This is to certify that the

thesis entitled

The Impact of HIV/AIDS on the East African Family and the Increasing Need for Formal Orphan Care

presented by

Kimberly A. Lay

has been accepted towards fulfillment
of the requirements for

Masters degree in Anthropology

Major professor

Date May 4, 2001

# THE IMPACT OF HIV/AIDS ON THE EAST AFRICAN FAMILY AND THE INCREASING NEED FOR FORMAL ORPHAN CARE

By

Kimberly Ann Lay

AN ABSTRACT OF A THESIS

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

MASTER OF ARTS

Department of Anthropology

2001

Professor Anne Ferguson

ABSTRACT

THE IMPACT OF HIV/AIDS ON THE EAST AFRICAN FAMILY
AND THE INCREASING NEED FOR FORMAL ORPHAN CARE

By

Kimberly Ann Lay

This thesis examines the impact of HIV/AIDS on the East African family. The case of Tanzania is specifically explored in a contextual manner through the review of literature. Tanzania is one of the poorest countries in Africa and it has one of the highest rates of HIV/AIDS infection. The family in Tanzania has traditionally cared for ill members and orphaned children. However, it is difficult for families to continue their caregiving responsibilities in areas in which a high number of young adults are dying as a result of HIV/AIDS. Adolescents and the elderly are likely to become responsible for supplying social and financial support for family members that remain. In East Africa the burden of caring for HIV/AIDS infected individuals and orphaned children becomes the responsibility of women. Women may be HIV/AIDS infected and in need of care themselves.

Feminist theory and family stress theory are utilized in this thesis. It is not only important to examine the ways in which the family in Tanzania copes with the stress of HIV/AIDS, but also to examine the ways in which women manage the stress and strain of their roles, and to ask how long they can continue to be overburdened with their caregiving responsibilities. Recommendations are offered for further research and program development.

To my parents, Patricia C. and James R. Lay

## ACKNOWLEDGMENTS

I would like to gratefully acknowledge and thank the members of my graduate committee, Dr. Anne Ferguson, Dr. Jacob Climo, and Dr. Harriette McAdoo for their continuous guidance and support. I would also like to express my appreciation to family and friends for their encouragement and support.

## TABLE OF CONTENTS

# INTRODUCTION

HIV/AIDS has spread rapidly in impoverished communities which depend on human labor for survival and where the levels of poverty are so great that resources for dealing with the care of the sick, dying, and orphaned are already extremely scarce. The countries of Sub-Saharan Africa have the highest rates of HIV/AIDS infection and death in the world (FAO 2000).

As HIV/AIDS infected adults fall ill and die, families face declining productivity, a rise in household expenditures for medical bills and funeral expenses, a loss of productive family members, and growth in the number of dependents. The HIV/AIDS epidemic poses tremendous challenges for families, communities, governments, non-governmental organizations, and the international community. HIV/AIDS is not just a medical problem, it is a social problem as well (FAO 2000).

The list below illustrates some startling facts about the HIV/AIDS epidemic.

- Eleven people worldwide are HIV infected every minute; 10 live in sub-Saharan Africa.
- By the close of 1999:
  900,000 adults and children were living with HIV/AIDS in North America,
  1.3 million in Latin America,
  5.6 million in South and South-East Asia,
  24.5 million in Sub-Saharan Africa.
- In 1999, eight percent of the population of Tanzania was HIV infected.
- 95% of all AIDS orphans live in Africa.
- In Africa, war and famine caused an orphan rate of 2%; AIDS pushed the rate to 12% in some countries.
- By the year 2010 Tanzania will have 4.2 million orphans who will have lost their parents because of AIDS. This means that every third child in Tanzania will be an orphan.
  (UNAIDS cited by Health Canada 2000).

This thesis will examine three overarching questions: 1) In what ways is the family in Tanzania affected by HIV/AIDS? 2) How does the family and the community cope with and manage during the AIDS crisis? 3) What related research and program areas need attention? HIV/AIDS presents a risk to the entire family unit. The family may not be familiar with nor prepared for the unique set of circumstances that HIV/AIDS brings. The family, nuclear and extended, may be infected by or affected by the disease in the form of illness or in the form of caring for the infected and/or orphaned. Women are often affected by HIV/AIDS as both caregivers and as needers of care. It is on women, within the family and the community, that the burden of care for ill family members and orphaned children falls (Campbell 1999).

Family coping patterns for managing circumstances induced by HIV/AIDS are likely to lead to family restructuring and role adaptation. The largest number of AIDS related deaths occur between the ages of 15 and 49. These years are usually the productive and child bearing years. It is common for adolescents and the elderly to become responsible for supplying social and financial support for those remaining (Hooyman and Gonyea 1995).

In this thesis I argue that in addition to examining the ways in which the family as a unit is being restructured due to the AIDS epidemic, it is important to look at the position of women as caregivers within the family and community. Women and men are differentially affected by HIV/AIDS, have unequal access to resources, and employ different coping strategies. It is essential to question in what ways does a household cope in the face of insecurity while taking into account gender inequalities. Specifically, we must consider in what ways the caregiving role of women has changed or increased during the AIDS epidemic, and if and how are women able to adequately carry out their responsibilities.

## Theoretical Framework

Two theoretical frameworks were implemented in this thesis: feminist theory with a focus on the gender and development (GAD) perspective and family stress theory.

### *Feminist Theory*

The ways in which family structure is affected by HIV/AIDS can be examined by utilizing feminist theory. In this thesis feminist theory is used to recognize and explore the position and responsibility of women in the context of Tanzania during the time of the HIV/AIDS crisis. Additionally, the broader social circumstances contributing to Tanzanian women's experiences of HIV/AIDS is examined and suggestions for transformation of these circumstances are offered.

GAD, a feminist development theory, "addresses the root inequalities (of both gender and class) that create many of the practical problems women experience in their daily lives" (Connelly et al. 2000). GAD focuses on both the practical needs and the strategic interests of women and takes a gender-sensitive approach rather than a woman-only approach (Parpart 1995). Addressing practical needs involves improvement of the immediate condition of women's lives. Whereas, addressing strategic interests involve long-term transformations in the societal position of women, and involve empowering women to be active agents in such transformations (Connelly et al. 2000). Rathgeber (1990) states GAD "sees women as agents of change rather than merely as recipients of development assistance, and stresses the need for

women to organize themselves for effective political voice" (cited by Rathgeber 1995).

Parpart (1995) asserts that GAD is situated within socialist feminist scholarship. Socialist feminists argue that "we should begin the analysis of subordination with the experience of women" (Connelly et al. 2000). Socialist feminism incorporates the social construction of gender into its analysis and views the concept of patriarchy from a historical standpoint. Furthermore, socialist feminists are concerned with "the relationship between reproduction and production and the capitalist male-dominated structure of both" (Connelly et al. 2000)

GAD focuses on the social construction of gender roles and gender relations. Gender is viewed as "the process by which individuals who are born into biological categories of male or female become the social categories of men and women through the acquisition of locally-defined attributes of masculinity and femininity ' (Kabeer 1991 cited by Parpart and Marchand 1995). Viewing gender from this perspective allows for the possibility of transforming gender roles and reveals "the gendered division of labor and power" as a social construction (Parpart and Marchand 1995).

The GAD approach takes a postmodern feminist perspective in valuing local knowledge and in acknowledging that the lives and experiences of women are heterogeneous. Women's lives are affected by multiple variables many of which are power related (Rathgeber 1995). Questions related to the condition of the lives of women and their position in society can be addressed by utilizing

"action-research undertaken from a GAD perspective, with a postmodern attention to difference, discourse, and power" (Rathgeber 1995).

*Family Stress Theory*

Family stress theory is implemented in this thesis as a framework in which to examine how the Tanzanian family functions in context under stress caused by the HIV/AIDS epidemic. Family stress theory examines "the ways families produce, encounter, and cope with stress" (McCubbin and Figley 1983). McCubbin and Patterson (1983) define a stressor as a "life event impacting upon the family unit which produces, or has the potential of producing, change in the family social system". Stress processes are viewed as occurring in an ongoing manner in which constant interaction and change take place. Multiple stressors can occur simultaneously and overlap (Burr and Klein 1994).

Family stress theory assumes that family systems are in a constant state of flux. The family experiences a continual flow of economic, social and ecological factors that require ongoing adjustment and adaptation by family members. Family systems may maintain somewhat predictable patterns of daily routines when not experiencing stress. Some stressors cause changes to occur within or outside of the family that are expected and predictable. However, other stressors can cause changes to take place from within or outside the family which cause it to become strained and over burdened (Burr and Klein 1994).

As families grow and change they develop "rules of transformation". These rules govern the daily routines of life. Families develop rules about how things should be done and are able to transform inputs into outputs in ways that

allow them to attain individual and family goals. If transformation processes are not sufficient for families to handle a change or new input in the system the process of stress will occur. If a family does not have rules to cope with the stressful situation, then it may have difficulty dealing with a new input. The attention of family members can be diverted to the stressful situation, thus disrupting other important interactions and activities (Burr and Klein 1994).

A stressful situation may cause families to make changes in structure and function. McCubbin and Patterson (1983) state "Families in crisis, which face excessive demands and depleted resources, come to realize that in order to restore some functional stability and/or improve family satisfaction in their system, they need to make changes in their existing structure which may include modifications in established roles, rules, goals, and/or patterns of interaction". Research on stressors such as HIV/AIDS that effect families and the subsequent transitions that occur can assist in supplying information to programs directed at promoting family strengths and capabilities so that families are enabled to manage crises (McCubbin and Patterson 1983).

**Summary of Chapters**

My objective in Chapter one is to present a picture of the current situation of the HIV/AIDS epidemic in Africa. In order to do this a statistical overview of HIV/AIDS in Africa is presented along with an explanation as to why it is important for the case of East Africa to be considered. The utilization of the family as the unit of analysis is discussed. The ways in which HIV/AIDS differs from other African crises are examined and supported by incorporating the family stress theory into the discussion. To understand the impact HIV/AIDS has upon the East African family it is necessary to examine the ways in which the disease

may differ from other crises the family has dealt with in the past. Finally, this chapter looks at what is called an underestimated consequence of HIV/AIDS: orphans. In East Africa many children will lose one or both parents to the epidemic. However, many communities and families have not come to grips with this consequence nor are they prepared for it.

Chapter two focuses specifically on the East African country of Tanzania. The importance of examining the family in context is emphasized. The effects of HIV/AIDS will vary according to physical and social location. This chapter examines the economy, health care services, structural adjustment program, and familial organization of Tanzania. The context in which a disease occurs will effect the way it is viewed, the impact it has upon families and communities, and the ways in which the impact is counteracted. The importance of the extended family in East Africa is stressed in this chapter.

The extended family is a source of support in times of crisis. The ability of the extended family to function in this capacity under the current conditions is called into question. Social conditions may be in such a state that the extent to which the extended family can act as a support system to its members is limited. Chapter two also examines gender based care issues directly related to the HIV/AIDS epidemic. Women have historically held the role of caregiver in African families and are being called upon in an extensive capacity to care for the ill and orphaned as a result of AIDS.

The increasing need for formal orphan care models is examined in Chapter three. A statistical overview of AIDS orphans in Africa is presented. This chapter discusses what happens at the family and community levels when a generation is lost. Who will be held responsible for the care of children, some of whom are HIV and tuberculosis positive? Three models of formal orphan care are examined: orphanage/child rehabilitation center, foster care program, and

community based volunteer program. Additionally, the fact that women are key players in informal and formal orphan care is explored.

Chapter four identifies gaps in the literature on the topic of this thesis. Suggestions are offered as to what areas need further research. Areas in which program development should be promoted and/or improved are identified and recommendations are offered to improve these areas.

# CHAPTER 1

# AN INTRODUCTION TO THE PROBLEM FACING AFRICA

HIV/AIDS has been called a crisis of pandemic proportions, the "human disaster" (UNAIDS 1998), the "grandmother's disease" (Kelso 1994). It is known as the cause of "skip generation parenting" (Campbell 1999), the "parentification of youth" (Campbell 1999), and the "beanpole family structure" (Hooyman and Gonyea 1995). Recent estimates present a disturbing picture of life in Africa, particularly in East and Southern Africa.

This chapter contains a statistical overview of the HIV/AIDS crisis in Africa and justifies the importance of examining the problem facing East and Southern Africa. Second, this chapter stresses the significance of looking at the problem from a familial perspective. Third, it examines the nature of AIDS as a disease of crisis proportions and the way in which the disease impacts the family in ways that other crises in the past have not. Fourth, this chapter looks at what has been called one of the worst repercussions of the AIDS epidemic; the rise in the number of orphaned children.

## Why Africa?

Barnett and Blaikie summarize the importance of examining the impact of HIV/AIDS upon Africa in their statement below.

> The importance of writing about Africa is that on that continent the disease is spreading very rapidly in impoverished communities which depend on human labor for survival where the levels of national poverty are already so great that the resources for dealing with the care of the sick and dying and the orphans are already extremely scarce (Barnett and Blaikie 1992).

As mentioned here, the kinds of health problems caused by HIV/AIDS directly

affect families' and children's quality of everyday life experiences and their ability to survive.

Statistics of the past few years paint a grim picture of sub-Saharan Africa in the wake of the HIV/AIDS epidemic. In 1997 the World Health Organization (WHO) estimated that more than 80% of people living with AIDS resided in Africa, with AIDS being the leading cause of death that year (BBC News 1997). UNAIDS and WHO estimated that 7 out of 10 people newly infected with HIV in 1998 lived in sub-Saharan Africa. Eighty-three percent of all AIDS deaths that have occurred since the epidemic began have been in the region of sub-Saharan Africa. Moreover, two million Africans died of AIDS in 1998. Yet, only one-tenth of the world's population lives in Africa south of the Sahara (FAO 2000).

WHO calculates that 20% to 40% of children born to HIV positive mothers will be infected, develop AIDS and die before the age of five. The remaining 60% to 80% of children will not be infected with HIV, but will be orphaned within the first 10 years of their lives (AIDS Analysis Africa 1992). The definition of AIDS orphan may differ according to locality. In most cases an AIDS orphan is defined as a child or youth 15 years of age or younger who has lost one or both parents because of AIDS (Status and Trends of the HIV/AIDS Epidemic in the World 1998). In some literature the term orphan is not distinguished as HIV-infected or non-infected.

Most children suffering from AIDS die within the first five years (Grant 1991), and most orphaned children are under the age of 5 years (Okeyo 1995). In 1998, four out of every ten children living in rural areas of East Africa who have lost one parent by age 15 have lost that parent to an AIDS related cause (Daley 1998). Commonly, more than one child from a family is orphaned. Children are usually incorporated into one household, although in some cases children may be divided and incorporated into more than one household.

HIV/AIDS has lead to increasing tuberculosis rates (Chintu and Mwinga 1999). HIV/AIDS "is the most important risk factor so far identified to turn latent TB infection into active tuberculosis" (Chum and Graf 1993). A person who is HIV/AIDS infected will be likely to develop active tuberculosis because her/his immune system becomes depressed (Chum and Graf 1993). According to Chintu and Mwinga (1999), "Continued transmission of infection in areas with high levels of HIV infection, coupled with poor standards of living, reduces the hope of controlling tuberculosis in the foreseeable future" (Chintu and Mwinga 1999).

Tuberculosis can be transmitted from HIV infected individuals to healthy members of the population (Chum and Graf 1993). Cure rates are often low in many parts of rural Africa because of "irregular drug supplies and inability to supervise treatment" (Chintu and Mwinga 1999). Chintu and Mwinga (1999) claim that the tuberculosis "epidemic has overwhelmed the health services of all sub - Saharan African countries".

