seen building new homes. These people provided ganyu to the girls and once this work was finished the girls said that they did not know what they would do next. Their parents had sold all household property during sickness. They were not able to get medication for the sick member and had serious problems obtaining food. They were not receiving any external assistance despite having some relatives. (Munthali, 1998).

very poor and there is not enough food to eat. This encourages the orphans to start stealing, so that they can sell the items and buy food and other things they want.

## **Communities Facing HIV/AIDS**

## The Role of Religious Groups

Religion is an important tool that brings people together (both relations and non-relations) in this age when communal ties seem to be disintegrating. In some circles the church has been referred to as a social parent which brings spiritual as well as moral support to its members (see Munthali & Ali, 2000). In both Christian and Islamic communities women's, men's and youth guilds play an important supportive role in times of illness as well as death.

During funerals and illness episodes religious groups support members by offering prayers of hope and giving financial, moral and material assistance. Some Christian groups have set aside Sunday afternoons to visit and cheer the sick. Church members contribute some money, maize flour, firewood, and other items to sick parishioners. As for the aged they may assist them cleaning the house, drawing water, and farming their gardens. In Rumphi district Mastwijk found church guild members collectively cultivate maize in gardens belonging to the church. The maize is sold and the money distributed to the destitute in the community. Church members are requested to contribute part of their yield after harvest to the church so that it can be used for assisting the needy in the community (Mastwijk, 1999). Churches also donate clothes and other materials to the orphans and in some cases they have also paid school fees for the orphans (see Munthali & Ali, 2000). During funerals, church women pound maize which has been contributed by the church members or provided by the bereaved family. They also assist in cooking for those people who have come to attend the funeral.

Given the changes in family and community networks, it seems that in Malawi more and more people these days are turning to religion. The faith communities play the role of a relative as each and every member of church behaves as if they are coming from the same family (see Munthali & Ali, 2000:21). Mastwijk has argued that while most people join a church for spiritual purposes and because the church "serves as a means to enlarge or to strengthen one's social support network in order to enhance one's

chances for material and mental support in times of need and distress." One of her informants said that people join the church because "they help you when you are sick with AIDS while others run away." (Mastwijk, 1999). Some churches also have arbitrated property disputes that arise when the relatives grab property after the death of a male relative (Mastwijk, 2000).

In general when there is death in the village traditional burial rites are followed. During such periods communities demonstrate a lot of support and this is one aspect which has not really been much affected by the AIDS pandemic despite the large number of deaths. Young men volunteer in their large numbers to dig graves, women stay at the home of the deceased cooking and (together with some men) consoling family members of the deceased. Church members who are from the same community are also present singing and praying. If the deceased was staying in urban areas arrangements are made to carry the body to his home village and the employers are in most cases who are responsible for buying the coffin as well as provision of transport.

## **Community Social Responses**

In the Tumbuka communities the large number of deaths due to HIV/AIDS has resulted in shorter periods of mourning. While in the past community members could stay at the home of the deceased for a period of up to a month or more, these days they just spend two to three days before returning home to do some productive work before another death occurs in the community (Munthali, 2001b). Additionally, in the past children never used to attend funerals "because they were told that the person who had died has been eaten by a monster which stays in the bush therefore since this evil thing is still around they are not supposed to come out of the house" and children were locked up. This is not the scenario these days as children attend funerals, as it is widely known that AIDS is the cause of death (village headman Chizuwo, Nkhata Bay District).

District associations, made up of migrants from the same home district, have been formed in urban areas, or re-formed as similar patterns existed in the mid-colonial period among urban men, in particular. The association members offer support to one another in times of need and distress, such as during funerals and illness episodes. Members of these associations contribute money every month to a central fund to cover for these contingencies (Mastwijk, 2000:17). The degree of effectiveness depends on the commitment of the members. Though they were not necessarily formed for dealing with HIV/AIDS related problems, by assisting in times of illness as well as death the district associations are assisting their members to deal or cope with problems brought about by HIV/AIDS. The formation of such social support networks in a way imitates the traditional support systems which are based on kinship.

