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ATTITUDES TO FOSTER CARE IN THE CONTEXT OF HIV/AIDS IN TANZANIA: THE ROLE OF
PERCEIVED STIGMA IN SHAPING CAREGIVERS' ATTITUDES TOWARDS AIDS-AFFECTED
FOSTER CHILDREN IN THEIR CARE

AN ABSTRACT

SUBMITTED ON THE SEVENTEENTH DAY OF MARCH, 2010

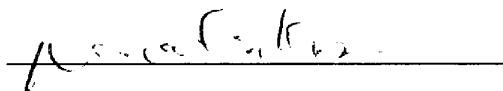
TO THE DEPARTMENT OF INTERNATIONAL HEALTH AND DEVELOPMENT

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS

OF THE SCHOOL OF PUBLIC HEALTH AND TROPICAL MEDICINE OF TULANE UNIVERSITY

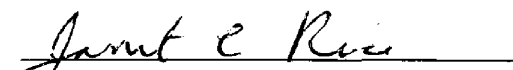
FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

BY



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ABSTRACT

In sub-Saharan Africa, the majority of children who have been orphaned by HIV and AIDS are cared for by extended family members. However, there is currently insufficient information available on these caregivers' attitudes towards these foster children in their care. This study sheds more light on the issue by examining the relationship between the psychosocial health of caregivers' and their foster children, as well as exploring the role of perceived stigma in shaping their attitudes towards these children in their care.

The analyses are based on a cross-sectional sample of 836 foster caregivers in Tanzania who are either participating in selected interventions for AIDS-affected children and their households, or who have been slated to participate in similar interventions in the future. Multivariate linear regression analyses were conducted, and study results suggest that foster children's psychosocial health is not associated with their caregivers' psychosocial health. However, severe household food insecurity, perceived stigma, particularly stigma channeled as gossip, living in an urban area and single motherhood most strongly contribute to poorer caregivers' psychosocial health. While poorer child psychosocial health was found to be significantly associated with negative caregivers' attitudes, no significant association was found between caregivers' psychosocial health and their attitudes towards their foster children. Other factors that were found to be associated with negative caregivers' attitudes include perceived stigma, living in middle income households, and living in a household with no chronically ill members. This study emphasizes that continued food support to AIDS-affected households is crucial, and highlights the need for a focus on stigma reduction through education. There is also the need to simultaneously address factors that influence both OVC psychosocial health and their caregivers' attitudes towards them due to the bi-directional nature of the association between these two variables. Finally, there is the need for the introduction of income-generating activities for caregivers living in poorer households, as well as the provision of counseling, particularly for single caregivers, as a way to improve their psychosocial health.

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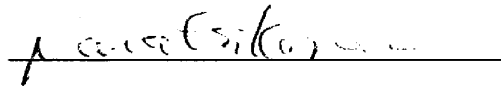
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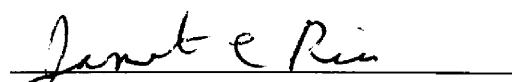
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CHAPTER 1 – INTRODUCTION

1.1 Background

According to a 2008 UNAIDS report, 67% of all people living with HIV and AIDS reside in sub-Saharan Africa, one of the world's poorest regions. In 2007, 75% of all AIDS deaths also occurred in sub-Saharan Africa (UNAIDS, 2008a). Although measures such as national HIV and AIDS education programs, social marketing of condoms and even abstinence programs for the younger, unmarried members of the population have been taken to curb the spread of the disease, in southern African countries such as Botswana, Lesotho and Swaziland, national adult HIV prevalence rates still actually exceed 30% (UNICEF, 2004). This disease has had a devastating effect on the continent, diffusing through all aspects of society from the individual and household levels to national levels. For example, in Botswana, HIV and AIDS has resulted in a decrease in overall household income, and the country's health sector is also overburdened by the large numbers of people suffering from the disease – UNAIDS (2000) reports that in 2000 at least 50% of hospital beds in Botswana were occupied by individuals suffering from AIDS-related illnesses. In other countries such as Ethiopia and Lesotho, the education sector is losing valuable teachers to the disease, resulting in a discontinuity in schooling for many students¹. At the individual level, HIV and AIDS has had a destructive impact on families, depriving households of much needed income from working adults, depriving children of their parents, and sometimes their childhood, and putting undue pressure on the extended family system of fostering (UNICEF, 2004).

Out of the approximately 15.2 million children under 18 years of age worldwide who have lost either one or both parents to AIDS, UNAIDS (2008a) estimates that roughly 12 million of these children are living in sub-Saharan Africa. In Zimbabwe, 24% of children aged 0 to 17 years have lost either one or both parents to HIV and AIDS (UNAIDS, 2008a). Given that about 41% of Africa's population live in extreme poverty², this

¹ http://data.unaids.org/Publications/IRC-pub05/aidsafrica2000_en.pdf

² <http://web.worldbank.org/WBSITE/EXTERNAL/NEWS/0..contentMDK:20040961~pagePK:64257043~piPK:437376~theSitePK:4607,00.html>

growing number of orphans on the continent has devastating economic and social implications for governments already restricted by limited resources and overburdened by other pressures such as tuberculosis, diarrheal diseases and malaria. Research shows that children orphaned by HIV and AIDS have a higher risk of exposure to the disease, are more likely to face stigma and discrimination, less likely to be attending school, more likely to be exploited and more likely to suffer from psychosocial stress or trauma (Andrews et al., 2006, Save the Children Fund UK, 2001; UNICEF, 2006). This is due to an intricate web of factors, including the socioeconomic status (SES) of the households in which they live, the relationship between caregivers and the children, HIV prevalence rates within the community, community attitudes towards HIV and AIDS and a multitude of other mitigating factors (UNAIDS, 2004; UNICEF, 2006).

1.2 Statement of the problem

In sub-Saharan Africa, the majority of these children orphaned by HIV and AIDS are being cared for by extended family members (Ankrah, 1993; UNAIDS, 2004), who take on the additional responsibility of caring for one or more orphaned child at a time, as well as managing their own households. In some instances, a child who has lost a parent resides with the surviving parent. Paternal orphans, or children who have lost their fathers, are more likely to be living with their mothers, while maternal orphans, or children who have lost their mothers, are more likely to be living with a female member of the family, rather than with their fathers. Double orphans - children who have lost both parents - very often live with other family members (UNAIDS, 2008a). According to UNAIDS (2008a), the estimated numbers of maternal, paternal and double orphans in Malawi, South Africa and the United Republic of Tanzania rose from 1.2 million in 2001 to 2.9 million in 2007.

Recent reports indicate that a significant weight of the burden of caring for all these children orphaned by HIV and AIDS falls squarely on the shoulders of grandmothers. According to a 2007 UNICEF report, in Namibia, the United Republic of Tanzania and Zimbabwe, roughly 40%-60% of orphaned children are cared for by grandmothers.

Surveys in rural South Africa also suggest an increase in the number of households headed by individuals over 50 years of age (Hosegood et al., 2007a). Other relatives such as aunts and older siblings are also involved in fostering-in orphaned children. Although media reports suggest otherwise, households headed by children under the age of 18 years are actually rare and have not increased significantly in the last couple of years (Hosegood et al., 2007b).

Very often extended family members have limited resources available to them to adequately provide for orphaned children as well as others already living in the household. Research shows that these caregivers of orphaned and vulnerable children (OVC) often experience poor psychosocial health due to increased stress and anxiety about how to provide for their households (Kipp et al., 2006; Kipp et al., 2007). Simultaneously, children who have lost either one or both parents to HIV and AIDS are forced to move from familiar household environments to new foster environments, while still trying to recover from the death of a parent (Adepoju & Mbugua, 1997; Ankrah, 1993; Foster, 2000; Foster & Williamson, 2000; Mann, 2002; Oleke et al., 2005). The loss of a parent or parents can result in a significant decline in the standard of living (UNAIDS, 2008a), and thus the movement of children between households is sometimes done to ensure that children's needs can be adequately met (Ansell & van Blerk, 2004). However, this lack of routine and stability can negatively impact a child's psychosocial well-being.

Despite these changing environments and the differing psychosocial needs of both caregivers and OVC, insufficient information exists not only on caregivers' attitudes towards OVC, but also on the factors that shape their attitudes towards these children. Caregivers' attitudes are important as they can affect, to a certain extent, the quality of care OVC receive in these foster households. Programs that aim at improving the lives of members of such households can only function effectively if adequate information exists on what makes one foster care situation a positive experience for both caregiver and child and what makes another a negative experience. By exploring what factors influence

caregivers' attitudes towards OVC in their care, better coping strategies can be developed to help improve the quality of life for caregivers and children.

1.3 Research Needs

Over the past several years, there have been many studies carried out on orphaned and vulnerable children. Fewer studies have been carried out on the caregivers of these children. A review of the literature in this area reveals several gaps. Firstly, there is insufficient information on the relationship between caregiver and OVC psychosocial well-being. As many studies suggest that both caregivers and OVC often experience poor psychosocial health for various reasons (Kipp et al., 2006; Makame et al., 2002), some studies have suggested that there is a bi-directional relationship between caregivers' psychosocial well-being and OVC psychosocial well-being (Mann, 2002), while other studies have found no significant association between these two factors (Lester et al., 2006). This contradictory information suggests that further research is required to determine the exact nature of the relationship between the two groups. Secondly, the relationship between caregivers' psychosocial well-being and caregivers' perceptions of OVC in their care is unclear. Some literature from the developed world suggests a significant association between caregivers' stress levels and their perceptions of children in their care (Jones, 1996; Oburu & Palmerus, 2005). Alternatively, literature from the developing world is contradictory, with some studies suggesting that psychosocial health and caregivers' perception of children in their care are not associated (Oburu, 2005a), while others have found that caregivers' psychosocial health can negatively impact their perception of children in their care (Oburu, 2005b).