According to Mukangara and Koda (1997) the number of AIDS related tuberculosis cases in sub-Saharan Africa has doubled between 1980 from 100,000 to 200,000 cases in 1990. In 1999 over 60% of children and 70% of adults who were HIV infected were also infected with tuberculosis (Chintu and Mwinga 1999). In Tanzania 25,210 tuberculosis cases were reported in 1991; 27,000 in 1992; and an estimated 36,000 in 1995. Approximately 30%-40% of tuberculosis patients in Tanzania in 1993 were also HIV positive. In 1993 forty percent to fifty percent of the Tanzania population around 40 years of age was infected with the tubercle bacillus. Tuberculosis can occur in children, however it is rarely infectious and can be cured with treatment if it is available (Chum and Graf 1993).

In the countries of East and Central Africa in the 1990s, between 1.5 and

2.9 million reproductive age adults died from HIV/AIDS. This estimate was expected to produce between 3.1 and 5.5 million AIDS orphans in the region. Meaning, 6% to 11% of the population under 15 was orphaned (Djeddah 1997). At least 95% of all AIDS orphans are Africans (Status and Trends of the HIV/AIDS Epidemic in the World 1998). According to UNICEF, by the year 2010, forty million children will lose one or both parents because of AIDS (Dispatch Online 1998). These figures are even more alarming when the number of non-AIDS orphans are added (The Status and Trends of the HIV/AIDS Epidemic in the World 1998).

AIDS rates vary according to country with some having relatively low levels of infection, while others, such as Kenya, Tanzania, Zimbabwe, Uganda, Rwanda, Zambia, Malawi, and Zaire are among the worst affected countries in Africa (BBC News 1997; Barnett and Blaikie 1992; UNAIDS 1998). The statistics clearly point to the countries of East and Southern Africa as the worst impacted areas. Therefore, it is necessary to examine what is occurring in these countries now in order to assist them in generating social and material resources in the future. Additionally, by studying areas that are worst impacted, lessons can be learned and solutions formulated for other areas that may be on a similar pathway.

**Familial Perspective**

In this discussion the family is defined as "a group of persons related to each other by blood and/or marriage" (Hogget and Pearl 1983 cited by Ncube et al. 1997). A fuller definition of the African family and its functions is found in chapter three. Examining the AIDS epidemic from a family centered perspective is necessary for two primary reasons. First, examining AIDS from such a perspective makes sense because the disease presents a health risk to the entire family unit (McGrath 1993 cited by Jackson and Civic 1994). If one spouse

within the nuclear family unit is HIV infected, the other spouse will have a great chance of infection also. One or more children of an HIV infected mother may also be infected. Second, specific to this discussion, it is the family unit in Africa that has conventionally cared for ill members and taken in orphaned children. Thus, the family, nuclear and extended, may be infected with or affected by the disease in the form of illness or in the form of caring for its members.

It is the family that mediates existing circumstances, be they positive or negative. The role of the family during periods of "threat, impact, and post-impact recovery" is of central importance to the continuation of the life of the family (McCubbin and Figley 1983). Historically, families have formed the first line of defense against stresses caused by disaster. The family as a unit acts as a natural stress buffer and support group for its individual members (McCubbin and Figley 1983). Adepoju and Mbugua (1997) state that within Africa "it is the family as an entity - rather than the individual members of the family - which defines the types of adaptation mechanisms as well as the boundaries of adaptation parameters employed by each member of the family".

This discussion will apply the family stress theory to the examination of the HIV/AIDS epidemic in the contextual setting of Africa. Family stress theory examines "the ways families produce, encounter, and cope with stress" (McCubbin and Figley 1983). Using this perspective will allow us to examine how the family in Africa has managed crises in the past and how the family may function under the stress of the current HIV/AIDS crisis.

A contextual model will be implemented in this examination. The family does not thrive in isolation, but is part of a larger cultural context that influences its function and the way it manages stressful events. The cultural context defines the larger society's rules for problem solving, management styles, and accepted methods of managing stress. The larger culture thus provides the rules by which

the family operates at its micro level (Boss 1988).

However, it is important to realize that not all families within the same community or culture are homogeneous. They may react differently to a stressor for various reasons. The ways in which families react to stress within their internal dimensions of kin and resources, and the ways in which they access and put to use external resources within the surrounding community may vary greatly. Application of the family stress theory should aid in exploring how the African family manages a stressor that has crisis potential. Moreover, it should aid in formulating and answering questions such as: what factors determine a family's ability to care for the ill and to absorb orphans; and what is the influence of kinship relations on patterns of caregiving within stressful or crisis situations?

**HIV/AIDS: Just Another African Crisis?**

Does the impact that AIDS has upon African peoples differ from the ways in which other crises such as famine, migration, previous wide spread heath epidemics, or war have affected the family and community? Other crises, including famine, war, and health epidemics have had a detrimental impact upon Africa. Even migration of peoples from one location to another has affected some peoples of Africa negatively. Can we realistically categorize the impact AIDS has upon African society into a different category than the aforementioned sources of change? Let us consider the distinct nature of HIV/AIDS by carefully examining the unfamiliarity of dealing with the disease, its chronic or long-term character, and the unique way in which the disease affects families and communities.

*The Unfamiliarity of HIV/AIDS*

According to Hill a stressor is "a situation for which an individual, family, or community has had little or no preparation, therefore posing a formidable problem with crisis potential" (Hill 1958 cited in Anderson 1990). An individual or

family may experience stress associated with many differing life events that cause change to occur. A stressor develops into a crisis when the family experiences an inability to restore stability to its daily life and an inability to perform usual functions. The family under a stressor of crisis proportions will experience "constant pressure to make changes in the family structure and patterns of interaction" (McCubbin and Patterson 1983). AIDS has proven to be a stressor of crisis potential.

When a family experiences a stressor such as HIV/AIDS that "disrupts their everyday life events, causes disorganization, or incapacitates the family system", various coping strategies are applied in hopes of alleviating stress (McCubbin and Patterson 1983). Coping is the process by which families make an effort to adapt to changing circumstances and to achieve a new level of organization or balance. Coping involves an interaction of resources and the management of resources. In other words, coping is a combination of the family's ability to acquire resources and to manage resources in a manner that will alleviate stress. Resources consist of the social and material attributes of families and communities (McCubbin and Patterson 1983).

When a population or family is aware of the occurrence of a potential event or situation because it has in some way in the past affected them or others around them, coping mechanisms can be developed in advance (Barnett and Blaikie 1992). Information about such events or situations becomes "knowledge" that facilitates action. This knowledge may reside in "tradition" or "custom" and may facilitate various methods of contextual "problem solving" (Barnett and Blaikie 1992). Moreover, in order for an impacted population or family to deal with crisis causing circumstances they must first be able to identify and understand the circumstances in a way that is meaningful to them (Barnett and Blaikie 1992).

In a crisis that is perceived as familiar and as having some normalcy, meaning that it has occurred at sometime in the past, it is expected that the circumstance, coping strategies, and outcomes will be consistent with the past. For example, coping strategies applied during famine may be an extension of practices conducted in some form during a normal year (Barnett and Blaikie 1992). Barnett and Blaikie (1992) contend that a "vast majority" of coping strategies are "in situ" strategies that can be "broadly classified as self-help".

Conversely, AIDS presents an unfamiliar crisis of "abnormal" content. In the rise of an unfamiliar crisis "the past does not provide a satisfactory guide for the future" (Barnett and Blaikie 1992). Throughout African history, various countries have experienced famine, drought, war, health crises, and economic disasters. However, these crises causing circumstances do not provide adequate guidance for developing viable coping strategies to contend with the effects of the AIDS crisis. Moreover, "No model of a fatal illness comparable to AIDS, striking both parents and children, exists" (Boland, Czarniecki, and Haiken 1992 cited by Campbell 1999). A "situation of uncertainty" is brought about by an unexpected circumstance such as the AIDS epidemic (Barnett and Blaikie 1992).

Although many regional areas have already been affected by the AIDS epidemic; individuals, families, and communities are still searching for and experimenting with coping mechanisms that will allow them to continue their life in some form of normalcy. As the number of family and community members who fall ill and die increases other stress management strategies will be tested. Moreover, AIDS affects many families at the same time limiting the helping capacity of social networks. It is true that all societies have mechanisms that allow them to cope with death, but large numbers of deaths may overwhelm those mechanisms (Barnett and Blaikie 1992).

Over time in impacted areas families and communities will experience a

transition from "known" to "unknown" circumstances and from "normal" to "abnormal" daily routines as infection and mortality rates increase (Barnett and Blaikie 1992). Information defined as "knowledge" of how to handle the AIDS epidemic will remain in flux as circumstances change. Even families that have developed useful coping strategies to deal with their current situation will experience periods of transition if their situation changes and will thus seek to develop other strategies to assist them with the newness and uncertainty of their condition (Barnett and Blaikie 1992).

Additionally, "the burdens of having HIV disease, particularly the secrecy and stigma associated with it, may be worse than those of other illnesses" (Campbell 1999). Taylor-Brown et al. (1998), claim "there is a conspiracy of silence among family members and other caregivers" who are associated with HIV/AIDS infected individuals. The stigmatization surrounding HIV/AIDS may have a detrimental effect on family support. Often family members do not understand HIV/AIDS and have not been educated about it. Families are afraid of contracting HIV. Children are especially susceptible to stigmatization associated with AIDS even if they are not infected. When a child or children lose one or both parents to AIDS they may be assumed to be HIV infected also. Adults may consider children from such families as less desirable especially if they are ill and showing signs of HIV infection. In addition to the stigma associated with HIV/AIDS, children may also carry the burden of being stigmatized if they have tuberculosis.

The way in which the public views HIV/AIDS, and likewise tuberculosis, has a great influence on the lives of infected individuals and those in which they are in contact. In turn, this has an effect on the support system and coping mechanisms of the infected. The stigmatization of the infected may affect their access to informal and formal support and other resources.

*Chronic/Long-Term Crisis*

A chronic stressor can be defined as a "situation of disturbed equilibrium that persists over a long period of time" (Boss 1988). Chronic stressors pose four characteristics that affect the degree of stress experienced in a family:

1. Long duration: the stressor will persist over a long period of time and it will be difficult to change the situation (Boss 1988).
2. Ambiguity in the stressor's origin, progression, and conclusion: there is an uncertainty surrounding the situation's onset, development, and conclusion (Boss 1988).
3. Pile-up: a stressor of long duration will have a great chance of coinciding with other stressors causing a pile-up of stressors (Boss 1988).
4. The stressor situation will develop slowly and/or have a long aftermath: the stressor has the potential to drain the resources of family and community alike. Thus, the stressor may disrupt kin and friendship networks (Patterson and McCubbin 1983).

AIDS has been described as a long wave disaster by Barnett and Blaikie (1992) "because it is a disaster that is a long time in the making and in which the major effects have already begun to occur long before the magnitude of the crisis is recognized and any response is possible". Furthermore, AIDS can be described as possessing the other three characteristics listed above. Its long duration may leave the family in a state of ambiguity and may also exhaust their financial resources. Likewise, there is a strong possibility that other stressful events or situations will arise within the family during the duration of the illness. For example, circumstances such as food shortage, financial difficulties, and other situations that strain the family may occur within the time frame in which a family member becomes ill and passes due to AIDS.

*Impact Upon Families and Communities*

Why reference AIDS as the "grandmother's disease" (Kelso 1994), the cause of "skip generation parenting" (Campbell 1999), the "parentification of youth" (Campbell 1999), and the "beanpole family structure" (Hooyman and

Gonyea 1995)? These references reflect the unique impact AIDS has upon the family. In the case of a chronic illness such as AIDS, family patterns of managing life situations are likely to be disturbed in such a way that family restructuring and role adaptation will inevitably occur.

AIDS presents families with a unique configuration of challenges. Within the family multiple AIDS related deaths can occur. Families in which one or more deaths occur must restructure their unit often by making alterations to the identity and role of members (Campbell 1999). The role of the ill or deceased family member will partially determine to what extent alterations are made within the family after her or his death. For instance, the death of a caregiver will impact the family in a different way than the death of a person that supports the family financially. Furthermore, the emotional and economic stress of ill health and death are experienced several times over in the case of multiple deaths, thus impacting the family in a cumulative manner (Barnett and Blaikie 1992).

The death of a family member results in "drastic reallocation of critical roles within the family" (Patterson and McCubbin 1983). Families that lose multiple members between the ages of 15 and 49 may take the form or a "vertical" or "beanpole" family. This occurrence leaves the young and the old to supply social and financial support for those family members remaining (Hooyman and Gonyea 1995).

Family "change is as much about the character of relationships within families as about the size and structure of family units" (Ncube et al. 1997). The "grandmother's disease", "parentification of youth", and "skip generation parenting" refer to the reality that grandparents and eldest siblings may transfer into the role of caregiver upon the death of a parental caregiver. In some instances, other members of the extended family, such as a sister or brother of a deceased parent may be called upon to care for children who have lost a parent

or parents. It is the nature of the disease that for most orphans the loss of one parent will shortly be followed by the loss of the other.

Sources of stress and hardships associated with chronic illness and family restructuring include: "modifications in family activities, burden of increased tasks and time constraints, increased financial burden, and increased caretaking burden" (Patterson and McCubbin 1983). Moreover, family members who take on increased tasks in addition to the duties that their role currently carries may experience role overload. For example, grandparents may experience role overload if they continue to perform conventional grandparenting duties and also take on the role of parent to their grandchildren (Weisner 1997).

AIDS presents a different situation for caregivers compared to other illnesses. Quite often a caregiver, who is generally a woman, will be HIV/AIDS infected as well. According to Campbell "infected women are often affected by HIV/AIDS both as caregivers and as needers of care" (Campbell 1999). Hence, gender plays a pivotal role in caregiving and is "highlighted in the presence of HIV disease" (Sherr 1995 cited Campbell 1999). Gender tends to be more of a determining factor in who assumes the caring role than kin ties (Hooyman and Gonyea 1995).

According to Campbell, "Women in general are more likely than men to care for their children, spouses, friends, and elderly relatives" (Baines et al. 1991 cited by Campbell 1999). Furthermore, "Women are found providing informal HIV/AIDS care in their roles as mothers, grandmothers, wives, daughters, sisters, and aunts" (Richardson 1988; Stephens 1989 cited by Campbell 1999). Increased economic and domestic obligations are being placed upon women who may not have access to needed resources that will allow them to adequately carry out the role of caregiver. Additionally, taking into consideration that grandmothers may be elderly and close to death themselves, and that roughly an

equal number of men and women die from AIDS, the result will ultimately be a shrinking pool of caregivers.

The impact of HIV/AIDS extends far beyond the family. As the AIDS epidemic progresses, its impact has become an expanding crisis with catastrophic consequences for not only families, but also for the communities in which they live (Taylor-Brown et al. 1998). AIDS is likely to cause the death of not only multiple family members, but also friends and neighbors. Moreover, the cumulative effect of generational loss associated with AIDS can affect an entire community's well being.

The loss of adults in their most economically productive and child rearing years is sure to impact both the family and community structure and functions. In other words, the death of these members will result in the loss of "the productivity potential of a generation of young people who will not be able to contribute to their family's and community's income and welfare" (Campbell 1999). According to Jackson and Civic (1994) community consequences that may result from the prevalence of HIV infection and the growing number of AIDS cases are:

> ... the availability of skilled and professional labor will be adversely affected; individual workplaces and the economy as a whole will come under increasing strain; health costs will escalate; home care will increasingly be needed instead of hospital care; and an increasing number of children will experience the death of one or both parents; increasing numbers of orphans will need care.