While members of the extended family are the ones who are primarily responsible for the welfare of the orphans, non-relations may sometimes play an important role as well. In some circumstances members of the community may assume responsibility for raising orphaned children if the grandparents are too frail or poor to adequately care for the children.

# Traditional Healers and the Chronically III

In most cases AIDS is a chronic illness: the patient has to suffer for a long period before finally dying. Chronic illness is not a new phenomenon in Malawian communities and already mechanisms existed for caring for those who are chronically ill. In the past chronically ill people were taken to the traditional healers for treatment because at that time the modern health facilities were not available or were situated very far. This was also being done because of the general belief that the person had been bewitched. Even these days there still exist people who think that AIDS is caused by witchcraft. Also, in some communities AIDS is confused with a folk illness called chinyera which does not require biomedical treatment (see Cook et al, 1999 and Munthali, 1999). The attribution of AIDS to witchcraft and the confusion of AIDS with the folk illness of chinyera tend to dictate the choice of traditional healers as a first line of treatment, although some Christian denominations do not allow members to consult traditional healers (Matinga and Munthali, 2001; Munthali and Ali, 2000).

Many traditional healers advertise in both the print and electronic media of cures for different types of symptoms, including those similar to AIDS. Many people have resorted to the traditional healers for

treatment. One of the most famous traditional healers who claimed to have a cure for AIDS was Billy Goodson Chisupe from southern Malawi. Between August 1994 and May 1995 hundreds of thousands of people (including people from neighboring countries) flocked to his village to drink his medicine which was dubbed "mchape"<sup>8</sup>. Chisupe came from a pre-colonial line of healers. He claimed that his uncle came to him in a dream and showed him a tree that can be used to cure HIV/AIDS. People were to come to his village to drink the medicine and that he should not take the medicine to any other place. At the peak of his activity, he prepared 17 drums (each 210 litres) of medicine everyday. He never charged for his medicine and those who wanted to give him something did that out of their own will. "While others went there only for the sake of entertainment, others were desperately seeing in Chisupe as the only help left. Still others arrived at the scene believing, or at least hoping, that the drug could not only cure AIDS but any other disease as well" (Probst, 1998). There are reports that people still continue to see Chisupe (de Gabrielle, 1997; Probst, 1998).

Chisupe like many traditional healers in Malawi offered hope for many people who were HIV positive<sup>9</sup>. In the developed countries the availability of anti-retrovirals helps HIV positive people to cope with the realities of the disease and live positively for many years. In Africa access to these expensive HIV/AIDS drug combination therapies is hampered by the very high prevalence of widespread abject poverty; hence in times of uncertainty they resort to traditional medicine.

While the traditional healers are still being consulted, many people first self-administer medicines they have bought from shops; when they do not get better, they go to a government health facility for treatment. When the situation does not improve they go to a private clinic and when this fails, a decision is made to go to traditional healers. While this might be the hierarchy of resort, many studies have revealed that people in general utilize multiple therapeutic techniques simultaneously (Munthali and Ali, 2000, Munthali and Matinga 2001, Munthali, 2001b; see also Crandon-Malamud (1991) on medical pluralism in Bolivia). When admitted in the hospital community members go to the visit and cheer the sick. If the one who is sick happens to be the mother, the children back home are looked after by the relatives. If it is the mother who is sick, the situation is really tough as children may be denied food and in some cases they hang around a friend's home until it is time to take meals. Though community support is on the decline, some members of the community do help in times of sickness by contributing money, maize or maize flour.

# **Community-Based Organisations**

Over the past decade or so Malawi has witnessed the establishment of many community-based organisations, mainly as a response to the HIV/AIDS pandemic. Some are formally organized at the instigation and support of government authorities. Many are much less formal, as in the district associations and church welfare initiatives.