As previously mentioned, there are few studies on caregivers' attitudes towards OVC in their care, particularly in sub-Saharan Africa and in the context of HIV and AIDS. Studies that have looked at attitudes to foster care in general have been mainly in the developed world, and have focused on populations such as children who run away from home and other street children (Fernandez, 2007; Holdaway & Ray, 1992), and have not necessarily been in the context of HIV and AIDS. The few studies that have been carried

out in sub-Saharan Africa in this area and that have examined caregivers' attitudes towards OVC in their care have been mainly qualitative, using techniques such as focus group discussions and in-depth interviews (Guest 2001; Mann, 2002). Very few quantitative studies are available for reference.

Generally, studies that have looked at caregivers' attitudes towards OVC in their care have focused mainly on community perceptions of caregivers' attitudes rather than on caregiver perceptions (Foster et al., 1995; Foster et al., 1997; Funkquist et al., 2007; Mann, 2002). That is, caregivers were rarely interviewed directly regarding this particular issue and rather information from community members were used to make generalizations about how caregivers of OVC may feel about these children and how they treat them. Other studies have focused on caregivers' willingness to foster OVC, rather than on caregivers' attitudes towards OVC (Howard et al., 2006; Foster et al., 1995). Finally, although much work has been done in the area of AIDS-related stigma in sub-Saharan Africa, and information exists on how it can affect the psychosocial well-being of HIV-positive individuals, how perceived AIDS-related stigma can affect caregivers' attitudes towards OVC in their care has not been very well studied.

This study will contribute to the existing literature by shedding more light on the relationship between caregiver and OVC psychosocial well-being and by exploring how perceived AIDS-related stigma and household socio-economic status may influence caregivers' attitudes towards OVC in their care. In recent years, many programs have been developed to help improve the quality of life of OVC in sub-Saharan Africa. However, with little information available on caregivers' attitudes towards these children, such programs may be unable to fully address all the factors that affect the quality of care OVC receive. Results may thus also help guide and/or improve interventions for OVC and their caregivers.

1.4 Study Context – United Republic of Tanzania

This study is based in the United Republic of Tanzania, where information from the most recent Demographic and Health Survey (DHS) indicates that the national HIV prevalence is at a high figure of 6.5%, with Iringa and Mbeya regions having the highest HIV prevalence (15.7% and 9.2% respectively). The World Health Organization (WHO)³ reports that at the end of 2005, there were at least 1.1 million children in the country under the age of 18 years who had lost either one or both parents to HIV and AIDS. Approximately 1% of these children have lost both parents (NBS & ORC Macro, 2005). 13% of children who have lost one or both parents also live in the southern highlands, which is the highest zonal prevalence of orphanhood in the country (NBS & ORC Macro, 2005), and is also the focus of this study.

As in other parts of sub-Saharan Africa, the majority of these children are absorbed into the extended family system (Foster, 2000). According to the 2004-2005 Tanzania DHS report, roughly 16% of all children in the country are fostered (that is, they live with neither of their natural parents), although caution must be used in interpreting this data as the result of HIV and AIDS, as fostering may not necessarily be due to HIV and AIDS, but could be as a result of other reasons such as parents working away in another town or city, divorce or illegitimacy. In general, younger children are more likely to be living with both parents as compared with older children, and children in rural areas are more likely to be living with one or both parents as compared with children living in urban areas (NBS & ORC Macro, 2005).

With regards to AIDS-related stigma, the report suggests that although the majority of the population appears to have a solid understanding of HIV transmission, stigma is still a significant problem as only 22% of women and 27% of men report acceptance of HIV and AIDS-infected individuals (NBS & ORC Macro, 2005). Education, wealth and residence are associated with positive attitudes towards people living with HIV and AIDS. Generally, individuals who have completed higher levels of schooling, live in wealthier households and/or live in urban areas are more likely to have positive attitudes

³ http://www.who.int/hac/crises/tza/background/Tanzania_Feb05.pdf

as compared with those with little or no education, come from poorer households and/or live in rural areas (NBS & ORC Marco, 2005).

1.5 Research Objectives

The primary study objectives are to examine the effect of psychosocial well-being on caregivers' attitudes towards AIDS-affected foster children in their care, and the role of individual perceptions of AIDS-related stigma on the relationship between a caregiver's psychosocial well-being and a caregiver's attitude towards a foster child. The study will also investigate if and how household socio-economic status changes these relationships, as well as examine the relationship between OVC psychosocial well-being and caregiver psychosocial well-being. While there may be other pathways through which relevant factors can shape caregivers' attitudes towards their foster children, this study will mostly focus on factors that influence their psychosocial well-being, and which in turn influence their attitudes.

CHAPTER 2 – LITERATURE REVIEW

2.1 Introduction

This literature review is divided into three main sections: a summary of fostering practices in sub-Saharan Africa, information on caregivers' attitudes towards AIDS-affected foster children in their care and the factors that may shape these attitudes and AIDS-related stigma and how it can affect caregivers' attitudes. It will begin by first outlining traditional foster care practices in sub-Saharan Africa and foster care practices in the context of HIV and AIDS. Some relevant terms used in this study, such as fostering, orphans and vulnerable children will also be defined in this section; see Appendix A for a list of definitions used for all primary terms. Information on what is currently known about caregivers' attitudes towards OVC in their care and the factors that may influence them will then be provided. The next section of the literature review is focused on AIDS-related stigma, its definition and the reasons why it exists. A brief overview of the types and expressions of stigma, and how AIDS-related stigma impacts caregivers and their households will also be presented.

2.2 Traditional foster care practices in sub-Saharan Africa

Child fostering is not a new phenomenon in sub-Saharan Africa and there is a wealth of literature documenting fostering practices in African societies, particularly those in West Africa. For the purposes of this study, child fostering is defined as when the primary caregiver (also referred to simply as a caregiver in this review) of a child is not his/her biological parent, regardless of whether or not the biological parent is also living in the same household as the child⁴. This is so as to account for households where the child's biological parent may be ill and although the biological parent and child live in the same household, the burden of childcare falls on another individual in the household such as a grandparent or an older sibling. Current literature is inconsistent in its definition of fostering. In some studies, it is defined as when a child "migrates away from his/her

⁴ A similar definition has also been used in past studies in Mali (Castle, 1995; Castle, 1996).

biological parents to a home of other people, who accept to bear the child rearing responsibilities” (McDaniel & Zulu, 1996), while in other studies, it is defined as when a child lives away from one parent, particularly his/her mother (Bledsoe & Brandon, 1992; Bledsoe et al., 1988; Lloyd & Desai, 1992; Verhoeff, 2005), or even as when a child is cared for by unrelated adults (Phiri & Tolfree, 2005). However, regardless of how fostering is defined, and in spite of the fact that much of the fostering literature comes from West Africa and this study is based in Tanzania, it nonetheless provides relevant background information on fostering practices before the devastating effects of HIV and AIDS on communities.

Unlike in Western cultures where children are generally raised by their natural parents unless there are exceptional circumstances such as death or abuse, literature dating as far back as over thirty years ago has documented different forms of living arrangements for children raised in African societies (Goody 1982; Isiugo-Abanihe, 1985; Lloyd & Desai, 1992; Verhoef, 2005). For instance in Tanzania, fostering is traditionally prevalent in the society and research shows that on average, 34% of children under 15 years of age are fostered, though only about 8% of these are orphans (Foster, 2000). This information is based on regionally-representative data. Madhavan (2004), in a study of fosterage patterns in the context of HIV and AIDS in South Africa, identifies two main types of fostering: voluntary fostering and crisis-led fostering. Voluntary fostering is defined as “arrangements made between biological and foster parents that accord with cultural norms and traditions about child rearing”, while crisis-led fostering is motivated by divorce, separation, economic hardship or death of one or both biological parents (Isiugo-Abanihe, 1985; Madhavan, 2004). For the most part, the decision on who fosters in a child is dependent on either kinship obligations (Goody, 1982) or the type of fostering (Isiugo-Abanihe, 1985; Madhavan 2004); however, evidence in the literature shows that the majority of fostering-in is undertaken by members of the biological parents’ extended families (Isiugo-Abanihe, 1985).

In voluntary fostering, Isiugo-Abanihe (1985) identifies different circumstances under which children can be sent away to foster parents. Under kinship fostering, children are

sent away to relatives, particularly grandmothers, so that mothers have more time to work, whether that is in the home or outside the home, or even to encourage mothers to have more children. This type of fostering is very often underlined by a flow of support, either in the form of food, money or clothing from the biological parents to the foster caregiver, as well as regular visitation. Sometimes, as in some Muslim cultures, children can be sent away to influential religious or political leaders to receive training, for example in the Koran. Children can also be sent away to learn a trade from those already well-established in their professions. This type of fostering, known as apprentice fostering, is motivated by the perception that children raised by influential foster parents will fare better in society than if they were raised by their own parents. Educational fostering, similar to apprentice fostering in that children are sent away to be formally educated by foster parents, is also motivated by social mobility and the belief that foster parents are able to provide better education than the children's parents (Gage, 2005; Isiugo-Abanihe, 1985). Most of the time, these foster parents are relatives; however children can be sent to live with non-relatives who live near better or preferred schools. Lastly, children, particularly females, can be sent to other households to help out with the household chores, either as housemaids or simply to be taught about women's roles in homes. They can also be sent out to provide emotional support to infertile couples so that they can have a child in the home to rear. This type of voluntary fostering is known as domestic fostering, and the child or his/her family may receive remuneration in exchange for the services provided (Isiugo-Abanihe, 1985).