Additionally, the transmission of local indigenous knowledge and expertise that flows from adults to children may be lost (FAO 2000).

**Orphans: An Underestimated Consequence**

One of the most distressing long-term consequences of AIDS is the increasing number of orphaned children. Black (1991) states, "Regardless of the exact rate of increase in orphaned children, many African countries will see a steep rise in their numbers which will have far-reaching effects on demographic and social patterns" (cited by Jackson and Civic 1994). The newspaper headlines and articles listed below illustrate the rise in the number of orphans and send a warning signal to the public. The rise in the number of orphaned children will place a tremendous strain on families and social systems to cope with the intensifying conditions (Foster 1998).

- AIDS Orphans - A New Epidemic with Disaster Implications (Okeyo 1995)
- Who will take care of the AIDS orphans? (AIDS Analysis Africa 1995)
- AIDS expected to orphan one third of children in Zimbabwe (Key 1996)
- Africa's emerging AIDS - orphans crisis (Baggaley and Needham 1997)
- 40m AIDS orphans by 2010, UNICEF chief warns (Dispatch Online 1998)
- Orphaned by AIDS, Zambia's lost generation fills the streets (CNN 1999)
- Africa's AIDS orphans are fast-growing population (Key 1999)

WHO estimated that there would be 10 million children orphaned by AIDS worldwide by the year 2000. Okeyo (1995) asserts that "failure to tackle the orphan problem with the resources it deserves could see the late 1990s and early part of the 21st century a period of economic disruption and political turmoil in Africa". Hence, in the long run, as a result of the death of the middle parenting/working generation, the work force will become younger, less educated, and may have physical problems due to malnourishment as a child.

At the family level burdens and stresses placed upon the extended family are increasing as they attempt to continue their conventional role as caregiver to orphaned children. There is also an increased burden at the societal level to provide services for ill and orphaned children that may include budgeting for orphanages, health care, and other areas at the community and national level (Foster 1998).

The indirect toll that the disease has upon caregivers and youth internationally is not always apparent nor is it at the fore front of efforts being delivered by international agencies to combat the spread of HIV/AIDS (Foster 1998). There has been a great focus on what can be done to prevent the spread of HIV/AIDS and to treat its victims, but what about the survivors, many of who are children, and those that must care for them? Some academics and development practitioners have realized within the past few years that the rise in numbers of orphaned children could pose a substantial problem to both the family and the community. However, it seems that efforts are slow to reach the ground and may be gradually reaching areas that are in need of assistance.

Why has this repercussion of the AIDS epidemic been slow to be acknowledged and not at the forefront of academic and development endeavors? This oversight has occurred for three primary reasons. Conventionally, the family in Africa has been perceived as the provider of a secure structure in which its members could find refuge and support . Second, because the AIDS epidemic has a cumulative nature many people within and outside of AIDS affected areas may not realize that occurrences at the micro level foretell a macro level crisis

(Adepoju and Mbugua 1997). The picture becomes alarming when looked at from a broad perspective. Third, HIV/AIDS is commonly treated as a medical problem and not recognized as a problem causing repercussions at the social level.

**Conclusion**

As this chapter has suggested, it is important to examine the impact of HIV/AIDS on African communities because the disease has spread rapidly through areas that are impoverished and that depend on human labor for survival. Such areas may not possess the resources to deal with the care of those affected by and infected with HIV/AIDS. Tanzania is one of the countries affected most by the spread of HIV/AIDS. The rate of HIV infection among adults from age 15 to 49 in Tanzania is 8.09%. Tanzania is also one of the poorest countries in the world (UNAIDS 2000 cited by Health Canada).

HIV/AIDS presents a health risk to the entire family. The family in Africa has traditionally cared for the ill and the orphaned. The conditions that AIDS presents differs from the ways in which other crises have affected the family and community. The disease is an unfamiliar crisis that presents unique challenges. HIV/AIDS affects the structure of the family and alters its function. The elderly and adolescents may be called upon to care for its infected and affected members. HIV/AIDS infected women are often caregivers and needers of care. The loss of a generation will impact the welfare and economic stability of both the family and the community.

# CHAPTER 2

## CONTEXTUAL SETTING AND FAMILY STRUCTURE

*Diseases are both biological and socio-cultural events. Their material and social profiles are shaped by particular political, economic and cultural circumstances (Lindenbaum 1997).*

According to Akeroyd (1997) "the personal, gendered and socio-economic impacts of HIV-related illness and AIDS will vary in different sociocultural and economic systems, between rural and urban areas, between social categories and age cohorts". Therefore, there is a need to situate local social forms within broader regional and national social structures. The family can be viewed as a social institution that is inherently connected to other social institutions. Changes that occur in other social institutions will to some degree affect the family. Moreover, "the changes affecting the family are unavoidable for they are from outside the family institution" (Omari 1991).

The family in Tanzania can be examined and understood from this perspective. Increasingly the extended family in Africa is fragmenting through the combination of pressures such as poverty, migration, urbanization, land shortage, conflict and disease (Owen 1996). Family relations have been seriously strained. A worsening crisis like that of AIDS often renders family support networks fragile and damaged. Moreover, as stated by UNECA (1989) "the wider social fabric in many areas is shredding, leaving many people without the safety net of social relations" (cited by Schoepf 1993).

AIDS deaths represent only a fraction of the total number of deaths from all causes in Africa. During the1970s and 1980s economic instability, the break down of government infrastructure and civil strife contributed to increasing the number of orphans. More recently, the number of orphans has grown due to the

AIDS epidemic. AIDS and the increasing number of orphans places a strain on an economy that is emerging from a long period of deterioration (Turshen 1999). It is only with an understanding of specific social and historical contexts that an effective mobilization for coping with the devastation of AIDS can be implemented.

Understanding the impact of AIDS requires researchers not only to contextually examine the struggles associated in coping with AIDS, but also to examine a number of issues that may assist or impair those involved in the situation (Bond et al. 1997). If we take a broad contextual look at the setting in which the AIDS epidemic is occurring we can then begin to see the other factors that play into the crisis and how they effect coping strategies employed.

This chapter will look at the country of Tanzania as a social entity which has gone through changes at varying levels that have affected the state of the family. In order to view Tanzania from this perspective it is necessary to look at the social and cultural aspects of the country as well as the people that inhabit it. The first section of the chapter will include a brief look at Tanzania's economic, education, and health care sectors; and structural adjustment program. The second section will consider the family contextually. The third section will take a look at the importance of the extended family. A gender perspective will be explored in the fourth section. The fifth and final section will offer a brief conclusion.

**Tanzania**

Tanzania's population, estimated in July, 2000 was 35,306,126: 0-14 years 45% (male 7,970,453; female 7,883,442), 15-64 years 52% (male 9,110,501; female 9,325,726), 65 years and over 3% (male 463,889; female 552,115) (The World Fact Book 2000). Tanzania is considered to be one of the poorest countries in the world. Its estimated per capita GNP for 1995 was $120

US. Tanzania has been successful in reducing rural poverty. The percent of the population living in severe poverty, earning less than $0.75 per day, dropped from 51% in 1983 to 42% in 1991. As a result of economic growth, there were fewer people living below $0.75 per day in 1991 (9 million) than in 1983 (11 million). Unfortunately, economic growth has been accompanied by greater gender inequality (World Bank 1997).

Tanzania's economy has been agriculturally oriented for centuries. The majority of people are small-scale farmers who cultivate small individual family plots. In 1989, eighty-five percent of Tanzania's population resided in rural areas (Omari 1989). In 1999 the rural population had fallen to 78%. Although the urban population is increasing, agriculture continues to be the backbone of the Tanzanian economy. More than 80% of the economically active population is engaged in food production. Agriculture constitutes the country's principal source of income, providing about 50% of the GDP and more than 90% of export earnings (The World Fact Book 1999).

*Education*

Tanganika was granted independence from Britain in 1961. The Tanganyika African National Union (TANU) party was designated control of Tanganika. It was through this party that Julius Nyerere, Tanzania's first president, created his version of African socialism. Nyerere's socialist program was called Ujamaa (Hedlund et al. 1989). Ujamaa meant "family cooperation" and an "attitude of sharing, cooperation and respect between people" (ILRIG 1988).

Nyerere designed the Ujamaa program with the intention to "extend the social protection existing within the family onto the wider concept of society as a whole" (Hedlund et al 1989). Ujamaa called for an education for self-reliance or independence. The policy of self-reliance came into effect under the Arusha

Declaration of 1967. The declaration "established that Tanzanian officials should be dealing with the practical problems of the country side and seeking to identify more closely with workers and peasants, rather than concentrating on making money in the capital" (Hedlund et al. 1989). Additionally, more money was to be spent on primary schools (ILRIG 1988).

Tanzania had a literacy rate of 61% in 1975 and 90% in 1984. In 1988 ninety-three percent of males and eighty-eight percent of females were literate. Literacy rates declined to females at 70% and males at 80% by 1997 (Mukangara and Koda 1997). Mukangara and Koda (1997) claim that the decline in literacy rates is a result of reduced government investment and donor support. Tanzanian education policies adopted after independence were meant to "distribute and equalize educational opportunities" and to expand "educational institutions at all levels (primary, secondary and university schooling)" (World Bank 1986). In an effort to supply equal access to secondary education Tanzania abolished secondary school fees in 1964. Primary school fees were later abolished in 1973. Educational equality was further sought by establishing a uniform primary school curriculum (World Bank 1986).

In 1985 the Tanzania Government adopted the first economic structural adjustment program. Cost sharing came into operation under this economic program. Cost sharing does not mean that parents must pay the full school fee, but that parents share part of the fee. For example, often parents are required to supply the cost of travel, books, paper, pencils, and other such items (Mosha 2001)

Since independence, the Tanzanian government has allocated about 20% of its budget to education. In 1977 universal primary education was established in Tanzania (World Bank 1986). In 1994 the enrollment rate for Tanzanian children in primary schools, public and private, was 1,923,062 males compared

to 1,873,768 females. In the same year, the enrollment rate for form I-IV, including public and private schools, was 81,699 females compared to 104,547 males; and in form V-VI the rates were 77,969 females compared to 95,651 males (United Republic of Tanzania 1995).

It was reported in 1996 that 47% of primary school age girls did not attend school in Tanzania (Lone 1996). The gross primary school enrollment rate fell from 93% in 1980 to 74% in the early 1990s and reached 78% in 1995. Tanzania's secondary school enrollment rate is one of the two lowest in the world. Tanzania had a secondary school enrollment rate of 5% in 1995, compared to a rate 11% in Uganda and 25% in Kenya (Lone 1996).

Although formal primary education starts at age seven in Tanzania delayed enrollment is common. The attendance rate reaches its peak of 85% at the age of 13 and then begins to drop. In 1993/94, the age for the average girl to begin primary school in Tanzania was 9 years old, while the age of the average boy was 10. About 50% of children ages 14 -17 have left secondary school or have never started secondary school. About 25% of students continuing to upper secondary school are female. Thus, one of the key issues is increasing the number of girls that successfully progress from primary to secondary school (World Bank 1997).

Why do these educational disparities exist to such a great extent between females and males in Tanzania? Economic limitations of the family and/or cultural practices cause some children, mostly girls, to not attend school and to sometimes do poorly if they do attend (Pollitt 1984). Household demands have been found to be a key determinant in girl's educational participation. Parents must weigh the benefits of the girl and her family against the costs to educate her. Studies indicate that limited job market opportunities for girls and women deter parents from sending their daughters to school (Tietjen 1991).

Parents may not consider education as necessary to fulfill women's role of wife and mother. When a daughter marries benefits stemming from her education may go to her husband's family and not her own. Education is often viewed as inappropriate for the traditional societal role of women because it could cause "them to exhibit less respect for male authority and to be unwilling to work as hard" (Tietjen 1991). Additionally, girls are commonly expected to care for younger children and work in agriculture. Tasks completed by girls such as agricultural work and caring for the sick allow their mothers more time to complete other tasks. Therefore, parents do not always view education as a way to increase their daughter's productivity or economic and social value (Tietjen 1991).

Even "free" education can cost too much for parents to send girls to school. School associated expenses such as "recreational and activity fees, exam fees, uniforms, supplies and material, transportation, lunches, and gifts to teachers, etc." must be paid by parents (Tietjen 1991). Lone asserts (1996), "when a poor family considers how much a daughter can help in cleaning, cooking, collecting wood and water, and looking after younger children, and how little opportunity there will be for her to get a paying job even if she is educated, then the returns rarely seem to warrant the expenditure".

It is this logic that explains how families decide to educate their daughters. Families living in conditions of poverty may not have the options from which to choose that wealthier families have. Girls who are enrolled in school still bear the burden of assisting with domestic chores and thus may be absent from class frequently and may not have an adequate amount of time to complete their homework (Lone 1996).

*Structural Adjustment Program*

The economic crisis experienced by Tanzania in the 1960s and early

1970s, led the government to submit to structural adjustment measures enforced by the IMF and the World Bank in the mid 1980s (Moshi 1995). In 1974 Tanzania faced a major balance of payments deficit resulting from huge food importation because of drought, and resulting from the effects of oil price increases (Shao 1992). The structural adjustment program (SAP) implemented in Tanzania, as well as in other African countries, involved cutbacks in government spending on social services in basic needs areas such as education, health, and employment (Moshi 1995). O'Brien states, structural adjustment programs "have ignored or given insufficient attention to the social costs of adjustment" (O'Brien 1991 cited by Gladwin 1993).

The poor of Tanzania, the majority of whom are women, are especially negatively affected by social service cutbacks. The expansion of the Tanzania health care network in the 1960s and early 1970s was short lived. The network became too costly to support as a result of the late 1970s economic crisis and the subsequent adjustment measures. The government designated its role as the provider of social services to district authorities and village communities. This venture began a decline in the health of the Tanzanian population. The structural adjustment program stated that the Tanzanian government "would not be in the position to restore social services to the level of the 1970s" (Moshi 1995).

Household level sustainability appears to be related to women's lack of power in the household. Economically, structural adjustments programs have added to the burden of individual women by reducing "her and her family's access to health, education and employment" (Mbugua 1997). SAPs have allocated "resources to the detriment of women because they have failed to take note of women's reproductive, productive and socializing roles" (Adepoju and Mbugua 1997). It is often overlooked that gender biases built into SAPs have not

only had a negative effect upon women, but consequently on their families (Adepoju and Mbugua 1997).

Obbo (1995) states that the "AIDS epidemic occurred just as the IMF's structural adjustment and cost-recovery programs were being implemented". The AIDS epidemic coupled with the effect of SAPs added to the already demanding responsibilities placed upon women. SAP policies tend to "reinforce the assumptions and stereotypes of women as nurturers" (Obbo 1995). The current trend in community based health care providers lends a false image to the reality of health care services. The reality is women are becoming overburdened because of their role in caring for sick family members. In some cases, women are coping with this burden by "re-instituting traditional community networking mechanisms that had fallen into disuse during the 1960s and early 1970s" (Obbo 1995). Traditional community networking mechanisms call upon other women in the close vicinity, whether family or friends, to assist with caring for the sick and orphaned (Obbo 1995).

All of these women are subject to a government that does not have the funds to adequately meet the needs of the sick and the orphaned. Moshi (1995) states that the "economic crisis has made it increasingly difficult for the government to be able to maintain its employment policy". These events and policy changes have led to an increase in unemployment and migration to urban areas in search of wage employment (Moshi 1995). Increasing numbers of family members, usually males, are migrating to urban areas for work (Campbell 1995).