Government, NGOs, and donors provide funding for some of the activities carried out by CBOs. The Ministry of Youth, Community Services and Social Welfare is responsible for the welfare of orphans and provides limited financial and material assistance to orphans and their guardians <sup>10</sup>. The Ministry has also been in the forefront in establishing the policy guidelines for the caring of orphans in the country (see Phiri & Leroy, 1998). Health surveillance assistants (HSAs), who are employees of the Ministry of Health and Population, facilitate the establishment of the Village Health Committees (VHCs) and Village AIDS Committees (VACs). The VHCs have taken an active role in promoting home-based care (HBC). These committees are involved in income generation activities and they channel their resources to affected children and adults. They have developed communal gardens where members of the community work together (see Hunter & Williamson, 2000b).

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<sup>&</sup>lt;sup>8</sup>Mchape means cleansing and it is a term first described by anthropologist Audrey Richards in her article AA modern movement of witch-finders" and later also used by Marwick. (For a detailed story of mchape see de Gabrielle, 1997 and Probst, 1998.

<sup>&</sup>lt;sup>9</sup>One traditional healer I interviewed in Hewe, western Rumphi, said that she sees patients suffering from AIDS and though she knows that AIDS has no cure, she however administers some medications which prolong the lives of those suffering from the illness.

<sup>&</sup>lt;sup>10</sup>The assistance that the Ministry provides is limited by financial constraints and its reliance on external assistance to run some of its programs.

The community-based organisations fulfil a number of activities in their respective locations, including HIV/AIDS prevention promotion, training of care givers in home based care, skill development of orphans with business skills, and income generation activities to assist those families affected by AIDS. to pay school fees for orphans, and so on. While a number of CBOs are engaged in income generating activities, the running of these activities is also beset with problems especially if they rely on volunteers, as most of them do. For example St. Joseph Community Based Orphan Care Organisation in Nkhata Bay district began a vegetable garden to boost their income. Work in the garden was on a voluntary basis. The initiative was not sustained and many of the plants died. CBOs promote the retention of orphans in the communities and encourage members of the extended families to take into their care these vulnerable children.

The following cases provide an overview of the activities of community-based groups.

## Kande Community Based Orphan Care Organisation

This CBO works in the south of Nkhata Bay District in northern Malawi. The initiative came from the district Social Welfare Office in consultation with the community to deal with the increasing mortality due to HIV/AIDS and the large number of orphaned children. To increase awareness of HIV/AIDS, the CBO built upon the activities of local clubs, known as AIDS TOTO clubs, that had existed for several years.

To assist orphans, the community began income generating activities (IGAs) and a community garden, the latter to provide food for malnourished children. One of the things that the members of the community found out was that orphans generally become malnourished after the death of their parents. Community members provided the labour to work in the garden.

In 2000 a government-aided seed multiplication project in the area benefited a number of orphans. Families were loaned cassava and sweet potato cuttings to plant in their gardens<sup>11</sup>. After two years farmers are supposed to return to government the cuttings, keeping additional ones that had been grown. Interviews with community members indicated that the program has also benefited orphans and families that keep orphans<sup>12</sup>. The orphans learned food production skills that may have been lost with the death of their parents to pass along such knowledge.

The initiative is not without it problems, however. Some children feel they are being punished by working in the gardens. They tend to complain that their peers are not being involved in such type of work and feel that this is one way of punishing them since they do not have parents<sup>13</sup>.

## Dunduweni Community-Based Orphan Care Organisation

This CBO is located within the catchment area of Ekwendeni Mission Hospital in Mzimba District of northern Malawi. Health surveillance assistants (HSAs) initiated the formation of the CBO in consultation with the members of the community. During these consultations it was recognised that both mission and government health facilities were not providing adequate care for those who were ill. Hence there was need to form an organisation to be responsible for home-based care. In order to assess the progress being made, each village submitted reports. One of these reports mentioned that one of the HBC groups was also taking care of orphans. The local coordinator was stimulated to form a separate organisation based in the village solely responsible for taking care of orphans. This led to the formation of Dunduweni Community-Based Orphan Care Organisation.