There are two fundamental differences between voluntary fostering and crisis-led fostering. While voluntary fostering is generally characterized by a mutual agreement between biological and foster parents (Aspaas, 1999), crisis-led fostering is borne more out of desperation and a lack of suitable alternatives. Crisis-led fostering includes children fostered as a result of divorce, separation or illegitimacy or death of a parent (Isiugo-Abanihe, 1985; Madhavan, 2004). With most types of voluntary fostering, biological parents are able to visit the child and provide clothing, food and other forms of support when they are able (Madhavan, 2004). However with crisis-led fostering, biological parents are usually unable to help support the children either materially or

emotionally, especially if they are ill or dead. This may mean that foster parents will have to bear the sole responsibility for a child in their care. Another problem with crisis-led fostering is that foster parents may be unprepared to take in a child. While with voluntary fostering foster parents not only want to have the child in their home, but are in a position to accept an extra child in the home, with crisis-led fostering, foster parents may not necessarily be ready to take in a child, but may be forced to do so because there are no other alternatives (Guest, 2001). In this era of HIV and AIDS, the fostering of orphans and vulnerable children in households where their primary caregivers are not their biological parents falls into this category of crisis-led fostering (Aspaas, 1999). Since there is considerable variation in the definition of orphans as well as the definition of vulnerable children in the literature, the next paragraph will provide a brief overview of the term as it applies to this study (for a full definition of all primary terms, please refer to Appendix A).

Literature, particularly those written in the earlier days of the pandemic, focused on the concept of “AIDS orphans”, a term invented by USAID referring to children who have lost either one or both parents to HIV and AIDS (Sherr et al., 2008), and vulnerable children, a term that is loosely used for children with parents ill with AIDS, children cared for by elderly guardians such as grandparents and even children living in extremely poor households (UNICEF, 2003). This definition of vulnerability may also include street children. In this study, orphans and vulnerable children fall into any one of the following categories:

- i. Children who, regardless of their own HIV status, have one or both parent(s)/guardian(s) who is either HIV-positive or ill with AIDS
- ii. Children who have lost either one or both parent(s)/guardian(s) to AIDS. This definition includes children who are classified in the literature as orphans, and the term “orphan” may sometimes be used in this review when referring to children who have lost either one or both parents to HIV and AIDS.
- iii. Children who are not included in the two categories described above, but are vulnerable due to lack of adequate adult support, AIDS-related

stigma and discrimination or other reasons, such as extreme poverty, identified by the community or by the non-governmental organizations from whom the study sampling frames were obtained.

This definition is in line with that used by UNICEF, which classifies orphans and vulnerable children as children who fit into any one of the following categories: children who are HIV positive or have AIDS, children whose parents/guardians are HIV positive or have AIDS and children who are affected by severe poverty, stigma and discrimination (UNICEF, 2003). Although some of these children are not necessarily HIV-positive themselves, they are still subject to the hardships brought about by the stigma surrounding the disease and the illness and/or death of their parents/guardians. Due to the limitations of the dataset, OVC in this study are aged between 8 and 14 years. However, OVC in the literature can range in age anywhere from birth to 18 years of age (Foster, Levine, & Williamson, 2005; UNICEF, 2006). Then again, UNICEF (2003) reports that about 50% of OVC are aged 10 to 14 years. The age criteria used for OVC in the different studies is worth mentioning as children have different needs at different stages of growth, and this may impact a caregiver's attitude towards that child.

2.3 Foster care practices in sub-Saharan Africa in the context of HIV and AIDS

Relatives who would normally have undertaken voluntary fostering are usually expected to foster children in times of emergencies (Goody, 1982), and indeed UNAIDS (2004) reports that extended families in sub-Saharan Africa are currently caring for 90% of all children orphaned by HIV and AIDS in the region. However, some researchers have suggested that while traditionally fostering was undertaken by relatives such as aunts, HIV and AIDS has resulted in an increasing number of grandparents having to take over parenting responsibilities (Foster & Williamson, 2000; Nyambedha et al., 2003; Olcke et al., 2005). In fact a study by Merli and Palloni (2006) in South Africa suggests that there will be a future increase in the number of grandparents who are caring for their grandchildren because their own children are unable to do so due to illness. Researchers attribute this trend of grandparents caring for orphaned children to the increasing number of children needing care and the decreasing number of adults available to provide this

care (Foster & Williamson, 2000; Oleke et al., 2005), and others have argued that it is this increased pressure on the extended family system of fostering children that has led to fracturing and in some cases a complete breakdown whereby overburdened relatives may refuse to take in children (Adepoju & Mbugua, 1997; Ankrah, 1993). As a result, they may be left alone in households where there are either no adults, no able-bodied, working adults or insufficient working adults to support the number of dependents living in that household, leading to high child dependency ratios⁵ (Adepoju & Mbugua, 1997; Ankrah, 1993; Foster, 2000; Foster & Williamson, 2000; Oleke et al., 2005).

Alternatively, a study in South Africa suggest that historically grandparents have always played a role in caring for their grandchildren, and rather it is the fact that they are now solely responsible for the care of these children that suggests the break down in the extended family system. This is because in the past, parents left their children in the care of grandparents so that they could seek work in bigger cities and towns. These parents often sent money home to help support their children and also stayed in contact with their children. However, due to illness and death from HIV and AIDS, grandparents are now solely responsible for the economic and psychological well-being of large numbers of children (Reddy et al., 2005). Research from UNAIDS (2008b) also support these findings by pointing out that the combination of deaths of parents and other caregivers of productive age and poverty-driven migration has resulted in a shortage of prime-age adults. Therefore whereas before the HIV and AIDS era grandparents were merely lending a helping hand to working parents, they are now solely responsible for their grandchildren.

Financial difficulties and the burden of care, consisting of an intricate web of high child dependency ratios and the presence of chronically ill persons in the household, have contributed to the change in the nature of fostering. Ansell and van Blerk (2004), in a study of the impact of HIV and AIDS on children's migration in Malawi and Lesotho,

⁵ WHO defines the dependency ratio as the ratio of persons in the "dependent" ages (under 15 years plus 65 years or older) to those in the "economically productive" ages (15-64 years). This ratio is usually referred to as the total dependency ratio, while the first component of the numerator (children under age 15) is called child or young dependency ratio, and the second component (those aged 65 and over), old-age or old dependency ratio.

argue that because AIDS-affected households often have limited resources available to them, children are moved from one household to another in an attempt to ensure that their needs are adequately met. However, unlike traditional fostering practices in the absence of the effects of HIV and AIDS, many of these households fostering-in children may be unprepared for the additional mouths to feed and clothe. Foster parents often have to be solely responsible for the upkeep of the foster child as biological parents may be dead or too ill to contribute, particularly financially, to the child rearing process (Foster, 2000). For example, research shows that in Tanzania, less than 25% of households caring for orphans received support from a surviving parent of the child, while less than 10% of orphan households received any kind of support from other relatives and elsewhere (Urassa et al., 1997). In some cases, foster parents may even have to take in multiple children at the same time and it is even possible that foster parents may also have to care for ill parents of foster children as well (Schatz, 2007), while also possibly being HIV positive themselves.

The underlying message of all these researchers is that the fostering of AIDS-affected children has changed the nature of fostering in sub-Saharan Africa. Box 2.1 below provides a brief overview of the major differences between traditional foster care practices and fostering in the context of HIV and AIDS.

Box 2.1: Primary differences between traditional foster care practices and fostering in the context of HIV and AIDS

Traditional foster care practices	Fostering in the context of HIV and AIDS
<p>“an arrangement made between biological and foster parents that accord with cultural norms and traditions about child rearing” (Isiugo-Abanihe, 1985)</p>	<p>No pre-arrangements – extended family members take in children because parents are ill or have died and the children usually have nowhere else to go</p> <p>Increasing number of grandparents having to take over parenting responsibilities</p>
<p>Foster parents and child usually receive material support from biological parents; parent is in contact with the child</p>	<p>No material support from parents; parent may or may not be in contact with the child</p> <p>In some instances, foster parents may also be caring for ill biological parents, as well</p>

	as OVC (e.g. grandmother caring for sick child as well as children of that sick child i.e. their grandchildren)
Foster parents are usually better off financially	Foster parents are not necessarily better off financially
Foster parents are mentally and financially prepared to care for an extra child	Since foster parents do not necessarily have a choice in taking in OVC, they may not be mentally and/or financially prepared to care for an extra child

Not surprisingly, financial difficulty is one of the major problems encountered by many caregivers of OVC (Foster et al., 1995; Miller et al., 2006). A study on orphan care in Botswana revealed that 48% of households caring for children orphaned⁶ by HIV and AIDS were experiencing financial problems and were having trouble providing basic necessities such as food and clothing for the children in their care (Miller et al., 2006). Another study in Uganda showed that due to the fact that the hardest hit adults are those in the economically productive ages of 15 to 45 years old, households caring for children affected by HIV and AIDS have very limited financial resources, particularly those headed by elderly caregivers such as grandparents (Aspaas, 1999). The issue of financial difficulties experienced by caregivers of OVC will be discussed in more detail when examining the issue of household socio-economic status and how it can affect caregivers' attitudes towards these children.

Having to care for a chronically ill person in the household, especially one suffering from a highly stigmatized disease such as HIV and AIDS also results in increasing stress levels of the caregiver and others in the household (Bor et al., 1993). One of the more troubling aspects of having an AIDS-infected individual in a household, apart from AIDS-related stigma which will be discussed in greater detail later on in this review, is the daily caring activities, which can be overwhelming for the caregiver. Normal household routines may be disrupted as the caregiver will have to spend more time on the sick individual, and as

⁶ In this study an orphan was defined as a child aged 0 to 17 years who had lost either one or both parents to HIV/AIDS.

such may not have sufficient time for other household members, including any OVC that may be in the household. This can create tension and even conflict between the caregiver and the patient, as well as the caregiver and other household members (Nostlinger et al., 2006; Lester et al., 2006). Patients may sometimes be filled with guilt and despair over the burden of their care and can be prone to mood swings due to anxiety and depression (Lyold, 1988). Caregivers may experience depression, displaced anger, and may feel resentful, as well as guilty for feeling resentful at the same time (Frierson et al., 1987). These conflicting emotions in both patients and caregivers also contribute to an atmosphere of tension in the household and only serve to increase the burden experienced by the caregiver.