As a result of rural economic decline migrants are increasingly staying in cities and cutting ties to rural family. This occurrence can be seen in contemporary Dar es Salaam (Campbell 1995). In the process of migration other family members, usually women and children, remain in rural areas. Migration

often breaks family ties and increases child-care and production responsibilities of women. (Ohuche and Otaala 1981). Remittances from the urban family member may help to some degree to meet daily responsibilities. However, in the light of the AIDS epidemic "rural populations may face a considerable economic and psychological burden, caring for sufferers who return to their rural villages, and/or losing remittances which maintain many rural households and may be critical for socio-economic differentiation" (Akeroyd 1997).

*Health Care Services*

Three health care systems exist in Africa: traditional medicine, biomedicine and itinerant drug vendors. Rural residents generally seek help from traditional medicine and itinerant drug vendors, while urban residents are more apt to turn to biomedicine in times of need. Rural residents may travel long distances to urban health facilities to use biomedicine (Oppong and Williamson 1996). Oppong and Williamson (1996) claim that many Africans today are self-medicating with drugs supplied by itinerant drug suppliers rather than going to a traditional healer or to an urban health facility that may be a great distance to travel and offer unaffordable medical care.

Basic Western medical care in Tanzania is provided by the state and Christian missions. Rural areas are likely to be served by local clinics. In 1999 the doctor/population ratio in Tanzania was 1 doctor per 22,900 people (HealthNet Tanzania 2000). In 1997 forty-two per cent of Tanzania's population had access to health services. That figure would have probably been lower if only rural residents had been taken into account (Mukangara and Koda 1997). Koda (1995) reports that Tanzania does not have adequate public child care facilities. Most Tanzanian day-care facilities are under staffed and poorly equipped. Day care facilities may also charge more than most parents can afford (Koda 1995). Hence, many parents, both rural and urban, count on family or

neighbors to assist with child-care when needed.

Fewer Africans are seeking care from formal sector health services because fewer free services are available. In the light of structural adjustment programs, governments have been forced to move from "free to paid health services, from public to private health care, and from minor to major roles for charities" in the health industry (Turshen 1999). As a result of these changes fewer Africans are turning to Western style health services for care. The changes in health services correlate "with increases in illnesses and fatalities" in Africa (Turshen 1999).

The Tanzania population is "under-serviced in the health sector and under protected against morbidity and mortality" (Turshen 1999). It is yet facing further strain on the ability to cope. The increasing number of ill children and adults and orphaned children due to the AIDS phenomenon is further straining the economy and family relations (Turshen 1999).

**Contextualizing the Family**

*The family does not thrive in isolation, but is part of a larger cultural context that influences its function (Boss 1988).*

Cheal refers to "social location" when emphasizing the importance of context and the need to recognize situational circumstances such as socio-economic status and culture as they affect individual and familial choices (Cheal 1991 cited by Dillaway 1999). Weisner (1994), similar to Cheal, emphasizes the "cultural place" as containing the "physical and ecological aspects, resources which provide constraints and opportunities for survival, demographic characteristics and health and mortality threats - as well as beliefs, practices and social arrangements shared by its residents which make living in that place

meaningful".

It is the larger culture of which families are part that provides the rules by which the family operates and interprets its surroundings at the micro level (Boss 1988). The cultural context also defines the larger society's "rules for problem solving, management styles, and accepted methods of managing stress" (Boss 1988). The definition of family reflects a cultural and historical moment in time. Moreover, the family is in a constant state of change.

The socio-economic context must be taken into consideration when examining the family and its functions. When looking at the country of Tanzania one must consider that the majority of the population lives or has lived in rural areas where traditional values and norms to a greater or lesser extent are still in operation. The families found in urban centers such as Dar es Salaam, are a small proportion of the entire population (Omari 1989). It is important to realize that the family's social and cultural location will influence the impact of a crisis and the ways in which it attempts to manage and overcome the crisis.

*Familial Organization in Tanzania*

Tanzanian culture is a "combination of the customs, norms, beliefs and traditions of more than 120 ethnic groups" (Mukangara and Koda 1997). Most African societies recognize descent through the male line (patrilineal descent) or the female line (matrilineal descent) (Potash 1984). Hence, those who can inherit land or property are related to the deceased by a common male or female ancestor (Munalula and Mwenda 1984). Eighty percent of the ethnic groups in Tanzania are patrilineal and guided by the patriarchal system (Mukangara and Koda 1997). Areas in which matriarchy predominated in the past are leaning towards a system of patriarchal beliefs. This change is due to "influences from foreign religions, commercialization, and intermarriages with people from patrilineal communities" (Mukangara and Koda 1997). A belt of predominately

matrilineal ethnic groups exists in the southern part of Tanzania. It is interesting to note that the same belt of matrilineal groups extends across central Africa to western Africa (Omari 1991).

Adepoju and Mbugua (1997) state, "in Africa it is the family as an entity - rather than the individual members of the family - which defines the types of adaptation mechanisms as well as the boundaries of adaptation parameters employed by each member of the family". Studies tend to look at "households" and "households don't always coincide with the family", the two are not interchangeable (Adepoju and Mbugua 1997). Family includes the network of kin who may or may not share a residence, and household refers to people that share a residential unit.

The family may be defined in a more extended sense of "kin relations that people may activate selectively, and which may include relations by descent and by marriage (affines), as well as fictive kin" (Campbell 1995). Potash (1984) states that African family ties "are based on the enduring, separate kinship ties of husbands and wives", and these ties commonly "take precedence over the bonds of marriage". Therefore, the African family can generally be characterized as a consanguineal system in which domestic groups are based on descent, and in which affinal ties have precedence over conjugal ties (Potash1984; Munalula and Mwenda 1984).

Extended family in Tanzania may "either be living in the same compound with different houses or the same house but having different and separate rooms" or "living in different compounds where separate houses are built" (Omari 1991) The extended family is more common in rural areas and the nuclear family in urban areas (Koda 1995). The membership of the family depends on the context and purpose for which it is constructed (O'Donovan cited by Ncube et al. 1997).

Among patrilineal groups a man's primary responsibilities may be to support his mother, sisters and other kin rather than his wife and children (Potash 1984). Inheritance tends to vary among patrilineal and matrilineal groups. In patrilineal groups in some cases inheritance goes to first and last sons, other sons, nearest male relative, eldest brother, half-brother or eldest son of the first wife (Mukangara and Koda 1997). In the case of divorce or death within the patrilineal system, children are usually incorporated into the father's side of the family. Children are considered property of men in the patrilineal system (Ncube et al. 1997). Hence, the socioeconomic status of men and women from the same family may differ greatly (Potash 1984).

When a male household head dies in a patrilineal society his eldest son generally inherits his social position, land rights, cattle, and other possessions. However, in some situations his possessions may be divided among other male heirs such as other sons and brothers. It is common for daughters to inherit little or nothing from their fathers, and wives to inherit nothing from their husbands. In fact, wives and unmarried daughters are often themselves inherited by the sons or brothers of the deceased. Thus, even after the death of her husband, a woman may be considered to "belong" to the patrilineage that paid her bridewealth (Davison 1997).

In matrilineal societies brothers or maternal uncles rather than husbands are responsible for the support of their sisters and their sisters' children (Potash 1984). Among matrilineal ethnic groups, "the wife's affinity may belong entirely to her own clan or partly to her husband's clan" (Mukangara and Koda 1997). The wife or husband can chose to stay in their home after the death of the other, but if she or he chooses to leave all property rights will be lost. Inheritance of land and possessions in matrilineal systems commonly goes to the mother's brother or her daughters; or the father's sister and her children (Mukangara and Koda 1997;

Davison 1997). Children belong to the mother's side of the family in matrilineal systems (Potash 1984).

Family members, from the patrilineal or matrilineal systems, may attempt to take the property of the deceased member such as "land, houses, cars, clothes, money and cattle" without taking into consideration the welfare of the family members remaining (Kayongo-Male and Onyango 1984). According to Mukangara and Koda, both the patrilineal and matrilineal kinship patterns are "heavily influenced by traditional socialization processes, ascribed gender roles, ownership and decision-making patterns that are disadvantageous to women and girls" (Mukangara and Koda 1997).

Patriarchal control patterns govern most households, especially those that are rural, whether they be matrilineal or patrilineal. Men may control and manage most agricultural resources including land, livestock, export crops, tools, means of transport, and credit. Additionally, men often control earnings from wage activities. Traditionally, in most patrilineal systems, property or land is not inherited by the wife; although she may be granted usage rights over portions of land which she is farming (Kayongo-Male and Onyango 1984). If a woman becomes a widow or divorces she may lose access to the land allotted to her by her husband (Davison 1997).

Residence patterns are important in determining the influence of the extended family and the degree of economic independence or dependence of a married couple in relationship to the extended family. In patrilocal systems, residence is established near the husband's family; in matrilocal systems, residence is established near the mother's family. The neolocal pattern of residence is established near neither the husband's or wife's family (Kayongo-Male and Onyango 1984). The martilocal system of residence benefits women in that they remain in their own community in which they may have established

rights of land and property ownership (Potash 1984).

**Importance of the Extended Family**

Although the extended family system has been discussed in the previous section, it is an important part of African life that warrants further discussion. Kayongo-Male and Onyango (1984) claim that the "most significant feature of African family life is probably the importance of the larger kin group beyond the nuclear family". Members of the larger kin group often do not live near other relatives. However, extended family members are connected by reciprocal support obligations (Kayongo-Male and Onyango 1984).

Care and respect for the elderly are still very important in African families (Kayongo-Male and Onyango 1984). Adult children have a traditional "obligation to support their parents, grandparents as well as siblings and their children who may be in difficult circumstances thereby making the membership of a family nearly indeterminate" (Ncube et al. 1997). The supportive relationship may change members from time to time and the flow of support will vary according to circumstances. Familial obligations involve the sharing of "labor power and time" (Ncube et al. 1997). The entry of family members into wage employment and the subsequent migration out of rural areas changed "the reciprocal labor obligations into money obligations for those people engaged in employment and therefore unable to contribute the fullness of their labor to the family" (Ncube et al. 1997).

The extended family system in Africa, especially those in rural areas, is viewed as a form of a social security system (Kayongo-Male and Onyango 1984). The quote below from Ocholla-Ayayo (1997) summarizes the concept of "*harambee*"; the ability of the extended family to operate as a system of support.

> The concept of harambee at the household, lineage and clan levels suggests that kinship ideology and kinship systems of production, distribution and

> consumption are more positive than any system that could be introduced in Africa. The fact is, no government will come to support an individual or a household unit - the family - in time of need, but the kinship network can do this and has done it.

Flexible family boundaries and an extended network of kin that can be activated selectively may provide the means for families to survive in economically harsh environments (Campbell 1995; Boss 1988). Flexible boundaries of the extended family network are engaged during times of stress. One such time is when deceased family members leave children with one or no parent. Kayongo-Male and Onyango (1984) claim that according to African customary law children who lost one or both parents "were actually in the custody of an extended family unit, so that illness or death of parents simply entailed a relative taking over responsibility for the child".

Orphaned children incorporated into the extended family are thought to belong to everybody in the family system, meaning that anybody of adult age can discipline them (Kayongo-Male and Onyango 1984). According to Ncube et al. (1997), "changing social and economic conditions together with changing social values have affected the traditional operations and functions of the extended traditional family". In recent years African society has experienced increasing capitalist development which has in turn affected local forms of social organization at the family and household level. Urbanization has altered the manner in which kinship is constructed (Campbell 1995). Kinship will be constructed in such a way that it will function within evolving circumstances. Enabulele defines modernization as "those components, such as industrialization, urbanization, education, economic development and the general improvements which enhance the quality of life" (Enabulele 1993).

As stated previously, outward - systemic changes impact the family and

cause changes to take place within the unit. Modernization and the increase of families migrating to urban areas are two such changes. An increase in modernization is "often accompanied by a decline in the functions of the familiar group, similarly there is also a decrease in the social control exerted by this group over its members" (Enabulele 1993). Thus, as families move into the urban social environment they are exposed to more forms of modernization and in turn make adjustments in their social habits to accommodate the requirements of the new environment (Enabulele 1993).

**Gender Based Care Issues**

*The poorest peasant is one without a wife –*
*An AIDS patient without a sister or mother is doomed (Obbo 1995).*

The above quote highlights the role of women in production and nurturing (Obbo 1995). It is on women that the burden of care for ill family members and orphaned children falls. Therefore, it is necessary to look at the role of women as caregivers within the family and to look at their access to resources needed to fulfill this role. While we should question in what ways the familial system is fragmenting or changing, we must also question in what ways the caregiving role of women has changed and/or increased. It is women who bear the role of caregiver and nurturer to their families, to the community, and to society at large (Mbugua 1997).

It is imperative that an account "be taken of the status of women as the main focal point of change" because "the problems encountered by women are a reflection of the family's problems and an expression of its conditions which cannot be understood in isolation" (Adegboyega et al. 1997). Therefore, "questions must arise sooner or later regarding the extent to which the African woman will continue to be the pillar of the African family, with all the stress that

this entails, without herself breaking down" (Adepoju and Mbugua 1997).

Are the capabilities of women looking after an increasing number of orphaned and sick children stretched to the breaking point? If so, what can be done to strengthen her economic capabilities and decision making power within the family and community? Part of securing a future for orphaned children requires not only seeking to strengthen the family, but also taking a closer look at the problem from a gender perspective.

AIDS and its impact upon families and individuals is clearly a gender issue. Women and men are differentially affected by the disease, have unequal access to resources, and will thus employ different coping strategies. It is necessary to question in what ways a household copes in the face of insecurity while taking into account gender inequalities (Laier et al. 1996). Two significant areas of examination are: "what happens within the household and in its immediate locality (e.g. actual food production, social relations underpinning livelihood systems); and how external influences (e.g. access to land and other inputs, macro-policy changes, state interventions) have differential impacts on men and women" (Laier et al. 1996). In sum, can female family members acquire needed resources in times of crisis?

Seeley et al states "there is a link between an individual's lack of access to resources and the economic strategies adopted to survive and to support a family" (Seeley et al. 1994 cited by Akeroyd 1997). Given women's role as caregiver within the family, it is apparent that they play a key role in sustaining the family in times of stress. Thus, men and women play different roles in the process of coping due to culturally prescribed gender roles and resources available to each (Laier et al. 1996). According to Laier et al. (1996), coping options which women have to choose from "depend on access to kinship and other social networks, common resources, particular types of migration, and a

range of gender specific forms of off-farm employment". Laier et al. (1996) continues by stating that "key constraints on women's adaptive capacity are linked to ownership of assets and access to income, community-based resources and services provided by government and NGOs".

It follows that female-headed households and women in male-headed households tend to develop specific types of coping strategies in times of crisis (Laier et al. 1996). Deaths of women are generally more problematic for families than the death of men. The death of mothers is crucial, because as stated earlier, the responsibility of child-care falls primarily to women (Bourdillon 1987 cited by McAdoo and Obi 1999). As women attempt to cope with the loss of adult family members and the subsequent lose of labor, they may employ children, especially girls, to help with household and agricultural tasks (Laier et al. 1996). This strategy only provides an immediate solution. In the long run, children are better able to become employed in wage earning positions, and assist the family financially if they have obtained an education.

Turshen stated in 1999 that a greater number of women compared to men were living in economically poor African rural areas. Tanzania is experiencing a rise in single – parent households and also in the number of female-headed households. The population of Tanzania consisted of 18.6% of female-headed households in 1995. This occurrence is the result of "divorce, widowhood, separation, or women deliberately deciding to have children of their own or failing to identify the biological father of her children" (Koda 1995).