The CBO has worked to alleviate the problems that orphans face in their lives and educate members of the community on the dangers of HIV/AIDS. There is a committee which runs this CBO and it works hand in hand with the village health committee. Kindergarten schools, run on volunteer basis, have been formed in almost every village. The schools are also open to other children who are not orphans.

<sup>&</sup>lt;sup>11</sup>In Nkhata Bay district cassava is the major food crop.

<sup>&</sup>lt;sup>12</sup>This data was collected in March 2000 and according to informants the orphans and families keeping orphans also got

<sup>&</sup>lt;sup>13</sup>This information was provided by the chairperson of Kande Community Based Orphan Care Organisation

Volunteers were trained as teachers in these kindergarten schools. As of early 2000, each school of eleven school had two female teacher volunteers who had been trained.

The CBO members raise money to buy some of the basic needs of orphans, such as notebooks and clothes. At one time, Dunduweni Community Based Organisation paid school fees for a secondary school pupil, but they were unable to sustain the cost. While the CBO is striving to assist the orphans those involved know that the assistance they provide is far from adequate.

The CBO uses its member's membership in local religious groups to get additional assistance. Whenever there is need to raise funds for the community based orphan care organisation, word is sent to the religious leaders by the CBO area committee. Arrangements are then made by the respective churches to put a special plate during a church service on a Sunday for orphan's collection<sup>14</sup>.

### Tilerane Orphan Care Centre

Tilerane Centre is located in Lilongwe, the capital of Malawi. As of March 2000, one hundred and forty orphans were affiliated with the center. It was established in 1995 and as of 2000 it was able to pay school fees for eleven secondary school students. The centre provides free primary and nursery education. The centre mainly receives funding for its operations from UNICEF but there have also been donations like money, sugar, milk, scones, and second hand clothes from individuals. Children at the centre are fed and they are also given clothes, notebooks and pencils.

Apart from the provision of food, paying school fees and provision of materials like clothes and school materials, the centre is also involved in the identification of vulnerable children and analysing their needs, the provision of free basic education to nursery and primary school going children, making available resources for the orphans attending training in vocational skills such as tinsmith, carpentry and bricklaying, provision of economic empowerment for guardians of orphans through activities like embroidery, quarry stone making and gardening, facilitation of HIV/AIDS awareness campaigns by the youth and lastly provision of HBC to ill parents. In order to fulfil these activities the centre uses out-of-school youths as volunteers (Munthali & Ali, 2000).

\* \* \*

The community based organisations described above are very small-scale initiatives which in most cases are managed by the community themselves on a voluntary basis. Such initiatives are widespread in Malawi and have been formed as a direct response to the impact of the HIV/AIDS. By contrast, the village orphan committees (VOC) have in most cases been initiated by outside agencies, notably the social welfare officers from the Ministry of Gender, Social Welfare and Community Services, and development facilitators from non-governmental organisations like the Save the Children.

Though the initiatives have come from outside the communities, communities have responded positively because they also recognise the extent of the problem and they have adopted these programs as their own. This has been exemplified in Namwera where Save the Chiildren (US) was implementing the COPE program. Although the program has ended, the VOCs it initiated continue to function. Others, however, have not lasted, primarily because of the lack of funding to facilitate supervision. The link between effective VOCs and external resources is one often cited by local people. A member of one community said, "Whatever assistance comes from the community based organisation is appreciated. Unfortunately however, this assistance is never adequate due to the increasing number of orphans."

The success of the CBOs which rely on volunteering from the community members depends on the commitment of its members and good relations among the community members.