Financial difficulties and the burden of care in the household often have psychosocial consequences for caregivers of OVC. For example, a study in western Kenya revealed that although elderly grandparents were happy to take in grandchildren orphaned or made vulnerable by HIV and AIDS, they very often were incapable of providing adequately for these children, and this sometimes caused them great emotional distress (Nyambedha et al., 2003). Other studies also found that caregivers of children affected by HIV and AIDS experienced high levels of stress, poor physical health and increased loneliness and isolation (Oburu & Palmerus, 2005; Schatz, 2007). More studies have also shown that the psychosocial health of OVC is also compounded by the burden of care due to their unmet needs for basic requirements such as food and clothing (Atwine et al., 2005; Cluver & Gardner, 2006; Makame et al., 2002; Mann, 2002; Zhao et al., 2007). Caregiver and child psychosocial well-being are relevant because some studies have suggested that there may be a bi-directional relationship between these two factors (Mann, 2002), and both these factors may influence caregivers' attitudes towards OVC in their care. This issue will be further discussed later on in this review.

2.4 Caregivers' attitudes towards AIDS-affected foster children in their care

Insufficient information exists on caregivers' impressions of their foster children in the context of HIV and AIDS. Studies exploring perceptions of orphan care and the living

situations of orphans in the context of HIV and AIDS have examined these issues from the perspectives of community members in general and from that of OVC, and less often from the perspectives of the caregivers themselves (Foster et al., 1995; Foster et al., 1997; Funkquist et al., 2007; Mann, 2002). Other studies have focused on issues such as willingness to foster, and not directly on the caregivers' perceptions of the foster children in their care (Howard et al., 2006; Foster et al., 1995).

On the whole, reports from community members about foster caregivers have been negative, giving the impression that OVC are generally unwanted by their foster parents, and are viewed as a burden (Mann, 2002; Nyblade et al., 2003; UNICEF, 2003). However a few studies soliciting information directly from caregivers of foster children show that some foster parents, particularly grandparents, are more than willing to have foster children in their homes, and others even see it as their duty, especially if they are biologically related to the child/children (Foster et al., 1995; Guest, 2001; Nyambedha et al., 2003; Siaens et al., 2003). In a study of caregivers in rural Zimbabwe, Howard et al. (2006) found that 98% of caregivers were willing to foster-in children. The driving forces behind the decision to foster-in children was the absence of others available to care for the child, family duty and love for the child or children in question. A majority of these caregivers reported that although there were challenges to caring for orphans, there were also benefits such as satisfaction of doing their duty, satisfaction of helping the child and the joy of having the child in the household. Some caregivers also believed that by taking in orphans, they gained respect from community members for having taken on a difficult task. Ansell and van Blerk (2004) found that in Malawi and Lesotho, relatives who fostered-in AIDS-affected children did so because they felt that it was their responsibility to care for these children. Some of these relatives reported feeling sorry for the children and being genuinely concerned about what would happen to them if they (relatives) did not take them into their households. Others also reported feeling affection for the children. In South Africa, Juma et al. (2004), found that some caregivers felt it was even their duty to provide love, compassion, counseling and spiritual support to not only sick household members, but to affected children as well. A caregiver said this of AIDS-affected foster children in her household:

“You have to get closer to them and console them [children] so that they do not think of their parents. You console them by talking to them and finding out what their needs are.” (Juma et al., 2004).

In fact, another study in South Africa on the plight of elderly caregivers in the era of HIV and AIDS found that sometimes elderly caregivers such as grandparents liked having their grandchildren in the house because the children would be able to help them with labor-intensive activities such as fetching water, which they were too old to do themselves. The study also found that some caregivers completely took over parenting responsibilities such as bathing children, washing their clothes, and cooking for them to the extent that they sometimes referred to the children as if they were their own children. Although most of the caregivers in this study acknowledged that caring for children was difficult, it was clear that all of them saw it as their responsibility to be concerned about the welfare of the children in their care. One grandmother caring for her grandchildren was quoted as saying,

“These are my grandchildren. If they are hungry and ask for food, I buy it for them. If I don't give to them [what they need], my heart is painful....” (Schatz, 2007).

However it can be argued that just because a caregiver believes it to be his/her duty to take in a foster child, it does not necessarily mean that they will have a positive attitude towards that child. If anything, he/she may actually resent the foster child as he/she may view the child as a burden. However, other researchers have counter-argued that potential foster parents who view foster children as burdens usually do not take in these children at all (Howard et al., 2006). Research also shows that grandparents, in particular, have expressed strong feelings of wanting to care for their grandchildren regardless of whether or not they are able to financially support these children (Freeman & Nkomo, 2006; Guest, 2001; Nyambedha et al., 2003). A case study of caregivers in Zimbabwe revealed that grandparents, although they were struggling financially, had positive attitudes towards orphaned grandchildren in their care as they viewed these children as a reminder of their own children who had passed away. These caregivers were motivated to provide care for orphans not only because no one else was available to care for them,

but also as a demonstration of love for those orphans and a desire to ensure that they were comfortable. Some caregivers even found solace in the presence of orphans in their households as they were previously lonely living alone. Other caregivers appreciated having orphans in their households as these children helped with the housework and assisted them in the fields (WHO, 2002). A study in Kenya also found that sometimes grandparents went without food themselves so that grandchildren in their care could be fed (Nyambedha et al., 2007).

Studies conducted amongst American grandparents, though not in the context of HIV and AIDS, have confirmed some of these findings. Ross and Aday (2006) report that although American grandmothers caring for their grandchildren experienced financial challenges, as well as suffered from increased depression, stress and medical problems, many reported a sense of satisfaction and appreciation for helping their grandchildren, receipt of the Lord's blessings, reason for living, and an improvement in their psychosocial well-being because they knew that their grandchildren were safe and well cared for.

On the other hand, some caregivers have been known to express negative feelings towards the foster children in their care, such as complaining that the children are too difficult to manage or that they behave badly (Mann, 2002; Ntozi & Mukiza-Gapere, 1995). For example, some caregivers may feel that a foster child needs to be grateful to them for providing him/her with food and shelter and thus he/she is not allowed to complain about not getting enough to eat or not being able to go to school, while others may feel that it is natural to want to treat a biological child more favorably than a foster child and thus the foster child is being unreasonable by expecting to be treated similarly to a biological child (Mann, 2002). Research shows that some caregivers also perceive AIDS-affected foster children in their care as being overly sensitive, jealous, demanding and hard to satisfy. These children were viewed as being rebellious and difficult to manage (Juma et al., 2004). Caregivers who perceive AIDS-affected foster children to have behavioral difficulties may also have negative attitudes towards these children.

Another study conducted amongst Ugandan caregivers found that although caregivers may view foster children as their responsibility, their perception of this responsibility was that it was a burden. This was because these caregivers found themselves having to feed and clothe a greater number of children than they were able. Many of these caregivers received no financial support from the children's biological parents due to various reasons such as illness and death, and as a result, having to shoulder the entire responsibility of caring for these children left them frustrated and sometimes resentful (Williams, 2003).

2.5 Factors influencing caregivers' attitudes towards AIDS-affected foster children in their care

2.5.1 Individual-related factors

2.5.1.1 Caregiver-related factors

Caregivers' psychosocial well-being

Emotional distress can impact caregivers' attitudes towards foster children in their care. A study in the Democratic Republic of Congo (DRC) of women caregivers found that close to 90% of the women reported that caregiving was "difficult" and "very stressful", and that they found themselves constantly worrying about having insufficient food and irregular drug supply for those who needed medical care. As a result, many also expressed deep unhappiness and desperation with their situation (Kipp et al., 2006). Another study of family caregivers in three rural districts in western Uganda also revealed similar results – caregivers often felt overwhelmed by their daily caregiving activities and were constantly worried about their financial resources (Kipp et al., 2007). In a study of elderly caretakers in western Kenya, Nyambedha et al. (2007) found that some caregivers were caring for more than one orphan at a time and the major problems facing these caregivers were paying for schooling, lack of food in the household and lack of access to medical services for the orphans. A few caregivers were over 70 years of age and yet had multiple children in their care. Due to age, these caregivers were unable to engage in income-generating activities and meaningful subsistence activities to allow them to adequately provide for their large households. These challenging situations

caused caregivers to suffer deep emotional distress and a loss of interest in activities in which they had been previously engaging in. Some caregivers even experienced lack of sleep because they had to get up in the middle of the night to nurse babies or because they were worried about how to find money to pay medical bills for sick orphans. This lack of sufficient rest and anxiety about money can also result in poor psychosocial health for caregivers (Nyambedha et al., 2007). Caregiving can also be particularly taxing for grandparents and other elderly caregivers because they are at the point in their lives where they were expecting their children to provide for them. As a result, they are not emotionally, financially and/or physically prepared to have dependents (UNAIDS, 2008b).

Another study carried out in Kenya also substantiates these findings. This study compared the stress levels of grandparents who were caring full-time for their grandchildren to those of grandparents caring only part-time for their grandchildren, that is, those who only supplemented caregiving responsibilities to transient biological parents. As expected, the total stress experienced by full-time caregivers exceeded that experienced by the part-time caregivers. Full-time caregivers felt overwhelmed and experienced elevated levels of emotional distress (Oburu & Palmerus, 2005). A Ugandan study also found that caregivers who had lost their children and were having to care for the orphans left behind were experiencing grief and sadness for their loss, while at the same time increased stress levels as a result of their caregiving duties. Some caregivers even reported a sense of helplessness (Williams, 2003). Such caregivers may not even be able to grieve properly after deaths in the household as they have to be emotionally and physically strong to care for the dependents left behind (UNAIDS, 2008b). Caregivers may also experience social isolation due to being too busy with daily caregiving activities to participate in community events and also to socialize with friends and neighbors. Social isolation leads to increased emotional distress (Juma et al., 2004).