Women's informal and family duties are broadening as poverty increases and public services decrease. As a consequence of inadequate medical facilities and support services women increasingly find themselves caring for ill relatives and for the children of relatives who have died (Turshen 1999). In the absence of government support services, more burdens are placed upon women to fulfill

the role of caregiver. These women may in turn look to extended family and community networks for help in dealing with a crisis situation (Antrobus 1989; Walu 1987 cited by Schoepf 1993). Additionally, these women may be sick due HIV/AIDS and will eventually die; most likely passing on their burdens to another woman.

Household coping and coping strategies employed by the community usually mean a wider and wider circle of women will be called upon to assist in caring for the ill and orphaned in the context of AIDS (Akeroyd 1997). The same women who will be called upon in such a great time of need are the women who "often lack access to cash, credit, land or jobs", and "engage in activities in the informal sector" in order to make a living (Schoepf 1993). Development and policy planners add to the disadvantageous position of women by "explicitly or implicitly" expecting them "to shoulder the burden" of caregiving (Akeroyd 1997).

**Conclusion**

> *What is certain is that the family has been in a constant state of change both historically and geographically and, from this point of view alone, it is evident that if we are to understand and meet the needs of the African family, which is a construct created from the interactions of many cultural and legal sources, we need to explore it as broadly and widely as possible (Ncube et al. 1997).*

The Tanzanian family is a reflection of today's reality. One may question can the people of Tanzania hold on to their traditional coping mechanisms in the present time? It is apparent that as the social environment changes it follows that adjustments must take place at the micro level of family interaction. Thus, it is logical to conjecture that traditional coping practices in Tanzania are bound to change to some degree. The degree to which change occurs will depend on the location, the way in which the individual family interprets their social environment, and their access to needed resources whether they be material or human. The

preexisting societal construction of gender roles and the responsibilities attached to those roles will dictate, in this case, which family and community members are expected to care for the ill and orphaned.

# CHAPTER 3

## THE RISING NEED FOR FORMAL ORPHAN CARE MODELS

*Indeed, Africa's youth face an uncertain future, a future for which they are ill-prepared and bear no responsibility in the first instance and over which they have little control (Adepoju and Mbugua 1997).*

In the above quote are Adepoju and Mbugua referring to something more than the uncertain conditions that African youth have always faced? What they are referring to is the AIDS epidemic and its impact upon today's African youth, and the effects it will have upon tomorrow's youth. The toll the disease has upon youth internationally is not always apparent nor is it at the forefront of efforts delivered by international agencies. There has been a great focus on what can be done to prevent the spread of HIV/AIDS and to treat its victims, which is necessary, but what about the survivors of the disease, many of whom are children? What are the direct and indirect effects on children who are HIV/AIDS infected and on those that are affected by the disease but not infected?

This chapter will examine the direct and indirect impact of AIDS upon the lives of African children and their care environment. The chapter is divided into five sections. The first contains an introduction to the issue of AIDS orphans. The second examines what happens when a generation dies. The third looks at the issue of taking responsibility for orphans and what options exist. Section four explores formal care options from a feminist perspective and section five concludes the chapter.

**AIDS Orphans**

Impact of HIV/AIDS Upon Children

Loss of family and identity
Psychosocial distress
Increased malnutrition
Loss of health care, including immunization
Increased demands for labor
Fewer opportunities for schooling and education
Loss of inheritance
Forced migration
Homelessness, vagrancy, starvation, crime
Exposure to HIV infection
Exploitation and exposure to violence
Gender differentials in impact
(The Status and Trends of the HIV/AIDS Epidemic in the World 1998)

This list illustrates the ways in which orphanhood may impact the lives of African children. Most orphans are not HIV infected but are at high risk of economic deprivation, a range of behavioral and developmental problems, as well as engaging in high-risk behaviors associated with HIV transmission (Levine 1996). Various people have hypothesized about what will happen in Africa in the not so distant future if the increasing number of orphans is not taken into account. Okeyo (1995) claims that in urban areas orphaned children may turn to the streets and become involved in roaming gangs. For example, the number of street children in Lusaka, Zambia in 1991 was 35,000; by 1998 the number had risen to more than 90,000 (Daley 1998). Daley (1998) asserts "the street children here are like street children everywhere -- hardened and focused on immediate survival". As the number of abandoned children living on the street increases the children will likely become involved in activities that will perpetuate the spread of HIV/AIDS (McAdoo and Obi 1999).

Ninety percent of AIDS orphans reside in Africa and thus will end up dealing with some or all of the aforementioned circumstances. As mentioned

previously, WHO estimates that 20% to 40% of children born to HIV positive mothers will be infected, develop AIDS and die before the age of five. The remaining 60% to 80% of children will not be HIV infected, but will be orphaned within the first 10 years of their lives (AIDS Analysis Africa 1992).

While the previous list refers to the impact of AIDS upon children, the crisis has been looked at in broader terms as well. Okeyo (1995) states that "failure to tackle the orphan problem with the resources it deserves could see the late 1990s and early part of the 21st century a period of economic disruption and political turmoil in Africa". Hence, in the long run as a result of the death of the middle parenting/working generation the work force will become younger, less educated, and may have physical problems due to malnourishment as a child. These circumstances will affect not only individual lives, but also the well being of communities and countries as a whole.

**What Happens When a Generation Dies?**

Orphaned children are not a new phenomenon in Africa. Africans have dealt with many children over the years whom were orphaned for various reasons including famine, migration, and disease. Orphaned children were usually absorbed into the extended family and not considered a problem. When a crisis arises that leaves a child orphaned generally "the problem is discussed by the family elders, and a family member, usually the father's eldest brother, is assigned the care of the orphan" (SAFAIDS & CFU 1996). After this informal decision-making process the orphaned child is raised as part of the father's eldest brother's family where they may be taken care of by a grandmother or an aunt (SAFAIDS & CFU 1996).

In Zambia, it was reported in 1998 that close to 75 percent of households were taking care of at least one orphaned child (Daley 1998). As the AIDS epidemic continues to take its toll on many African lives the family "undertakes

the long-term and time-consuming nursing of its stricken members, while AIDS orphans also become the responsibility of the surviving kith and kin" (Adepoju and Mbugua 1997). It is important to realize that families caring for kin who are suffering from AIDS will feel the impact of their death long before it occurs. A family member with AIDS will likely cause the family economic loss by not being able to contribute to the workload and by requiring extra funds for care.

As a result of an increasing number of AIDS related deaths "we are seeing the emergence of grandparent-headed and adolescent-headed households" that "may be ill-equipped for the role" (Drew, Makufa, & Foster 1998). Surviving relatives can become overwhelmed with the increase in the number of orphans and fewer working-age adults in their family and community. Hence, kin support networks that elders rely upon for economic and labor assistance may be shrinking yet further under the current conditions (Kinsella 1996 cited by McAdoo and Obi 1999).

Although the times may be tough, providing for orphans is still thought to be the responsibility of grandparents (McAdoo and Obi 1999). Female fatalities, especially those of mothers, are critical more so than male fatalities because it is women who shoulder the main responsibility of childcare and child rearing (Bourdillon 1987 cited by McAdoo and Obi 1999). When mothers are no longer available the responsibility of childcare generally becomes that of grandmothers (McAdoo and Obi 1999).

It is considered culturally appropriate for grandparents to assume economic support of grandchildren in crisis situations. In fact, for a grandparent to refuse to care for a grandchild is to "go against cultural convention" (Ocholla-Ayayo cited by Weisner 1997). It is also culturally appropriate for the relationship between grandparents and grandchildren to operate reciprocally (Ocholla-Ayayo cited by Weisner 1997). The reciprocal relationship usually involves

grandchildren aiding grandparents with domestic tasks or income generating activities. However, the reciprocal relationship cannot function if the child is too young to assist in activities or if the child is sick because of HIV and/or tuberculosis infection. In the case of AIDS, grandparents may be left with more than one grandchild in their care and in turn may experience labor and economic strain.

It is important to remember that normally the wealth flow is from children to adults; parents and grandparents. Grandparents will lack support from an adult family member or members if they are suffering from AIDS or deceased. Thus, role overload may occur as grandparents assume the role of parent to one or more grandchildren who may or may not be HIV infected. It is usually grandmothers more so than grandfathers who are expected to care for grandchildren (Ocholla-Ayayo cited by Weisner 1997). When these grandmothers are no longer able to care for their grandchildren, or when they die, what will happen (Campbell 1999)?

At times financially better-off extended family members of a "lineage are obliged to share the benefits of their education or businesses by looking after poorer relatives, either through substantial financial outlays or through accommodating and sheltering them" (Adepoju and Mbugua 1997). The taking in of children from other family members known as child fostering, is a common practice in some African countries. Child fostering may be considered a traditional coping mechanism by which better-off family members take responsibility for one or more of their monetarily poorer relative's children and sometimes non-kin children (Adepoju and Mbugua 1997).

The practice of child fostering gives children from poor homes the opportunity to attend school and receive job training, while their foster parents acquire assistance with domestic chores in return. In some African countries

there is little tradition of accepting non-kin as foster children. Biological parents sometimes fear that their children will be neglected or abused by other families (SAFAIDS & CFU 1996).

Children may be stigmatized and unacceptable for fostering if they are from a family in which members were suspected to have died because of AIDS. The extended family and community may fear contracting HIV/AIDS and/or tuberculosis from the orphaned children whether they are infected or not. Children are not often tested for HIV infection. The actual infected status of the child does not matter, what is taken into account is their association with others who were infected. This fear ties into lack of education on the transmission of HIV/AIDS. According to Miyanda (WHO), lack of non-kin child fostering could cause problems in the "future because of the way AIDS tends to devastate whole families, particularly in villages" (Daley 1998).

Conventionally, the extended family assisted not only with the care of orphans, but also with the survival needs of kin and non-kin in times of other crises. Vaughan (1992) claims that as the effects of famine worsen traditional familial and tribal reciprocal customs of helping break down; "increasingly each family, and then each individual" tend only to their own needs. In other words, families recognize that during escalating situations they must care for their own immediate problems first and may not have the resources to aid extended family members or non-kin.

Vaughan's famine analysis and other such analyses of crisis coping may be applied to the AIDS epidemic. As the number of orphans increase, the pool of "potential caregivers shrink" and "traditional coping mechanisms stretch to the breaking point" (The Status and Trends of the HIV/AIDS Epidemic 1998). Current health care systems in many African countries are unable to care for the growing number of AIDS victims placing the responsibility on the family. The

increasing number of orphans is coming at a time when surviving relatives may be financially unable to properly care for them (Adepoju and Mbugua 1997). Furthermore, relatives might not take in orphans because they see them as carrying the same disease that killed their parents and therefore will become a financial strain without long-term benefits. The increased strain of caring for ill family members and orphaned children may cause conventional support mechanisms of the extended family to be near the breaking point. Families may no longer have adequate resources to offer help to extended members let alone non-kin.

**Who is Responsible?**

If the extended family's ability to care for orphans is lost, other forms of care must be put in place. The question is to whom does the responsibility fall? Should institutional and foster care programs such as those implemented in the West and elsewhere be implemented in Africa? Are there other options to caring for orphans and if so what are they?

As stated earlier, caring for orphans is not a new development in Africa. What is new is the large number of orphans. Due to the "historical role of the extended family there are few established institutions in Africa able and willing to take on the task of caring for orphans" (AIDS Analysis Africa 1992). The family in Africa has been perceived as the provider of a secure structure in which sick family members and orphans could find refuge and support.

Recent literature has presented alternatives to family care of orphans. In this chapter three alternatives to extended family care will be examined: orphanage/child rehabilitation centers, foster care programs, and community-based volunteer programs. All have been implemented to differing degrees by various people in assorted countries of Africa. Each of these three methods of orphan care are explored, an example of each given, and the strengths and

weaknesses of each pointed out in this section.

Orphanage/Child Rehabilitation Center

Missions located in Africa, in the past and the present, have at times included an orphanage on their grounds. The structure may or may not be referred to as an orphanage, but will operate as one all the same. These facilities, sometimes referred to as child rehabilitation centers, also exist outside of missions within various communities. Children usually come to be placed in an orphanage due to abandonment, parental death, financial hardship or other circumstances that leave them without family. Some children only remain in an orphanage for a short time before members of their immediate or extended family are able to care for them and retrieve them from the orphanage.

*Example*

The Mgolole Orphanage Home was founded in 1950 by the Roman Catholic Missionaries of Morogoro, Tanzania. Today the facility still exists on the grounds of the Catholic Mission just outside the city limits of Morogoro. In July, 1998, five sisters of the Roman Catholic Church cared for 37 orphans. The orphanage is sponsored by the Catholic Church and received no outside funding at that time. The Tanzanian government has not offered any funding since 1993. The orphanage provides shelter, food, clothing, some medical care, and schooling. In the case of parental abandonment or death, children are brought to the orphanage by Morogoro hospital staff or by town officials. Sometimes extended family visit their kin in the orphanage and will take them home when they are able to care for them. The orphanage cares for both HIV infected and non-infected children (Mkumbaye 1996 & 1998).

*Strengths*

Orphanages can help children who have no extended family or non-kin from which to receive support. These facilities may be able to offer care in terms

of material needs that include shelter, food, clothing, and some medical supplies (Drew, Makufa, and Foster 1998). Children can find a sense of security within the shelter and companionship with other children. If the orphanage is well funded the children will probably be able to attend school. Orphanage existence is bound to increase the odds of child survival when compared to street existence.

*Weaknesses*

Problems seem to arise when these facilities are unable to properly care for children. According to Drew, Makufa, and Foster (1998) orphanages, "have limited capacity and are very expensive to run and do not provide adequately for other needs such as belonging to a community". Governments do not have the financial resources to undertake a program of this kind. It was reported in 1992 that 70 children's homes existed in Uganda with a total capacity for 2,500 children. The Uganda Minister of Health, estimated that 50,000 children could be orphaned annually (AIDS Analysis Africa 1992).

In 1992 in Zimbabwe, "orphanages in the province of Manicaland were becoming overcrowded, leading to a mortality rate of 25% for children under one year of age" (AIDS Analysis Africa 1992). Obbo mentions two instances in which individuals solicited cash and supplies such as food, clothing, and medicine to set up informal orphanages. Officials, after finding out about the orphanages, reported that health risks came in the form of overcrowding, sharing of eating and drinking implements and sharing of toilet outlets. Many of the children were sick and had been given only small portions of food. Individuals attempting to run the facilities lacked the experience to operate orphanages that could properly care for children. Government officials did not have the resources to help with these orphanages. However, the homes continue to operate with increased funding from international NGOs (Obbo 1995).

Placing children in institutional care will put them at risk of stigmatization when integrated into community settings, as well as causing them to develop feelings of unwantedness, resentfulness, rebellion and could possibly lead to delinquency (SAFAIDS & CFU 1996). Orphanages may not receive enough funding to pay children's school fees, to supply nutritious food, and to adequately staff facilities let alone staff them with trained workers. Additionally, staff may or may not teach children domestic skills or other basic skills such as farming and gardening.

Programs of this nature require a substantial amount of resources. Most donor agencies are reluctant to fund comprehensive orphan rehabilitation programs. They prefer to spend money on preventative programs that disseminate information and/or educate the public. While these are useful interventions, providing for orphans is also important and will in turn permit a preventive message to be delivered to a high-risk population (Okeyo 1995).

Foster Care Program

Here I am speaking of a non-kin foster care system in which families volunteer to care for unrelated children. These programs generally offer some sort of incentive to the foster family in return for their taking one or more orphaned children into their home. Some of these programs are operated by NGOs and community-based organizations.