## **Orphan Institutions**

In addition to community-based organisations, a number of orphan care institutions have also been established in Malawi over the last decade. Institutionalisation of orphans is generally looked upon as a

<sup>14</sup>This information was provided by a committee member and community members from Kaithazi Village which falls under the catchment area of the Dunduweni Community Based Orphan care Organisation

last resort, it is expensive and often fails to meet the developmental needs of children. One of the most well known orphanage in Malawi is the SOS Children's Village in Lilongwe District (Phiri & Leroy, 1996).

The SOS Children's Village started in 1994 and takes orphans from birth to 10 years. Younger orphans live in small modern homes with furniture, electricity and tap water and a "mother." The mother looks after 10 orphans per household and the village has a father who is regarded as a father of all orphans. In addition to this there is an assistant village father, a social worker, youth workers, activity officer and special education teachers besides the regular teacher. Older children move into youth homes where they learn to run daily activities by managing finances, cleaning and cooking for themselves. The institution has a kindergarten, primary and secondary school that enrols pupils from surrounding communities. SOS Children's Village also has a clinic, playground and maize mill also open to surrounding communities.

Each orphan has a donor who sends financial assistance that is kept for him or her in a savings account, and they start managing these accounts when they move into youth homes. There are currently two homes in the campus. Although all these facilities are provided, the children at SOS experience a lot of psychosocial problems and there are five causes for this namely: living in very protective environments and isolated village, living in a totally different world than where they came from, lack of parental care, grief because of losing parents and teasing. These aspects often result in "isolation, more violent behaviour, restlessness, shyness and stigmatisation" (Kortlever, 1998:3). The children themselves note the lack of freedom to visit relatives and make social visit to the market, missing of parents.

#### The Role of NGOs

A number of non-governmental organizations have carried out projects in different parts of Malawi aimed at strengthening the community initiatives in responding to the HIV/AIDS pandemic. The activities carried out in these projects have included the distribution of materials like blankets, food, clothes etc and initiating the formation of village orphan committees. The distribution of material goods is mainly done through the already existing orphan care committees or CBOs as the case may be. While the initiative of distributing the material goods to orphans and their families is good, the major problem is the sustainability of such ventures.

The Community-based Options for Protection and Empowerment (COPE) project offers a model of facilitation and mobilization with communities for HIV/AIDS prevention and care. The program was run by the Save the Children Federation (USA) in Mangochi District. The program was implemented primarily through the existing government and community structures. At district level COPE worked with the District Social Welfare Officer of the Ministry of Youth, Community Services and Social Welfare while at community level the project worked with the community AIDS committees. As noted earlier, the project helped villages to set up village orphan committees which detect, monitor and assist vulnerable families and children. Communities and the local committees make the decisions about how to address HIV/AIDS and related problems. Everyone including women, children and the youth participate in the decision making process. The role of SCF (USA) staff and those from the Ministry of Youth, Community Services is to provide technical and financial support wherever needed. In order to assist the vulnerable children and families the community at Namwera opened up communal gardens. At the same time UNICEF assisted families and guardians with loans to boost income-generating activities. These income generating activities have included paper recycling, tinsmiths etc. The role of SCF was phased out after four years, but the village AIDS committee are presently running the activities set up by the COPE project (Munthali & Ali, 2000; Unicef, 1999; Phiri, 2001; www.savethechildren.org/crisis/fieldcope.shtml).

#### Conclusion

The demise of economically productive young men and women robs children, the aged and other members of the extended family of the social security system that they all depend on. Personal insurance schemes, pensions and worker's compensation only cater for a very small per centage of the population.

The extended family system is still the first choice of coping though it is under great strain due to HIV/AIDS. This applies to both caring for the chronically ill as well as taking care of orphans. In the absence of relatives (or unwilling relatives), children assume the role of caregivers to their parents or indeed in the case of the death of both parents children care for themselves. Early marriages, dropping out of school in order to head a family, casual labor and piece work, small scale sales, are some of the strategies being used in Malawi to cope with the impacts of HIV/AIDS. In addition to these informal social safety nets, community based organisations have also been established in different parts of Malawi with the aim of assisting those families affected by HIV/AIDS.

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