WHO (2002) also found that in Zimbabwe, caregivers, particularly elderly caregivers, were under serious financial, physical and emotional stress due to their caregiving responsibilities. Some caregivers worried that if anything were to happen to them, the

future of the orphans in their care would be bleak. These caregivers reported feeling emotionally drained and this fear of the future for the children in their care heightened this pain. Other caregivers were also frequently frustrated about the lack of available resources to adequately provide for all household members and complained about too many people living in their households.

Generally, caregivers of AIDS-affected foster children often experience poor psychosocial health for some or all of the following reasons:

1. Lack of financial resources to cover basic needs
2. Lack of food resources
3. Poor access to needed medical services
4. Grief and sadness due to the loss of their own children
5. Worry and fears about the future of orphaned children in their care
6. Lack of emotional and material support

Since caring for children affected by HIV and AIDS can be difficult and overwhelming, especially when resources are limited, the psychosocial well-being of these caregivers is important, particularly that of those also caring for a sick family member as well as OVC, as it can negatively impact the caregiver's attitude towards OVC in his/her care. A caregiver who is under undue stress and is constantly worried and anxious may blame their situation on OVC in the household, and thus resent the presence of the children in the household (Mann, 2002). Stress may also cause a caregiver to view OVC as badly behaved and ungrateful for the care they are receiving. However the literature in this area is somewhat contradictory, suggesting that more work needs to be done.

Studies conducted in the developed world showed a positive correlation between elevated levels of emotional stress of caregivers and perceived child adjustment problems (Jones, 1996). On the other hand, a study conducted in Kenya examining the link between caregiver stress and their perception of orphaned children's adjustment difficulties was unable to establish this connection. The results of the study showed that although caregivers of orphaned children in general did report elevated levels of stress, there was

no positive correlation between elevated stress levels and perceived child adjustment difficulties (Oburu, 2005a). However the author suggests that this may have been because, unlike the previous studies, a caregiver's age was controlled for in the model. However when a caregiver's age is not controlled for, a positive correlation is observed between elevated stress levels and perceived child adjustment problems. Another Kenyan study of elderly caregivers by the same author, which does control for age, found that grandmothers caring for orphaned children not only reported extremely high levels of stress, but that their total stress was significantly correlated with their perception of their grandchildren's behavior (Oburu, 2005b). However, the contradictory aspect of the literature with regards to this issue suggests that further research and analyses may be required to determine the exact relationship between caregiver stress and perception of a foster child in his/her care.

Caregiver socio-demographic factors

A caregiver's gender, marital status and headship status in the household may affect his/her attitude toward foster children in their care. Firstly, there is sufficient evidence from sub-Saharan Africa indicating that women are more likely to experience AIDS-related stigma and discrimination as compared with their male counterparts (Ogden & Nyblade, 2005; UNAIDS, 2007). As a result, female caregivers may be more likely to experience stigma and discrimination as compared with male caregivers. This may also cause female caregivers to be more likely to perceive themselves to be stigmatized as compared with their male counterparts, and perhaps causing them to be more resentful of AIDS-affected foster children in their care as they may blame the children for their situation. On the other hand, a study in Uganda examining the effect of gender and geographical location on the allocation of household resources found that orphans living in female-headed households were less likely to be discriminated against as compared with orphans living in male-headed households (Aspaas, 1999). The study showed that in male-headed households, orphans were less likely to be enrolled in school as compared with non-orphans in the same household. Other studies have also shown that living in a female-headed household is positively associated with a child's chances of completing

primary school (Case et al., 2002; Lloyd & Blanc, 1996)⁷. Less discrimination may imply a more positive attitude towards orphaned children in the household.

Marital and headship status in the household may also be significant since in many African societies, women and girls have the traditional role of caregivers, but have less access to education and training, often resulting in lower economic opportunities as compared with men, which prevents them from providing better care for their households (UNAIDS, 2004). As a result, female-headed households may be poorer and have higher levels of food insecurity (UNAIDS, 2006), possibly resulting in a female caregiver being more resentful of the burden of having extra mouths to feed because of the presence of foster children in the household. Alternatively, research also shows that female-headed households are more likely to take in orphans as compared with male-headed households, and that on average, female-headed households have more orphans than male-headed households (UNAIDS, 2006), and this may also suggest more positive feelings towards such children in female-headed households where the female head is also the primary caregiver. Clearly more research is needed to determine exactly how headship status may affect a caregiver's feelings towards an orphaned child in his/her care. With regards to marital status, research from UNAIDS (2008b) suggests that for married women, the burden of caring for sick individuals and/or children in their households tends to fall on their shoulders. A married caregiver whose partner is bringing in income may have a more positive attitude towards foster children in the household due to less emotional distress about how to care for all the children in the household. Larger child dependency ratios for female-headed households caring for OVC may suggest further pressure on household resources, which may negatively impact a caregiver's psychosocial well-being by increasing their stress levels, and thus making them more resentful of foster children in their care. The effect of a household's socio-economic status on caregivers' attitudes towards their foster children will be discussed later on in this review.

⁷ Studies on men's and women's expenditure indicate that on the whole, women are more likely to spend all or majority of their earnings on children in the household and on other household needs, as compared with men, who are more likely to hold back some of their income as personal spending money (Dwyer & Bruce, 1988). Thus in male-headed households, men may give priority to their biological children and ignore non-biological children so that they have more personal spending money available to them.

Age is also another factor that may shape caregivers' attitudes towards foster children in their care. Although there is little empirical evidence defining the relationship between age and attitudes towards foster children, in a study comparing caregivers of AIDS-affected foster children to non-caregivers, Ohnishi et al. (2008) found that younger caregivers in Nigeria were more likely to have positive attitudes towards OVC, as compared with older caregivers and non-caregivers. Forsyth et al. (2008) also found in their South African study that younger people in general were less likely to stigmatize OVC as compared with older people. However, this study was not specifically focused on caregivers and thus caution must be used in extrapolating these results to caregivers in general, and their attitudes towards OVC in their care. These studies are contrary to other research that show that older caregivers, such as grandparents, are not only more willing to foster OVC, but are also more likely to show genuine concern for these children (Freeman & Nkomo, 2006a; Nyambedha et al., 2003). Clearly more research is needed in these areas to determine associations, and the direction of these associations, between caregiver age and caregiver attitudes towards their foster children.

Educational level and understanding of how HIV and AIDS is transmitted may also affect caregivers' attitudes towards foster children in their care. Forsyth et al. (2008) found that individuals with a tertiary education were less likely to stigmatize those living with HIV and AIDS or affected by HIV and AIDS as compared with those with no schooling or those with schooling less than a tertiary education. Again although this study is not specifically focused on caregivers, their results may imply that caregivers with little formal schooling may be more likely to stigmatize OVC in their care because they are HIV-infected or AIDS-affected, thus suggesting a more negative attitude towards these children as compared with caregivers with more schooling who are less likely to stigmatize. An individual's education level is also important because it affects his/her ability to fully understand how HIV and AIDS is transmitted, and this lack of understanding compounds the stigma surrounding the disease (Forsyth et al., 2008; Nyblade et al., 2003) and makes it more difficult for a caregiver to fully accept an AIDS-affected foster child in his/her household. Ohnishi et al. (2008) in their Nigerian study

found that individuals with a more accurate understanding of HIV and AIDS transmission were more likely to have positive attitudes towards OVC.

Biological relationship to OVC in their care

One factor that has been well-established in the literature as not only influencing a caregiver's willingness to foster a child, but also the caregiver's attitude towards the child is the type of biological relationship between the caregiver and the child (Bledsoe et al., 1988; Bledsoe & Brandon 1992; Case et al., 2000; Fincham & Thomas, 1984; Van der Waal, 1996). Literature in this area suggest that the closer the biological relationship between a caregiver and a foster child, the more likely the caregiver is to have a positive attitude towards that child (Case et al., 2004). For example, Howard et al. (2006) found that in Zimbabwe, caregivers were more willing to foster-in a child if they biologically-related to that child. Amongst grandparents, the authors found that willingness to foster-in was highest for grandchildren and then gradually declined with increased distance in relatedness. The authors also found that while nearly three-fourths of caregivers were willing to foster-in a relative's child, less than half would take in a friend's child and only about one-fourth were willing to take in a complete stranger's child.

According to the socio-biological theory, parents and caregivers are more inclined to invest in an off-spring or a full sibling than in a cousin or half-sibling, and more in any of these than step-child (Malkin & Lamb, 1994). This theory is derived from Hamilton's rule, which suggests that individuals are more likely to favor those they are more closely related to, as compared with distant relatives (Case et al., 2004). The theory implies that in households where there are both biological and foster children, caregivers may be more likely to have a negative attitude towards foster children in their care as compared with their own biological children, especially if resources are limited and food insecurity is high. Caregivers may resent foster children for the pressure they put on household resources, thus making it more difficult for biological children to receive optimum care. However, if no biological children are in the picture, caregivers may have more positive attitudes towards foster children as there will be fewer competing obligations (Safman, 2004).

Nyambedha et al. (2003) found that in general in western Kenya, orphans preferred living with their grandparents as opposed to another relative even if they had to do extra work to make up for their grandparents' age. This was mainly because orphans perceived their grandparents, particularly grandmothers, as being more willing to do their best to help them (Funkquist, 2007). This may be because while other caregivers may have negative attitudes towards foster children in their care because they view them as competing with their own biological children for scarce resources, grandmothers are more likely to treat all foster grandchildren in their care equally.