*Example*

A study on the foster care system for orphaned children on commercial farms in Zimbabwe was undertaken in 1996 by the Southern Africa AIDS Information Dissemination Service (SAfAIDS) and the Commercial Farmers Union (CFU). The study found that the Department of Social Welfare was unable to offer financial assistance and no external support was expected to be available in the future. However, the foster scheme on this particular farm continues to

operate, but greatly because of the farm owner's personal commitment to ensure the care of the orphaned children by using their own financial input to supply incentives for foster families (SAFAIDS & CFU 1996). Workers on this commercial farm felt that the care of orphans "should ideally be through fostering by relatives in the traditional extended family system, but where no relatives can assist, fostering by non-relatives should be encouraged" (SAFAIDS & CFU 1996). The main concerns of farmers were sustainability of the foster program, administration of the program, and risks of abuse of the scheme in the form of exploitation of children (SAFAIDS & CFU 1996).

*Strengths*

According to Okeyo empowering "caregivers at community level would ensure that rehabilitation of orphaned children could take place in their own traditional extended family and clan environment. This would ensure psycho-social stability of the children and enable them to inherit land and other property of the deceased parent" (Okeyo 1995). Moreover, if community members, who may or may not be members of the child's extended family or clan, are economically empowered in the form of cash or other valuable incentive, the orphaned child would then be able to grow up within the community.

*Weaknesses*

Here again a major problem is securing funds to be used as incentives for foster families. Incentives do not necessarily have to come in the form of cash, but might include "improved or extended housing, more land to grow crops, free education for all children in the household and other benefits in kind" (SAFAIDS & CFU 1996). Nevertheless, the problem of obtaining these incentives still exists.

Another problem comes in the form of spiritual beliefs. Some groups in Africa will not foster a child because they fear the ancestral spirits of the

deceased parents (SAFAIDS & CFU 1996). For example, related or unrelated children are never fully assimilated into foster families in Tiriki, Kenya because of the traditional belief that the "blood (*masayi*)" of the child will bring illness and maybe death to the other children who are related to the foster parent (Sangree 1987).

Identifying the best-suited families to assume the position of fostering is very important. Community members as well as foster families could show resentment toward AIDS orphans, "both overt and subtle physical abuse and neglect is common" (Baggaley and Needham 1997). According to Baggaley and Needham (1997), orphans might "end up being used as a source of free labour, and young girls may be forced to work as prostitutes". Daley (1998) asserts that foster children might receive less to eat than the other children in the household, may be the last to obtain material resources such as clothing, and could be the last to attend school if they attend school at all. Concerns voiced by community members include: foster children would lack discipline and supervision; foster parents will invest in a child with schooling and care only to have the child taken away by her or his biological family afterwards (SAFAIDS & CFU 1996). Therefore, treatment of orphans and expenditures within the foster family should be monitored.

Community-Based Volunteer Program

This approach involves volunteers identifying and regularly visiting orphans within the local community. Volunteers provide material assistance and encouragement. The community-based volunteer program channels material assistance through volunteers, thus placing an emphasis on reliance of community cooperation (Drew, Makufa, and Foster 1998). These programs are generally initiated and/or supported by community-based organizations or NGOs.

*Example*

Drew, Makufa, and Foster (1998) mention a program in Zimbabwe known as Families, Orphans and Children under Stress (FOCUS). FOCUS is a program that supports community-based orphan initiatives in four rural sites of Manicaland, Zimbabwe. It is administered by Family AIDS Caring Trust (FACT) and supported by PLAN International. At each site volunteers from different churches are identified. In most cases these are women, many of whom are widows. They are provided with basic training that enables them to identify and register orphaned children in the community. The most needy orphans are then visited regularly. Material assistance has been provided and projects have been started in each site to encourage self-reliance on the part of the children (Drew, Makufa, and Foster 1998).

*Strengths*

The UNICEF representative of Kenya in 1992 suggested that an emphasis be placed on community-based care for orphaned children (AIDS Analysis Africa 1992). Community members are in a position that allows them to identify children who need assistance. According to Okeyo (1995), the empowerment of caregivers at the community level will allow orphaned children to be cared for in their community and possibly within their extended family. This would help engender the social well being of the children and could also enable them to inherit land and other property from their deceased parent/s (Okeyo 1995).

As mentioned previously in the foster care section, community members are closest to and part of the situation, thus they are in the best position to identify needy children, to monitor their situation, to offer encouragement, and to get material support to them. Foster (1998) claims that "orphan support programs can improve their situation substantially, by ensuring that at-risk households are regularly visited, children's health is supervised, food

supplements and income generating inputs are provided and primary school enrolment is maintained". Foster (1998) further states that community-based orphan support programs allow orphans to be supported in a way that "complements exiting coping mechanisms". This type of program tends to be cost-effective because large numbers of orphaned children can be sustained within their community (Drew, Makufa, and Foster 1998).

*Weaknesses*

Problems lie in the areas of recruiting volunteers and supplying housing for orphans. Individuals with the willingness and time to volunteer for such programs is difficult to find. The willingness of people to volunteer will probably to some extent depend on the economic condition of the community. A community volunteer in Zambia states "It is not that people are so cruel. But they have nothing themselves" (Daley 1998). Transporting volunteers to children in rural areas may prove to be difficult as well.

The literature on community-based volunteer programs in operation fails to mention where the orphans reside. Therefore, I am left to wonder about their housing circumstances or lack of such. I assume that the orphans assisted by such programs live with extended family, non-kin, or in an adolescent headed household. It is unclear if these programs are limited to orphans residing within a household.

**Women's Work**

What these three programs have in common is, the caregivers are most likely to be women. Caregiving is an overarching issue in the AIDS epidemic and deserves much attention when examining the issue of orphaned children. HIV/AIDS has been called the "woman's disease" not only because women are at risk of infection, but because they also fill the role of caregiver to the infected (Bennett et al. 1996), and to children that are orphaned as a result of the

disease.

The impact of caregiving upon women has been the focus of very few studies (Bennett et al. 1996). As mentioned earlier, it is usually women, a grandmother, an aunt, or other female relative, who informally care for orphaned children. This feminization of caregivers is mirrored in formal care programs. Three important questions arise: 1. Are the women serving in these caregiving positions well supported? 2. Are programs taking into account that it is women that informal and formal caregiving tasks fall to? 3. Do women have a voice in programs of this type?

Culturally, African women are defined as nurturers and caregivers. This cultural role is reflected in both formal and informal caregiving circumstances. Programs which focus on caregiving issues usually receive a minimal amount of funding due to structural adjustment cutbacks in the social sectors. Governments and international funders consider the care of orphans the family's responsibility, which in turn becomes the responsibility of women. Furthermore, women's work, which very often involves caring for children and other family members, is discounted because it is a non-wage activity.

Caregiving, if examined from a feminist perspective, "fundamentally alters the way caregiving is approached and solutions are formulated" (Hooyman and Gonyea 1995). According to Hooyman and Gonyea (1995) "a feminist perspective defines caregiving as a societal, not an individual, responsibility". Thus, caregiving does not necessarily have to be considered part of the female role. Caregiving is the responsibility of the particular community in which the need arises and society at large.

This issue will not go away by simple suggesting alterations in programming; the issue of caregiving necessitates "basic structural changes" (Hooyman and Gonyea 1995). As Hooyman and Gonyea (1995) suggest,

structural change "demands for gender equality and community responsibility as well as the commitment to alter the process and manner in which public and private lives are organized and conducted". So, either the capacity and capabilities of caregivers needs to be strengthened or a structural change needs to occur in which the position and role of caregivers would be modified allowing a broader spectrum of society to be held responsible.

Given the fact that structural change is slow to occur and immediate help is needed with orphan care, it may be of highest priority to strengthen the capabilities of those women already playing the role of caregiver to kin and non-kin orphaned children. This process can begin by lending a voice to women in the areas of decision making and program design. Women can say best which aspects of caregiving programs work, which areas need improvement and more support because they are the key players.

**Conclusion**

Details on orphan care programs are still emerging and it is unclear as to which programs function best. Program effectiveness is sure to vary depending on circumstances, location, and many other variables. However, something is to be learned from each case. One thing is clear, the overarching issue of caregiving is one that requires a feminist approach. To ensure that programs mentioned in this chapter function effectively is to ensure accountability and support to a task labeled as women's work.

# CHAPTER 4

## CONCLUSION: WHERE DO WE GO FROM HERE?

The recommendations arising from this thesis encompass two areas: filling in research gaps and promoting program development. What can be done by practitioners and scholars to improve the current care situation in East Africa? In order to confront the impact of AIDS upon families and communities, and to offer viable options for the increasing need of orphan care, it is important to attempt some summary of practical implications arising from this thesis. Let us examine the interlinking factors in the arenas of research and programming that require attention. What is said here by no means exhausts the topic under discussion.

There are four major areas that require more research to further identify interlinking factors related to the subject of orphan care. Those areas are: 1) More information is needed on the "primary needs of the various family members" and on the identification of "where the critical stress points occur" (Jackson and Civic 1994). 2) Detailed analyses of orphaned children and their circumstances. 3) Further identification of conventional coping mechanisms that may already be in use by families and individuals. 4) Existing helping programs should be evaluated and monitored for appropriateness and effectiveness.

It is clear that the HIV/AIDS epidemic crosses national and international boundaries. As in any effort to aid those outside of US boundaries, the first question to be asked is: "Should we as Western practitioners and scholars attempt to intervene in crises that occur outside of our local periphery?". If the answer is "yes", then the second question becomes: "How can we begin to look at a crisis such as HIV/AIDS and develop strategies to aid those in need?".

Emerging program issues that need attention cluster around two major

Emerging program issues that need attention cluster around two major areas: sustainability and context. Okeyo (1995) claims that HIV/AIDS "is a new epidemic with disaster implications that calls for a urgent co-ordinated global response". Connolly, in 1997, called the inactivity of the global community in the last 15 years concerning the impact of HIV/AIDS on children "the black hole of international development" (cited by Foster 1998). Carol Bellamy of UNICEF, while speaking at the 12th World AIDS Conference, called for a "concerted global effort" to help people become aware of the effects of HIV/AIDS (cited by Dispatch Online 1998).

**Filling in the Gaps: Research and Programming**

The remainder of this chapter will examine specific research and programming areas that require greater attention.

*Description of Orphans*

More detailed studies on orphans are needed. The number of orphans created by current epidemics is reasonably well known. However, characteristics such as age, gender; the impact on families according to locality and lineage; paternal, maternal, double orphaning; and the conditions in which orphans live is not well documented (Drew et al. 1998). Other questions that remain unanswered include the following.

- Do orphaned children from the same family stay in more than one location?
- Is there a gender difference in treatment of children?
- How do children feel about their care arrangement?
- Do orphaned children attend school, lose inheritance rights, or keep in touch with family if taken in by non-family members?
- Are orphaned children treated as well as biological children?
- How do child-headed households cope?
- What factors lead to orphaned children being incorporated into kin or non-kin families?

Better data collection on the direct and indirect impact of HIV/AIDS on

monitor the effects of the AIDS epidemic on children and families (Drew et al. 1998). More research in this area would enable communities to better define the magnitude of the problem and to conceptualize viable options.

*Family*

It is imperative that research be undertaken on the factors that determine if families are able to absorb orphans and how families as a unit deal with crisis. What exactly is the influence of family and kinship relations on patterns of orphan care? Jackson and Civic (1994) state "Careful analysis should be undertaken before service intervention to reduce the risk of undermining existing coping strategies". This point is made in other literature as well. For example, Barnett and Blaikie (1992), call for the development of policies that deal with the "problem of how best to achieve care within and in relation to the community". This conjecture makes sense because the majority of HIV infected and affected children live with their families and are cared for by various family members. Therefore, supporting the family is of primary importance in order to strengthen their capacity for childcare (Anderson 1990).

In an effort to stay abreast of the familial coping capacity it is essential that households and communities be monitored. If "their present coping mechanisms cease to be adequate" it is "important that these policies and programs do not replace but build upon the experience of local people" (Barnett and Blaikie 1992). Home-based care of orphans includes "improving the capacity of families, guardians and the community to actively participate in the provision of required care" (Grant 1991). Gathering data on familial coping mechanisms will ultimately assist programs in this effort.

HIV/AIDS has altered family size, roles, and relationships (Campbell 1999). Program planners should recognize grandparents, single parents, and adolescents as household heads. A two-parent household model cannot be

assumed. Foster (1998) states that a "large proportion of children indirectly affected by the HIV epidemic are at risk of poor health as a result of being cared for by alternative caregivers whose poor education limits access to information about symptoms and treatment of active disease". Thus, programs should be sensitive to the changing composition of the African household and examine the child care habits of each.

Programs that aim to assist with childcare might need to re-evaluate the household situation, and target not only mothers, but also grandparents and siblings with educational programming. Moreover, elderly and adolescent caregivers may be uninformed about the general care of HIV infected and affected children. Support programs must be sensitive to the cultural patterns of local people. Institutional support can only supplement, and not replace community support of families.

Ocholla-Ayayo (1997) asserts "Grandparents should be assisted financially in their crucial role of raising unwanted children". Furthermore, Ocholla-Ayayo (1997) suggests that "associations of grandparents" should be formed at the local and district levels. These associations could be supported by churches and other local organizations (Ocholla-Ayayo 1997). Similarly, Kilbride (1986), mentions that local grandmother networks should be strengthened to support their role as caregivers (cited by Kilbride and Kilbride 1990).

According to Chevallier (1992), only a small amount of "research has been undertaken on the socioeconomic consequences of AIDS for families and children, particularly in developing countries" (cited by Jackson and Civic 1994). Jackson and Civic (1994) identify five areas of research that should be undertaken on coping: 1) how do families perceive their needs, 2) what are the particular crisis points in familial coping strategies, 3) identification of alternative caregivers and providers within the family, 4) explore what types of services and

support would best assist families in coping, and 5) identify how families experience AIDS and cope with the death of caregivers and providers, and the ways in which cultural factors affect this. Additionally, it may be helpful to look at each stage of familial coping from the point of illness of a family member until sometime after her or his death.

When a husband dies often the family's resources are depleted as a result of funeral expenses and property removal by relatives of the deceased (Foster 1998). Perhaps, community-based organizations and NGOs could identify such families before death occurs and help the family understand and prepare for the death of their member. This is the best time to begin planning for the future of the remaining family. However, planning may not always be an option. In some African cultures planning for a death is taboo.

*Programming*

Research can play a major role in helping to identify interventions for families and communities. What do helping organizations need to know and how can researchers find out these things? To begin with, studies of the programs in place should be implemented and their usefulness and appropriateness to specific locations and situations should be evaluated. What impact do current programs have upon orphans, their families, and communities? Detailed information is needed on what arrangements such as foster care and community care entail and what the definitions of each actually mean within specific family and community settings.

Can researchers provide a model that will allow us to predict the differential impact of HIV/AIDS upon families and communities, in which sections of the community children will suffer, and which alternative care programs will work best? For instance, what are the responses of communities to the increasing number of orphans, and how do these responses in themselves

condition the course of orphan care (Vaughan 1992)?

Supportive programs, whether they be institutional or community-based, should be carefully documented. For example, detailed information on children enrolled in such programs, the parameters of the program, funding sources and overall operations would be of great help to other communities and program developers. Unfortunately, children's circumstances have not been well documented and evaluated, causing many programs to be based upon assumptions that may or may not be true (Jackson and Civic 1994).