Religiosity

Religiosity may also influence a caregiver's attitude towards his/her foster child, as HIV and AIDS are often associated with behaviors condemned by many religions. For example, a study in Nigeria found that Muslim caregivers were less likely to have positive attitudes towards OVC (Ohnishi et al., 2008), possibly as a result of AIDS-related stigma. In fact research suggests that AIDS-related stigma may be more pronounced in Muslim communities because of the strong association of the disease with "immoral" sexual practices and drug use (Hasnain, 2005). A study among Muslim Libyan high school students revealed high levels of AIDS-related stigma, attributed to the fact that HIV and AIDS is viewed as a "curse" and those living with HIV and AIDS are "sinners" who deserve to be sick (El-Gadi et al., 2008). This association of HIV and AIDS with sin and punishment is not limited to Muslim communities alone.

Other studies have shown that some church leaders view HIV and AIDS as a punishment from God and have called for those infected to repent for their behavior (Ogden & Nyblade, 2005; Tiendrebogo & Buykx, 2004). The opinions of church leaders are important because a study conducted in Tanzania found that church leaders had immense influence over members' attitudes towards HIV and AIDS in general, people living with the condition and their loved ones (Hartwig et al., 2006). Nyblade et al. (2003) also report a general association of HIV and AIDS with sin and punishment from God in Tanzania, contributing to high levels of stigma. The association of HIV and AIDS with

sin will be further discussed in the section on the causes of stigma. However results from these studies suggest that a deeply religious caregiver may associate an HIV and AIDS-infected/affected child in their care with sin and have a low opinion of them and/or their biological parents.

Alternatively, religion could be a source of strength and support for caregivers, and could thus improve caregivers' psychosocial well-being. Improved psychosocial well-being could result in improved attitudes towards AIDS-affected foster children in their care. For example, in South Africa, Juma et al. (2004) found that caregivers who were members of churches in their communities strongly believed and trusted that God would improve their situations. This belief provided caregivers with emotional strength to handle the challenges of their daily caregiving activities.

Support network

The presence of a support network may have a positive influence on caregivers' feelings toward their foster children. Support for caregivers is defined in this study as both material and emotional support. Material support includes direct or indirect financial support such as donation of food, clothes, payment of children's school fees, etc. Emotional support includes a good network of friends, family and/or loved ones that the caregiver feels he/she can rely on. It also includes psychosocial support from volunteers from NGOs, etc. A good support network is one that provides adequate material and emotional support as defined by the specific caregiver.

A good support network is important as it can help caregivers cope with the emotional stress and financial obligations that come with fostering-in orphaned children. A study conducted amongst American caregivers, though not necessarily in the context of HIV and AIDS, also highlights the importance of emotional support in decreasing emotional stress (Ross & Aday, 2006). The authors found that caregivers who received counseling were in better psychosocial health as compared with those who did not receive counseling. Now while there is little or no empirical evidence that directly connects a support network to caregivers' attitudes towards their foster children, Oburu and

Palmerus (2005) have suggested that the total level of stress experienced by caregivers of orphaned children is related to perceived social and instrumental support. In their study, the authors define emotional support as psychosocial support received from spouses, friends and relatives, while instrumental support is defined as assistance in carrying out childcare tasks and daily household chores. The research revealed that amongst both full-time and part-time caregivers, the lack of emotional and instrumental support was significantly associated with elevated stress levels and perceived child behavioral difficulty. Thus these results suggest that caregivers not receiving emotional and material support are more likely to perceive their foster children's behaviors as managerially difficult, which may result in negative attitudes towards these children.

Other studies have shown that caregivers are more willing to foster-in children if they can be assured of a strong support network in the sense that they will receive material and emotional support from either family members or the community or both for caring for OVC (Freeman & Nkomo, 2006b). Such caregivers may be more likely to have positive attitudes towards children they foster. In some instances, caregivers have even said that without financial assistance from outside sources, they would no longer be able to cope with foster children in their homes (Miller et al., 2006). Howard et al. (2006) found that in rural Zimbabwe, the greatest barrier to fostering-in orphans was the lack of financial support. The authors worked showed that although government-funded programs are available to caregivers of orphans, these programs are generally under-funded and difficult to access. As such, very few caregivers were benefiting from this assistance. As a result, caregivers become overburdened, may fall ill and the foster children in the household may be thrust into the role of caregiver or head of household themselves.

There have also been sporadic reports of caregivers abandoning foster children in their care due to financial stress (Adepoju & Mbugua, 1997). Such caregivers may have negative attitudes towards the foster children in their care due to the burden of caring for these children. Since a support network is important, having access to support services such as material support and counseling provided by non-governmental organizations and

other volunteers may affect caregivers' attitudes towards AIDS-affected foster children in their care.

Reason for fostering

The reason why a caregiver fosters in a child can influence his/her attitude towards that child. Some of the more altruistic reasons why caregivers foster-in include true concern for the welfare of the child and sometimes a need to fulfill a dying parent's wish (Howard et al., 2006; Mann, 2002). However, there is some evidence that some foster caregivers do take in children for personal gain such as to receive a share of the child's inheritance, to gain from the child's labor and to be able to register for assistance from non-governmental organizations (NGOs) and other organizations which provide support to households caring for foster children (Mann, 2002). Such caregivers may have positive attitudes towards foster children in their care as they are benefiting from having these children in their households. However this is a debatable point since it is also possible for them to have negative attitudes towards such children whom they only see as a means to an end and whom they would not have in their households at all if it were not for the fact that they were benefiting.

2.5.1.2 Relevant child-related factors

Child characteristics such as his/her age and gender may also influence a caregiver's rationale for fostering-in and thus their feelings towards his/her foster child. Mann (2002) found that in Malawi, female children and children aged between 3 years and 6 years were more desirable for fostering. This is because female children could help in household chores and could even be married off to wealthier men, which would help improve the financial status of the entire household, while younger children are desired because they are less likely to remember their parents and thus more likely to form stronger bonds with the foster parents as compared with older children who already have an attachment to their biological parents. However, more research is needed in this area to clarify the relationship between a caregiver's feelings towards a child and a child's age and gender.

A child's psychosocial well-being may also influence a caregiver's psychosocial well-being, and thus the caregiver's feelings towards that child. A child in poor psychosocial health may be more likely to misinterpret the actions of his/her caregiver and others in the household, and thus act out, and this may cause the caregiver to have negative feelings towards that child. For example, Nyambedha et al. (2007) found that some orphans in western Kenya living with their grandparents sometimes misinterpreted their caregivers' inability to provide them with food as a form of discrimination. Literature suggests that OVC are more likely to have poor psychosocial health as compared with non-OVC. Several studies have documented the emotional trauma OVC have to go through after watching their parents suffer a debilitating illness and eventually die. In Dar es Salaam, Tanzania, Makame et al. (2002) found that orphans, as compared with non-orphans, were more likely to have increased internalizing problems and more likely to have contemplated suicide in the past year. A study in rural Uganda comparing the psychosocial well-being of orphans to those of non-orphans found significantly higher levels of psychological distress amongst orphans – orphans had a greater risk for higher levels of anxiety, depression and anger (Atwine et al., 2005). A third study in Cape Town, South Africa supports these findings. Results of the study showed that orphans, as compared with non-orphans, were more likely to have constant nightmares, more likely to suffer from post-traumatic stress disorder and more likely to have concentration difficulties (Cluver & Gardner, 2006).

Researchers have conducted a number of studies in an attempt to pinpoint the exact reasons why OVC are more likely to experience psychological problems as compared with non-OVC so as to help program developers find ways to intervene to help these children. A study of American children of HIV-infected parents found that age of the child at the time of the parent's HIV diagnosis, baseline emotional distress and prior traumatic exposure were significant predictors of lifetime anxiety disorders. Being female, parental bereavement and prior traumatic exposure were also significant predictors of lifetime depressive disorders. The study surprisingly found no significant association between parental psychosocial well-being and child psychosocial well-being (Lester et al., 2006). Most studies conducted in sub-Saharan African on the psychosocial

well-being of orphans did not measure factors such as prior traumatic exposure, and although developed country situations are very different from those in the developing world, the results of this study do suggest parental illness and death is directly linked to poor psychosocial well-being observed in OVC, which is an expected conclusion. Another issue with extrapolating these results to an African setting is that studies conducted in developing countries regarding OVC have been done usually when the parent is in the terminal stages of the disease or after the parent has already passed away, unlike the above study which had the opportunity of exploring psychosocial well-being following an HIV positive diagnosis. In a study amongst European children living with HIV positive parents, researchers found that perceived healthy family functioning⁸ was strongly associated with good psychosocial well-being among children (Nostlinger et al., 2006), thus suggesting that family functioning could be a factor in explaining the reasons behind poor psychosocial well-being of orphans. A study conducted in China found that factors associated with orphans' increased psychological distress included the inability to grieve properly following parental death, stigmatization from the community and lack of adequate care from extended family members (Zhao et al., 2007). These results may be more applicable in an African setting due to similar developing country characteristics such as poverty and higher levels of AIDS-related stigma.