Short and long term follow-up of programs will allow developers to evaluate the outcome of programs (Jackson and Civic 1994). Although it may not be best to replicate program models in other locations; principles used may impart an understanding as to how similar problems can be approached (HIV InSite 1998).

*Local Knowledge: Participatory/Action Research*

Researchers should understand the reality and context of people's lives and ground their research in it. There is a pressing need for researchers to aim to benefit others with the data they gather, rather than contributing to a body of knowledge that may be only accessible and understandable by other academics. Research findings should be distributed to the community in written form and presentation/seminar format. People need information, but they also need more. They need information that offers practical application or insight into a problem.

Participatory research generally gives a better perspective into what the community wants and needs and generates realistic action. A holistic approach to research is needed that looks at the function of the community, its resources, and its culture. Research in which outsiders and local people are equal learners and teachers is needed to determine the situation of families and individuals affected by AIDS and to respond to their situation in an appropriate manner.

It is important that planners value the knowledge of local people. Blaikie et al.'s (1994) quote below illustrates this point.

> Coping strategies of all kinds are crucial elements in understanding vulnerability and designing interventions which provide sustainable self-help solutions to recovery and future disaster prevention. Indigenous knowledge provides the basis for much coping behavior, and patterns of coping interact with official attempts at disaster prevention and mitigation. Official relief and recovery practice pays little heed to what the ordinary people do. The result is wasted resources, squandered opportunities, and a further erosion of coping skills.

Without an understanding of indigenous coping strategies, planners and policy-makers may attempt to "make stereotyped responses" (Blaikie et al. 1994). The variables of age, gender, and class will often cause differences in local coping strategies. This fact, if overlooked, can cause a deterioration of coping mechanisms already in place (Blaikie et al. 1994).

It is imperative to build upon local coping strategies and to strengthen the efforts of local organizations (Blaikie et al. 1994). Linking family, community, and institutional care efforts may facilitate improvement of each (HIV InSite 1998). A participatory approach in which local people are involved in the planning and implementation of programs will likely result in programming that is relevant to the needs of a particular location and will disperse the burden among community members.

Sometimes only predetermined services are funded by international organizations. This can contribute to the institutionalization of children if the funding is allocated to building Western forms of care facilities such as orphanages or children's rehabilitation centers. These types of facilities may not

meet the needs of the specific location, but be built nonetheless because donors have contributed money strictly for that purpose (Ressler et al. 1988).

*Lending a Voice to Children*

The perspective of the community and individual families including both adult and child members should be examined. The voices of children have generally been silenced in studies. Their views about their needs, whom they would prefer to live with if orphaned, and what they perceive as problems should be taken into consideration. It would be helpful if studies were completed on children who had been taken into various care situations.

Within the realm of international development, "issues affecting children are often given less priority than those affecting adults directly" (Drew et al. 1998). Planners with notions of childcare stemming from the Western world may promote institutional care without fully taking into consideration what children prefer, the community location, and the community's economic condition and culture. It would be advantageous for development planners to view each situation locally and contextually, including not only local leaders in planning, but also the beneficiaries of the program (Drew et al. 1998).

Policy makers should be sure to create policies and programs that address the different needs of female and male orphans as well as addressing the various ages of the orphans (The Status and Trends of the HIV/AIDS Epidemics in the World 1998). Chambers (1997) calls for "baskets of choice" rather than "packages of practices" from which beneficiaries can choose the plan that best fits their needs.

*Policy/Ethical Issues*

Research should be undertaken that examines ethical and policy questions including: "1) how can children be protected from the potential familial exploitation that may accompany placement in a new home 2) how can practices

that make it difficult for female headed households to survive be changed 3) how can children who must be cared for by someone other than family be treated in ways that do not discriminate against them because of their own or their parents HIV status 4) how should the short-term needs be balanced against the need for sustainable programs" (Levine 1996). 5) how can policies protect orphans and women from losing inheritance to other relatives (Daley 1998).

*Cultural Sensitivity*

> *...it does not pay in the long run to blindly copy foreign systems of thought and then, without digesting them, seek to apply them (Sunday Nation 1984 cited by Kilbride and Kilbride 1990).*

As the quote above states, it does not pay to use pre-set programs without taking a close look at the cultural context in which programs are being placed. It is of great importance for donors and planners to remain sensitive to cultural issues including the stigma associated with HIV/AIDS and the differential impact of HIV/AIDS according to gender.

Stigma

HIV/AIDS is compounded by stigma. Studies should examine the influence of stigma surrounding HIV/AIDS on people who are infected and on those related to or associated with the infected. If it is known that a child has been orphaned by AIDS the extended family, prospective foster/adoptive parents, and even institutional facilities may not assist him or her because they fear the child may infect other members of the family or other children in the institution. Grant (1991) claims that "Children with AIDS are seen as a poor investment because they are bound to die quickly". More detailed data are required on the ways in which orphaned children and their caretakers, informal and formal, are stigmatized.

Planners and program developers should be aware of the stigma attached

to HIV/AIDS and the ways it can impact the infected and caregivers. Preble and Foumbi (1991) claim the "Unstable economic status of the African family, the changes in family dynamics, the stigma associated with AIDS, and the fear that orphans are themselves infected can contribute to the rejection of these children" (cited by David 1997). Hence, grandparents and other family members may not always be willing to take care of children orphaned by AIDS (SAFAIDS and FCU 1996 cited by McAdoo and Obi 1999). Likewise, workers in care programs may exhibit fear in associating with those children. It should be taken into consideration that some children may have tuberculosis or may be suspected to have tuberculosis. Children in such a case may be doubly stigmatized.

Gender

Does HIV/AIDS have a differential impact upon women and men? Studies thus far say it does. If we accept that men and women are affected differently by HIV/AIDS, what are the implications for the care of orphaned children which generally is the responsibility of women? Do care and support barriers exist that specifically affect women and what can be done to diminish these barriers?

A person with HIV/AIDS may experience a break down in her or his social relationships. Does gender make a difference in the social networks and social support of people with HIV/AIDS? In Uganda, for example, it is reported that women with AIDS may be abandoned by their partners, and may be left with no means to support themselves (De Bruyn 1992 cited by Green 1996). Similarly, the fact that most East African women have no inheritance rights is of great importance for women who lose their husbands to AIDS and for orphaned children who may not receive an inheritance (Preble and Foumbi 1991 cited by David 1997). How do women survive when they lose their spouse to AIDS and have children? What support networks and resources are available to female heads of households who may be widowed with children and HIV infected

themselves? If the mother dies due to AIDS, what childcare options will the father consider?

Researchers must keep in mind that family care and specifically, orphan care, is considered the responsibility of women. Thus, informal and formal care options should be explored from the perspective that caring affects the daily lives of women. According to Farmer et al. (1993), the "impact of HIV/AIDS upon women and families is highly interdependent with kinship, economic, and life-cycle variables" (cited by Green 1996). Hence, the way in which AIDS impacts women and men is directly related to how families handle stress and their access to resources. Therefore, the societal and cultural position of the caregiver should be taken into consideration when completing research on the care of orphaned children (Farmer et al. 1993 cited by Green 1996).

It is important for program developers to take into account that it is women who undertake the role of caregiver to orphaned children both informally and formally. Program development should be grounded in local experiences of women rather than a predesigned package of assumptions and generalizations imposed upon communities. McAdoo and Obi (1999) call for "more support for the women of all ages, an acknowledgment of the extra burdens that are faced by women and children, and the development of more supportive services within communities". It is essential for program developers to "start with women's experience in order to better understand the difficulties they face daily in their ... lives and to adequately meet their expectations and actual needs" (David 1997).

Access to resources often differs between men and women. Blaikie et al. (1994) define resources as "the physical and social means of gaining a livelihood". Planners should take into consideration that access to resources is based upon "social and economic relations" which include "the social relations of production, gender, ethnicity, status, and age" (Blaikie et al. 1994). This clearly

points to unequal access to resources, with women who are key players in orphan care, possibly lacking access to material resources and labor.

The affect the AIDS epidemic has upon family members is likely to change over time. Access to resources may change as various family members fall ill and die. Hence, a breakdown in access to resources may occur quickly (Blaikie et al. 1994). Taking this into account, can planners design programs that will assist family members obtain equal access to needed resources in times of crisis?

While it may be true that women carry the primary responsibilities of caregivers, it is important to not over look the part that men play in this role. Climo (2000) makes an important point in his article about eldercare. He explains that researchers must be careful not to overlook the role of men in caregiving. He further claims that "incomplete descriptions or research that focuses on women and excludes men serves to perpetuate low cultural expectations for male caregiving" (Climo 2000). Furthermore, program developers should aim to enable and motivate both female and male family members to perform caregiving tasks.

*Program Sustainability*

The foremost problem with orphan care schemes tends to be sustainability. The problem with program sustainability may come in the way of financial funding, securing workers, and any number of other variables. For example, a drop-in-center in Gweru caters to the needs of more than 22,000 AIDS orphans. Funding needed to build the center was $12 million (Herald Reporter 1998). Governments are not prepared to supply the amount of funding required to construct and maintain programs of this nature.

Okeyo (1995) states that there is a lack of global funds overall allocated to AIDS prevention in Africa. Studies indicate that in 1995 "although more than half

of the global AIDS cases are in Africa, only about 2% of global funds for AIDS prevention are spent in Africa" (Okeyo 1995). If this statement still holds true today, then it would be wise to advocate for a more balanced distribution of donor funds to programs that are applicable and useful in the economic and social context of Africa.

In regard to the limited government resources in East Africa, non-governmental organizations are needed to play a major role in supporting communities at the local level. According to Grant (1991) "Indigenous NGOs, particularly women's groups and youth groups should be encouraged to support activities relating to community-based care". There is a need for the "coordination and collaboration" of NGOs "in order to maximize the use of available resources" (Grant 1991).

It is important to remember that support for orphans must not only be supplied by international donors, but also by community members who strive to mobilize in ways that best suit their circumstances. NGOs and community-based organizations must work together with local community members to secure international donors and to identify and assist orphaned children. A concerted effort that involves cooperation and action at all levels is needed.

International organizations may or may not be fully aware of the increasing number of orphans in the midst of the AIDS epidemic. Such organizations should take this situation into consideration when allocating funds. According to Okeyo (1995), many donor agencies focus their attention on intervention and education measures when addressing HIV/AIDS. Although these measures are worthy of donor funds, agencies fail to realize that today's orphans may well be tomorrow's generation of street children who will be at high risk to HIV infection and other medical problems as well as social problems if not adequately cared for.

Donors should identify and fund programs that can best meet the needs of each specific location. Effective programs should be documented and replicated to other areas that can benefit from the same type of programming. The community needs to feel that they own their particular orphan care program and that they are contributing to it (The Status and Trends of the HIV/AIDS Epidemics in the World 1998).

**Conclusion**

Words such as coordination, collaboration, and strengthen have been used in this chapter many times, but what is really being done in research and program areas to address the problem of HIV/AIDS and orphan care in Africa? Have there been improvements in programming, are researchers attempting to uncover issues that will aid families, communities, and helping organizations to actively take part in planning for the increasing need for orphan care?

This literature review was not completely exhaustive. For example, I was not able to obtain some articles published in African countries or papers presented at recent HIV/AIDS conferences. However, the foregoing analysis indicates that while some data on the topic under study exists, there continues to be a need for more detailed current information on the aforementioned issues. Furthermore, extensive data will not only lend a better understanding of the changing family structure in Tanzania, but will also impart knowledge on methods by which development agencies and community based organizations can better supply aid and programming to orphans and families affected by the AIDS epidemic.

Families should be studied in context taking a holistic approach to family lives. More specifically, studies are needed that ground findings in the everyday lives of women. Studies should examine the emotional and practical responsibility of caring for the ill and orphaned and the societal role of women in

providing care as either low-waged support or as unpaid volunteers in community health and social services (Kimoto 1998). According to Chafetz (1988) "As researchers, it is our responsibility to investigate the contexts, both private and public, ... to question the historical definitions of the caring role" (cited by Kimoto 1998).

It is my hope that more people will be led to action by the content of this thesis. I intend to expand the examination of this topic in my dissertation research. It is a problem of great magnitude that is worthy of much thought and action. It calls for a deeper understanding of the disease, the people it affects, and how we as academics and practitioners can alleviate the struggles and suffering that are experienced in many forms in the lives of those it touches.

## BIBLIOGRAPHY


Adegboyega, Oluwole; Ntozi, James P.M.; and John B. Ssekamatte-Ssebuliba
1997 The African family: data, concepts and methodology. *In* Family Population & Development in Africa. Aderanti Adepoju, ed. Pp. 25-40. London: Zed Books Ltd.

Adepoju, Aderanti and Wariara Mbugua
1997 The African family: an overview of changing forms. *In* Family Population & Development in Africa. Aderanti Adepoju, ed. Pp. 41-59. London: Zed Books Ltd.

AIDS Analysis Africa
1995 Who gets the donor money - government or NGOs? January/February.

1995 Empowering the street children. January/February.

1992 AIDS orphans: what can be done? March/April.

AIDS in Africa Conference, Marrakech
1994 Of sport and migration: of children and orphans: of companies and politicians: the welcome 'new realism' on AIDS, society and economics.

Akeroyd, Anne V.
1997 Sociocultural Aspects of AIDS in Africa: Occupational and Gender Issues. *In* AIDS in Africa and the Caribbean. G.C. Bond, J. Kreniske, I. Susser and J. Vincent, eds. Boulder: Westview Press.

Alexander, David
1993 Natural Disasters. New York: Chapman & Hall.

Anderson, Gary R.
1990 Children and AIDS: Crisis for Caregivers. *In* African Families and the Crisis of Social Change. Thomas Weisner et al., eds. Westport: Bergin & Garvey.

1990 Creating Programs to Care for Children with HIV/AIDS. *In* African Families and the Crisis of Social Change. Thomas Weisner et al., eds. Westport: Bergin & Garvey.

Baggaley, Rachel C. and Dale Needdham
1997 Africa's emerging AIDS - orphans crisis. Canadian Medical Association Journal,156(6):873-875.

Barnett, Tony and Piers Blaikie
1992 AIDS in Africa Its Present and Future Impact. New York: Guilford.

BBC News
1997 AIDS Worldwide. Website, news2.thls.bbc.co.uk.

Bennett, Lydia; Casey, Kathleen; and Patricia Austin
1996 Issues for Women as Carers in HIV/AIDS. *In* AIDS as a Gender Issue. Lorraine Sherr, Catherine Hankins, & Lydia Bennett, eds. London: Taylor & Francis.

Blaikie, Piers; Cannon, Terry; Davis, Ian and Ben Wisner
1994 Natural Hazards, People's Vulnerability, and Disasters. London: Routledge.

Bond, George C.; Kreniske, John; Susser, Ida; and Joan Vincent
1997 The Anthropology of AIDS in Africa and the Caribbean. *In* AIDS in Africa and the Caribbean. G.C. Bond, J. Kreniske, I. Susser, and J. Vincent, eds. Boulder: Westview Press.

Boss, Pauline
1988 Family Stress Management. London: Sage.

Burr, Wesley R. and Shirley R. Klein
1994 Reexamining Family Stress: New Theory and Research. London: SAGE Publications.

Campbell, Carole A.
1999 Women, Families, and HIV/AIDS. Cambridge: University Press.

Campbell, John
1995 Conceptualizing gender relations and the household in urban Tanzania. *In* Gender, Family and Household in Tanzania. Colin Creighton and C.K. Omari, eds. Aldershot: Avebury.

Chambers, Robert
1997 Whose Reality Counts? Putting the first last. Britain: Bath Press.

Chintu, C. and Alwyn Mwinga
1999 An African Perspective on the Threat of Tuberculosis and HIV/AIDS -- Can Despair be Turned to Hope? The Lancet 353(9157).

Chiurayi, S.M.
1995 "Cutting the Gordian Knot: The Case For Girls' Education". *In* "The Case for Girls' Education in Sub-Saharan Africa". Keith Hart and Ann Cotton, eds. Pp. 1-12. Cambridge: Newnham College.

Chum, H.T. and Petra Graf
1993 Challenge in Tanzania (National Tuberculosis & Leprosy Programme). World Health. 46(4).

Climo, Jacob
2000 Eldercare as "Women's Work" in Poor Countries. Journal of Family Issues 21(6):692-713.

CNN
1999 Orphaned by AIDS, Zambia's lost generation fills the streets. Website, www.cnn.com/

Connelly, M.P.; Li, T.M., MacDonald, M.; and J.L. Parpart
2000 Feminism and Development: Theoretical Perspectives. *In* Theoretical Perspectives on Gender and Development. J.L. Parpart, M.P. Connelly, and V.E. Barriteau, eds. Pp. 51-159. Ottawa: International Development Research Center.

Daley, Suzanne
1998 In Zambia, the Abandoned Generation. The New York Times. September 18.

David, Martine
1997 Gender Relations and AIDS. Center for International Cooperation in Health and Development. Website, www.ccisd.org.

Davison, Jean
1997 Gender, Lineage, and Ethnicity in Southern Africa. Boulder: Westview Press.

Dillaway, Heather
1999 Western Macro-Level Family Theories and Contemporary International Families: Can They Inform Each Other? A Critical Review. Unpublished paper. Michigan State University.

Dispatch Online
1998 40m AIDS orphans by 2010, Unicef chief warns. July, 4. Website, wildnetafrica.co.za/africa/inc/news/dispatchonline.html.

Djeddah, Carol
1997 Wars and Unaccompanied Children in Africa: Who They are and Major Health Implications. IPA Journal 8(2).

Dodd, Rebecca
1994 Home-based and community care: the only way to cope? AIDS Analysis Africa 4(5).

Drew, R.S.; Makufa, C. and G. Foster
1998 Strategies for providing care and support to children orphaned by AIDS. AIDS Care; Abingdon. April.

Enabulele, Arlene Bailey
1993 Modernization, Child Rearing and the Working Mother in Nigeria. *In* The Family in Africa. New Delhi: M.D. Publications.

Food and Agriculture Organization (FAO)
2000 HIV/AIDS: a rural issue.
Website, www.fao.org/Focus/E/aids/aids1-e.htm

Foster, G.
1998 Today's children--challenges to child health promotion in countries with severe AIDS epidemics. AIDS Care; Abingdon (10).

Gladwin, Christina H.
1993 Women and Structural Adjustment in a Global Economy. The Women and International Development Annual (3):87-111.

Grant, Susan
1991 Children Affected by AIDS. Nairobi: Child Welfare Society of Kenya.

Green, Gill
1996 Stigma and Social Relationships of People with HIV: Does Gender Make a Difference? *In* AIDS as a Gender Issue. Lorraine Sherr et al., eds. London: Taylor and Francis.

Health Canada
2000 Website, www.hc-sc.gc.ca/hpb/lcdc/osh/info/hivaids_e.html

HealthNet Tanzania
2000 Website, www.healthnet.org/hnet/tanzania.html

Hedlund, Stefan and Mats Lundahl
1989 Ideology as a Determinant of Economic Systems: Nyerere and Ujamaa in Tanzania. Uppsala: Scandinavian Institute of African Studies.

Herald Reporter
1998 Gweru foundation need $12 m to cater for 22,000 Aids orphans. June 8.

HIV InSite
2000 Context of the Epidemic. Website, hivinsite.ucsf.edu.

1998 Monitoring the AIDS Pandemic. Website, hivinsite.ucsf.edu.

Hooyman, Nancy R. and Judith Gonyea
1995 Feminist Perspectives on Family Care: Policies for Gender Justice. London: Sage.

International Labour Research and Information Group (ILRIG)
1988 Tanzania: The Struggle for Ujamaa. Cape Town: Creda Press.

Isiugo-Abanihe, Uche C.
1984 Prevalence and Determinants of Child Fosterage in West Africa: Relevance to Demography. Population Studies Center University of Pennsylvania.

Jackson, Helen and Diana Civic
1994 Family Coping and AIDS in Zimbabwe, A Study. Harare: Journal of Social Development in Africa.

Kayono-Male and Philista Onyango
1984 The Sociology of the African Family. London: Longman.

Kelso, B.J.
1994 Orphans of the Storm. Africa Report 39(1):50-55.

Kilbride, Philip Leroy and Janet Capriotti Kilbride
1990 Changing Family Life in East Africa: Women and Children at Risk. London: Pennsylvania State University Press.

Kimoto, Diane M.
1998 Affirming the Role of Women as Carers: The Social Construction of AIDS Through the Eyes of Mother, Friend, and Nurse. *In* Women and AIDS: Negotiating Safer Practices, Care and Representation. Nancy L. Roth and Linda K. Fuller, eds. New York: Harrington Park Press.

Koda, B.O.
1995 The economic organization of the household in contemporary Tanzania. *In* Gender, Family and Household in Tanzania. Colin Creighton and C.K. Omari, eds. Aldershot: Avebury.

Laier, Julie Kock; Davies, Susanna; Milward, Kirsty and Jane Kennan
1996 Gender, Household Food Security and Coping Strategies. Brighton: Institute of Development Studies.

Levine, Carol
1996 Ethical Issues in Developing Policies for Orphans of the HIV Epidemic. International Conference on AIDS 11(2):389, abstract no. Th.D.4874.

1996 Children in Mourning: Impact of the HIV/AIDS Epidemic on Mothers with AIDS and their Families. *In* AIDS as a Gender Issue. Lorraine Sherr et al., eds. London: Taylor and Francis.

LeVine, R. A.; Leiderman, S.; Herbert, P.; Brazelton, T. B.; Dixon, S.; Richman, A. and C. H. Keefer
1994 Child Care and Culture: Lessons from Africa. Cambridge: University Press.

Lone, Patricia
1996 Commentary: Keeping girls in school. *In* The Progress of Nations 1996 (UNICEF). Website, www.unicef.org/pon96/edgirls.htm.

Mbugua, Wariara
1997 The African family and the status of women's health. *In* Family Population & Development in Africa. Aderanti Adepoju, ed. Pp. 139-157. London: Zed Books Ltd.

McAdoo, Harriette Pipes and Lawrence Obi
1999 Aging and Elderly in Rich and Poor Countries: Facing the 21st Century. Unpublished paper. Michigan State University.

McCubbin, Hamilton I. and Charles R. Figley
1983 Bridging Normative and Catastophic Family Stress. *In* Stress and the Family Volume I: Coping with Normative Transitions. Hamilton I. McCubbin and Charles R. Figley, eds. New York: Brunner/Mazel.

McCubbin, Hamilton I. and Joan M. Patterson
1983 Family Transitions: Adaptation to Stress. *In* Stress and the Family Volume I: Coping with Normative Transitions. Hamilton I. McCubbin and Charles R. Figley, eds. New York: Brunner/Mazel.

1983 The Family Stress Process: The Double ABCX Model of Adjustment and Adaptation. *In* Social Stress and the Family: Advances and Developments in Family Stress Theory and Research. H.I. McCubbin, M.B. Sussman, and J.M. Patterson, eds. New York: Haworth Press.

McKinley, James C. Jr.
1998 AIDS Brings New Scourge to War - Torn Rwanda. The New York Times: May 28.

McNeil, Donald G. Jr.
1997 AIDS Stalking Africa's Struggling Economics. The New York Times: November 15.

Ministry of Education
1992 Basic Education Statistics in Tanzania. Dar es Salaam.

1982 Some Basic Facts About Education in Tanzania. Dar es Salaam.

Mkumbaye, Sr. Helena
1998 Personal conversation

1996 Feasibility Study Analysis of the Orphans Home in Morogoro.

Moshi, H.P.B.
1995 Reforms in the Public and Private Sector Management: The Parastatal Sector Reforms and Private Sector Development in Tanzania. *In* Beyond Structural Adjustment Programmes in Tanzania. L.A. Msambichaka, A.A.L. Kilindo, and G.D. Mjema, eds. Dar es Salaam: Economic Research Bureau.

Mosha, Theobald
2001 Personal conversation.

Mukangara, Fenella and Bertha Koda
1997 Beyond Inequalities Women in Tanzania. Harare: SARDC.

Munalula, Margaret Mulela and Winnie Sithole Mwenda
1984 Case study: women and inheritance law in Zambia. *In* African Women South of the Sahara. Margaret Jean Hay and Sharon Stichter, eds. New York: Longman.

Ncube, W.; Stewart, J. E.; Kazembe, J. L.; Donzwa, B. R.; Gwaunza, E. C.; Nzira, T. G. and K. Dengu-Zvobgo
1997 Continuity and Change: The Family in Zimbabwe. Harare: Women and Law in Southern Africa Research Project.

Obbo, Christine
1995 What Women Can Do: AIDS Crisis Management in Uganda. *In* Women Wielding the Hoe: Lessons from Rural Africa for Feminist Theory and Development Practice. Deborah Fahy Bryceson, ed. Pp. 165-177. Oxford: Berg Publishers.

1993 Reflections on the AIDS orphans problem in Uganda. *In* Women and HIV/AIDS: An International Resource Book. Marge Berer and Sunanda Ray, eds. London: Harper Collins.

Ocholla-Ayayo, A.B.C.
1997 The African family between tradition and modernity. *In* Family Population & Development in Africa. Aderanti Adepoju, ed. Pp. 60-77. London: Zed Books Ltd.

1997 HIV/AIDS Risk Factors and Changing Sexual Practices in Kenya. *In* African Families and the Crisis of Social Change. Thomas Weisner et al., eds. Westport: Bergin & Garvey.

Ohuche, R. Ogbonna and Barnabas Otaala
1981 The African Child and His Environment. New York: UNEP.

Okeyo, Tom Mboya
1995 AIDS Orphans - A New Epidemic with Disaster Implications. Discovery and Innovation 7(1):1-2.

Omari, C.K.
1991 The Family in Tanzania. International Journal of Sociology of the Family (21):51-71.

1989 Socio-Cultural Factors in Modern Family Planning Methods in Tanzania. New York: Edwin Mellen Press.

Oppong, Joseph R. and David A. Williamson
1996 Health Care between the Cracks: Itinerant Drug Vendors and HIV/AIDS in West Africa. African Rural and Urban Studies 3(2):13-34.

Owen, Margaret
1996 A World of Widows. London: Zed Books.

Parpart, Jane L.
1995 Deconstructing the Development "Expert": Gender, Development and the "Vulnerable Groups". *In* Feminism/Postmodernism/Development. Marianne H. Marchand and Jane L. Parpart, eds. Pp. 221-240. London: Routledge.

Parpart, Jane L and Marianne H. Marchand
1995 Part I Exploding the Canon: An Introduction/Conclusion. *In* Feminism/Postmodernism/Development. Marianne H. Marchand and Jane L. Parpart, eds. Pp. 1-22. London: Routledge.

Patterson, Joan M. and Hamilton I. McCubbin
1983 Chronic Illness: Family Stress and Coping. *In* Stress and the Family Volume II: Coping with Catastrophe. Charles R. Figley and Hamilton I. McCubbin, eds. New York: Brunner/Mazel.

Pollitt, Ernesto
1984 Nutrition and Educational Achievement. Paris: Nutrition Education Programme.

Potash, Betty
1984 Women in the changing African family. *In* African Women South of the Sahara. Margaret Jean-Hay and Sharon Stichter, eds. New York: Longman.

Rathgeber, Eva M.
1995 Gender and Development in Action. *In* Feminism/Postmodernism/Development. Marianne H. Marchand and Jane L. Parpart, eds. Pp. 204-220. London: Routledge.

Report on the Global HIV/AIDS Epidemic
1998 Website, www.who.int/emc-hiv/global_report/

Ressler, Everett M.; Boothby, Neil; and Daniel J. Steinbock
1988 Unaccompanied Children. New York: Oxford University Press

Rubinstein, Robert L.
1987 Childless Elderly: Theoretical Perspectives and Practical Concerns. Journal of Cross Cultural Gerontology (2):1-14.

SAfAIDS and Commercial Farmers Union
1996 Orphans on Farms: Who Cares? An Exploratory Study into Foster Care for Orphaned Children on Commercial Farms in Zimbabwe. Harare, Zimbabwe.

Sangree, Walter H.
1987 The Childless Elderly in Tiriki, Kenya, and Irigwe, Nigeria: A Comparative Analysis of the Relationship between Beliefs about Childlessness and the Social Status of the Childless Elderly. Journal of Cross-Cultural Gerontology (2):201-223.

Schoepf, Brooke Grundfest
1993 Gender, Development, and AIDS: A Political Economy and Culture Framework. The Women and International Development Annual (3): 53-85.

Shao, Ibrahim
1992 Structural Adjustment in a Socialist Country: The Case of Tanzania. Harare: Sapes Books.

Specter, Michael
1998 Doctors Powerless as AIDS Rakes Africa. The New York Times. August 6.

Status and Trends of the HIV/AIDS Epidemic in the World
1998 Website, hivinsite.ucsf.edu/InSite.jsp?page=pr-02-01

Tanzania Gender Networking Programme
1993 Gender Profile of Tanzania. Dar es Salaam: Tanzania Gender Networking Programme.

Taylor-Brown, S.; Teeter, J.A.; Blackburn, E.; Oinen, L.; and L. Wedderburn
1998 Parental Loss Due to HIV: Caring for Children as a Community Issue - The Rochester, New York Experience. Journal of the Child Welfare League Of America, Inc. LXXVII(2):137-160.

Tietjen, Karen
1991 Educating Girls: Strategies to Increase Access, Persistence, and Achievement. DC: U.S. Agency for International Development.

Turshen, Meredeth
1999 Privitizing Health Services in Africa. New Brunswick: Rutgers University Press.

UNAIDS Report
1998 AIDS in Africa. Website, hivinsite.ucsf.edu/international/africa/

UNICEF
1996 The State of the World's Children. New York: Oxford University Press.

United Republic of Tanzania
1995 Basic Statistics in Education. Dar es Salaam: Ministry of Education and Culture

Vaughan, Megan
1992 Famine Analysis Family Relations: Nyasaland in 1949. *In* The Social Basis of Health & Healing in Africa. Steven Feierman and John M. Janzen, eds. Pp. 71-89.

Webb, Douglas
1995 Who will take care of the AIDS orphans? AIDS Analysis Africa. March/April.

Weisner, Thomas S.
1994 The Crisis for Families and Children in Africa: Change in Shared Social Support for Children. Health Matrix: Journal of Law-Medicine (4):1-29.

1997 Support for Children and the African Family Crisis. *In* African Families and the Crisis of Social Change. T. S. Weisner, C. Bradley, and P. L. Kilbride, eds. Westport: Bergin & Garvey.

World Bank
1997 Staff Appraisal Report Tanzania Human Resources Development Pilot Project.

1997 Human Resources Development Pilot Project Document. WAIS Document Retrieval. Website, www.worldbank.org/cgibin/waisgate?waisaction=retrieve&waisdocid.

1986 Implementing Educational Policies in Tanzania. DC: World Bank.

World Fact Book
1999/2000 Tanzania.
Website, www.cia.gov/cia/publications/factbook/geos/tz.html