It could also be argued that OVC psychosocial well-being is a product of negative attitudes from household members, especially caregivers, and poor treatment received while in the care of extended family members, since children who are not liked in their foster households, or who feel they are treated poorly (for example, unduly punished for seemingly little things, etc) may feel depressed. However, there has been other research in Africa showing that psychosocial distress among OVC resulting from the trauma of parental death could be a confounding factor when examining factors that influence attitudes towards AIDS-affected foster children. For example, Mann (2002), in her study of orphans in Malawi, has argued that orphaned children with unmet psychosocial needs

⁸ The authors base their definition of family functioning on the McMaster Model of Family Functioning, which views the family as an open system consisting of individuals, extended family, schools, etc. all of which are related to each other, and all of which have an impact on each other, thus determining the behavior of family members (Epstein et al., 1978).

are liable to act out and this behavior may cause the caregiver to feel unappreciated, and therefore have a negative attitude towards children in his/her care. Thus she is suggesting that rather than orphan psychosocial health being a result of the kind of relationship between the caregiver and the child, it is rather a contributing factor to the kind of relationship between the caregiver and the child. It is highly likely that the reality is a mixture of the two cases, especially since it is clear from the literature that orphans do suffer psychological distress as a direct result of having to watch their parents suffer through AIDS-related illnesses and then die. Thus, whatever new home OVC move to, they will take with them some amount of emotional distress, which may affect their views of the foster household and new caregiver. If these children face hardships in their foster households, which may simply due to the lack of resources in those households, they may sometimes remember with nostalgia the good care they used to receive when their parents were alive, and this can cause even more emotional distress (Nyambedha et al., 2007). They may also encounter situations in their new homes such as being deliberately denied food by their caregivers that may also compound the psychological distress they are already feeling.

2.5.2 Household-related factors

2.5.2.1 Household socio-economic status

The availability of economic resources in a household can impact caregivers' attitudes towards OVC in their care. Evidence from studies conducted in sub-Saharan Africa suggests that HIV and AIDS is a disease driven mainly by poverty (Whiteside, 2002). Research shows that on the whole, orphans in sub-Saharan Africa live in generally poorer households than non-orphans living with their biological parents (Ainsworth & Filmer 2002; Foster et al., 1996; Nyamukapa, 2003), and that these households become even poorer with the progression of time, especially if they were already poor to begin with (Deininger et al., 2003; Hosegood et al., 2007a; Siaens et al., 2003). For example, a study of the challenges faced by households caring for orphaned and vulnerable children in South Africa found that generally, the socio-economic status of these households was low, and the proportion of household members who worked and earned income was also

low. Reported income from income-generating activities was also found to be low. The authors found that these households also experienced events that deepened their poverty. Such events included death, serious illness, property grabbing, loss of crops and/or livestock and loss of remittances. Many of these households also did not have any financial assets, which made it difficult for them to plan for adverse and destabilizing events (Horizons, 2004).

Caregivers are also more likely to have multiple orphans in their households (Masmas et al., 2004), as well as chronically ill members, thus implying a strain on available financial resources, as compared with smaller households. In a qualitative study amongst AIDS-affected households in KwaZulu Natal, South Africa, researchers found that often times, households were not only caring for multiple AIDS-affected children, but also for ill members as well. This meant that economic resources were stretched to the limit and caregivers found themselves unable to afford healthcare, schooling and adequate food (Hosegood et al., 2007a). Another issue is that, female-headed households, which are more likely to take in larger numbers of orphans (UNICEF, 2003), are also more likely to have food insecurity and have less access to economic opportunities (Dawson, 1991; Schiller, 1996; UNICEF, 2003). In fact, according to UNAIDS (2008b), two-thirds of primary caregivers of people living with HIV and AIDS and AIDS-affected children in sub-Saharan Africa are women, and women account for 70% of the world's poor, and two-thirds of the world's illiterate. Some of these female caregivers in AIDS-affected households are also household heads. A study in South Africa found that close to 50% of AIDS-affected households surveyed were headed by women, and these households were more likely to report monthly incomes that were at or below the poverty line as compared to male-headed households. Female-headed households were also more likely to be caring for a greater number of orphans as compared with male-headed households (Horizons, 2004). Another issue is that women face gender discrimination and thus have little or no rights to inheritance and property, particularly if they are widowed (UNAIDS, 2008b). This further diminishes their ability to adequately provide for their households.

Generally, there are multiple reasons behind why households caring for orphans are generally poorer than households without orphans. Firstly, households caring for an adult family member with an AIDS-related illness lose an adult who could be working and thus contributing to the household income. For example, a study conducted in Botswana to examine the economic impact of caring for an HIV-infected individual on households and caregivers showed that the primary concern of caregivers was reduced income or income loss (Rajaraman et al., 2006). As one individual in the household is primarily concerned with caring for the sick household member, further income may be lost since the caregiver will have a limited ability to engage in income-generating activities (Knodel et al., 2003). Hosegood et al. (2007a) also point out that even if households are able to pull resources together for one sick member, they are unable to recover if that member is a pivotal member of the household and if other members also become ill in quick succession. Such households also experience diminishing support from friends and relatives who are either unable or unwilling to support them.

AIDS-affected households also have increased expenditure due to medical costs associated with the ill individual. The loss of a working adult increases the household economic dependency ratio - income from fewer adults is now required to sustain more people – thus increasing the risk that these households will become even poorer (UNICEF, 2006). If such households are also caring for OVC, there is an even greater strain on financial resources. Another problem is that in general, the burden of caring for orphaned children tends to fall increasingly on grandparents who are elderly and cannot work, and thus experience severe financial constraints due to their limited earning ability (Nyamukapa & Gregson, 2005; UNAIDS, 2004). Grandparents are also more likely to have no education at all or low levels of education, which reduces their economic opportunities (Horizons, 2004). In a South African study of elderly caregivers, focus group discussions and in-depth interviews revealed that most AIDS-affected households headed by elderly caregivers were poor and had trouble making ends meet. Some of these caregivers also lived in sub-standard housing that leaked during the rainy season, but insufficient funds were available to fix these problems (Juma et al., 2004). Another challenge for elderly caregivers is that they may face age discrimination in terms of work

opportunities as they may be considered to be beyond productive working age, and this further impedes their ability to earn income for their households. The situation is further exacerbated if these elderly caregivers are illiterate (UNAIDS, 2008b).

Financial constraints in the household may affect caregiver attitudes towards their foster children by impacting psychosocial well-being. The lack of financial resources to provide adequately for all children in the household may cause a caregiver anxiety and emotional distress. He/she may be angry at the economic situation and seek to blame someone for their problems. Any orphaned children in the household may become scapegoats for such a caregiver, as he/she may be resentful of the extra mouths to feed (Mann, 2002).

2.5.2.2 Household food security

“I would say inadequate food is really frustrating me since I cannot feed my grandchildren well. I don't have the ways and means of getting this food...”
73 year old female caregiver (Juma et al., 2004).

According to report by UNECA (1999), food security is defined as “enough nutritious and safe food being available and accessible for a healthy and active life by people at all times”. It is dependent of four main factors⁹:

1. Food availability (food supply security)
2. Access to available food (food consumption security)
3. Appropriate use and physiological conversion of available food (conditions that allow for the conversion of food into an adequate nutritional status)
4. Stability of food availability, access and conversion over time

According to the United Nations International Fund for Agricultural Development, at the household level, food security can be loosely defined as the capacity of a household to procure a stable and sustainable basket of adequate food¹⁰. A household's food security is closely linked with their socio-economic status, and the lack of adequate food may also affect a caregiver's attitude towards AIDS-affected foster children in his/her care. AIDS-

⁹ UNECA, 1999

¹⁰ http://www.ifad.org/gender/tools/hfs/hfspub/hfs_1.pdf

related illness and death are major contributors to household food insecurity and research shows that the disease normally strikes the most productive – and reproductively active – members of a household. A study by Kraak et al. (1999) suggests that when one or both heads of a household are living with and AIDS-related illness, there is a significant drop in household production and income due to a reduction in labor supply and a shift in spending from food to medicine and other needed healthcare services. Such households may also be forced to purchase poorer quality and less nutritious food. A report from the Food and Agriculture Organization (FAO) also agrees with these findings. According to the report, when a breadwinner in a household becomes sick, that household not only loses his/her income and labor, but also the labor of the individual primarily responsible for caring for the sick member. AIDS-related illness and death can also result in an increase in the number of children in the household with no farming skills as parents and other adults may become ill and die before they are able to pass on their skills to their children (FAO, 2003).

According to Gillespie and Kadiyala (2005), the loss in labor both from a sick individual and his/her caregiver is particularly significant as agriculture is the main source of livelihood for the majority of people affected by HIV and AIDS around the world. In research conducted on behalf of the International Food Policy Research Institute (IFPRI), the authors found that HIV and AIDS impacted subsistence agriculture in rural areas through a reduction in labor, and thus affected food security. Other research in sub-Saharan Africa also supports this finding. Donovan et al. (2003) found that in Rwanda, the majority of rural households that had experienced deaths or that had sick members reported a reduction in farm labor. In the event that a male in the household died, these households tended to cultivate less land compared with households that had not lost a male member. The authors also found that when a father died, 53% of households ate a less nutritious diet, while when a mother died, 23% of households reported a less nutritious diet. In Kenya, Yamano and Jayne (2004) found that the death of a prime-age male household head was associated with a 68% reduction in per capita household crop production value. Generally, male deaths resulted in an overall reduction in the cultivation of cash crops, while female deaths resulted in an overall reduction of crops

such as cereal consumed in the household. However, Gillespie and Kadiyala (2005) caution that the effect of AIDS-related illnesses on agriculture and therefore food security may depend on the community and the household in question, and point out that a study by Beegle (2003) in Kagera, Tanzania, found that some households experiencing adult AIDS-related deaths reported no significant decrease in labor supply, especially as orphaned children in the household were also available to work on the farm. Another study also in Tanzania found no significant impact of HIV and AIDS on livelihoods (Barnett et al., 1995). Despite these contradictions, there appears to be a general consensus in the literature that HIV and AIDS can negatively impact household food security.

Evidence from UNAIDS (2008b) suggests that because women in the developing world are primarily responsible for producing 60 to 80% of the food consumed in households and also because women are also primarily responsible for caregiving, the presence of ill members in a household or extra children needing care can result in a decrease in the availability of food in that household. This is because daily caregiving duties can divert these women's labor from productive agricultural work. Bukusuba et al. (2007), in a study of the impact of HIV and AIDS on household food security, report that in households where the number of dependents is large, the risk of household food insecurity is much higher than in households with a smaller number of dependents. The authors found that in such households, members were forced to eat less preferred foods, eat portion sizes smaller than what was required to make them feel satisfied, skip meals and skip eating for the entire day.

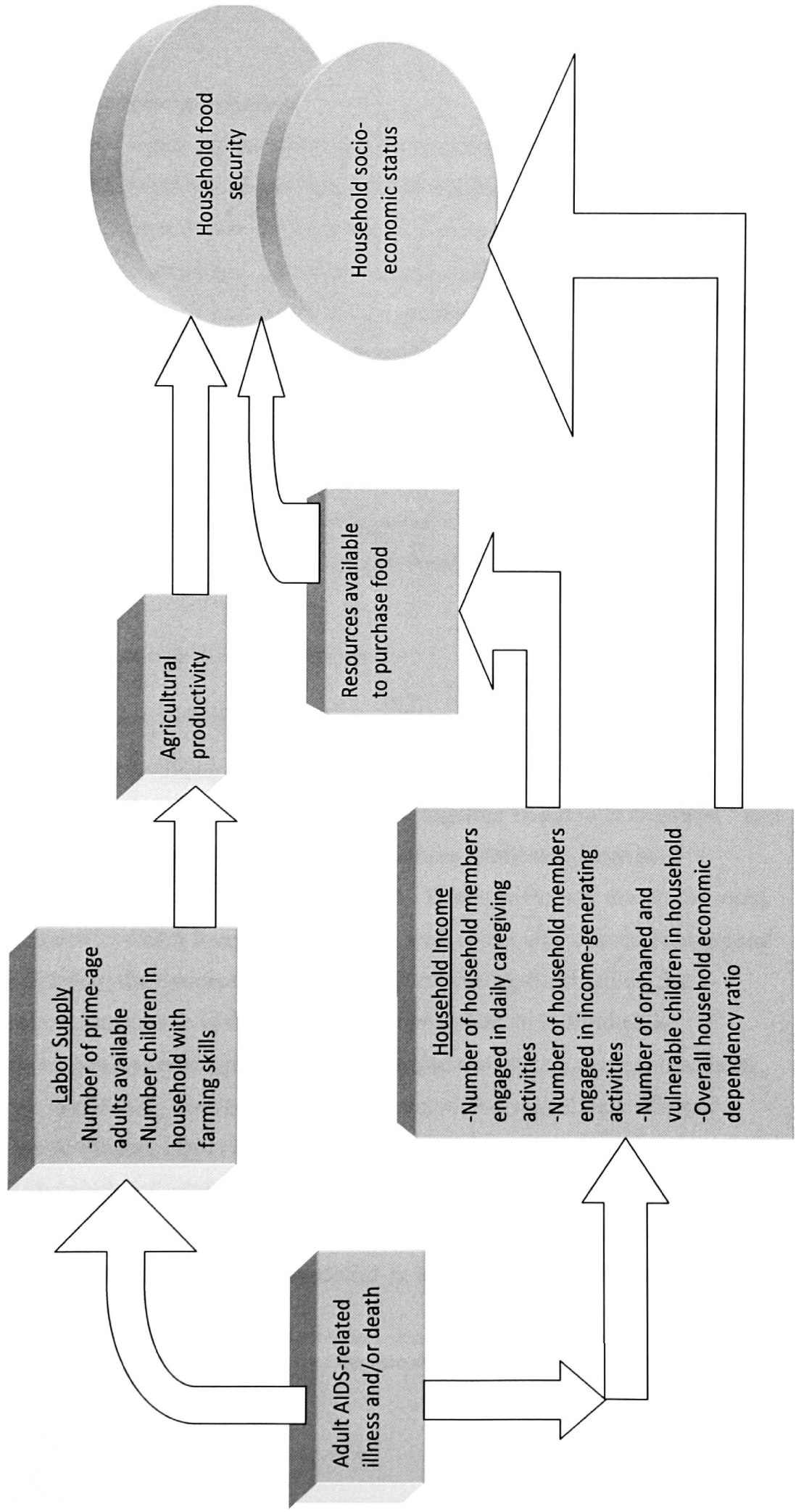
While urban AIDS-affected households do not have access to land for their own food production, these households also experience similar consequences as rural households dependent on agriculture. Bukusuba et al. (2007) found that since urban households were dependent on their ability to purchase food, the loss of income from an ill member and the income from the individual responsible for caring for that ill member seriously jeopardized household food security. Households with large numbers of children found it particularly difficult to manage and many adopted coping strategies such as sending some

of these children and/or the ill members to other households in rural areas. Another study in Malawi that examined the effect of HIV and AIDS on food security amongst urban households concluded that the negative effects of the disease on human, financial and social capital strongly contributed to the food insecurity issues experienced by these households. This is because sick individuals were forced to withdraw from work, resulting in a loss of income, and thus implying a greater number of dependents and fewer resources available to purchase food. The study estimated that in these households, the loss of income when a working adult is forced to leave work due to an AIDS-related illness is approximately 60% (Palamuleni et al., 2003).

Household food insecurity may affect caregivers' attitudes towards AIDS-affected foster children in their care in much the same way as household socio-economic status may affect this variable. Caregivers' living in households with food insecurity may blame foster children in the household for causing the food shortage as these children may be viewed as extra mouths to feed. Food insecurity may also cause additional anxiety and stress about how to provide for all household members, thus further exacerbating the situation.

The diagram below provides a framework for understanding how adult AIDS-related illness and death, and the resulting increase in the number of orphaned and vulnerable children may impact household socio-economic status and household food security. It is a pictorial summary of the information presented in the previous two sections on these issues.

Figure 2.1: Framework for understanding how adult AIDS-related illness and death, and increasing numbers of orphaned and vulnerable children impact household socio-economic status and household food security



2.5.2.3 Other household characteristics

Location, in terms of rural versus urban areas, can be very important as it impacts an individual's access to important social services such as medical care, schooling and livelihood opportunities, which in turn affect household socio-economic status and food security, thereby impacting caregivers' attitudes towards their foster children. For example, research shows that HIV and AIDS have a greater economic impact on rural subsistence households as compared with urban households. This is because the increase in household size and the loss of able-bodied individuals results in a reduction in agricultural productivity, leading to loss or reduction of income, savings and assets and an increase in food insecurity (Baylies, 2002; UNAIDS, 1999). These financial constraints may impact caregiver and child psychosocial well-being, thus impacting caregiver attitudes towards OVC in their care, as previously outlined.

2.6 AIDS-related stigma in sub-Saharan Africa

2.6.1 Definition of AIDS-related stigma

Link & Phelan (2001) define stigma as an interaction between labeling, stereotyping, status loss, separation and discrimination, which occur together in a power situation¹¹ and is dependent on the cultural context. However, the authors admit that there is considerable variation in the definition of stigma in the literature mainly due to the many different circumstances to which it can be applied, as well as the educational background of the researcher defining the concept. The 1963 work of Erving Goffman on the definition of stigma, based on the idea that stigma occurs when an individual is deliberately excluded from a social group to which he/she was once a part of, has been used as a yardstick in outlining the relationship between stigma and disease (Castro & Farmer, 2005; Link & Phelan, 2001; Parker & Aggleton, 2003). Building on this definition and on the works of other researchers, Deacon (2006) defines health-related stigma as a social process in which the illness is believed to be preventable and controllable, is associated with "carriers" identified as belonging to a different social

¹¹ By power situation, Link & Phelan (2001) are referring to a situation whereby some individuals have access to social, economic and political power, and thus they are able to stigmatize individuals who do not have these same positions in the community.

group and with what are perceived to be immoral behaviors, in which individuals can be blamed for becoming ill and which results in a disadvantage to the individual being stigmatized. AIDS-related stigma falls directly into this category and the use of this definition of stigma allows for both the individual and social aspects of stigma to be considered (Malcolm et al., 1998).

Stigma research points to two main forms of stigma – primary stigma and secondary stigma. Primary stigma refers to stigma aimed directly at HIV positive individuals and those who are believed to be HIV positive, while secondary stigma refers to stigma aimed at partners, loved ones, and family members of HIV positive individuals, as well as professionals and volunteers who work with HIV positive individuals (Herek et al. 1998). Discrimination is the consequence of stigma and usually results in the devaluation, rejection and exclusion of the stigmatized individual or group from society (Link & Phelan, 2001). It disrupts social interactions leading to isolation from a social network that an individual originally belonged to, job loss, and even psychological effects such as anxiety, loneliness, depression (Varas-Diaz, Serrano-Garcia & Toro-Alfonso, 2005). Stigma that directly results in discrimination is known as enacted stigma (Brown, Macintyre & Trujillo., 2003). For example, a child who is asked not to return to school because he or she is or is suspected to be HIV positive experiences enacted stigma or discrimination.

Felt or perceived stigma refers to the fear of potential discrimination because of one's association with an undesirable group or disease (Brown, Macintyre & Trujillo, 2003). In terms of HIV and AIDS, this fear may prevent an individual from seeking medical care for fear of exposing his/her HIV status and being shunned as a result (Brown, Macintyre & Trujillo., 2003). In many instances, felt or perceived stigma can result in much of the same consequences as enacted stigma as individuals may isolate themselves from community events and stop engaging in activities that they otherwise would have in anticipation of negative reactions and discrimination (Duffy, 2005; Malcolm et al., 1998; Thurman et al., 2008). This study will examine how perceived AIDS-related stigma, in

terms of caregiver perceptions of community attitudes towards AIDS-affected households, shapes caregivers' attitudes towards their foster children.

2.6.2 Causes/reasons behind AIDS-related stigma

Research indicates that there are two major reasons behind the stigmatization of those infected with HIV and AIDS – erroneous beliefs surrounding the transmission of the disease, thus creating a fear of contamination and the association of the disease with “abnormal” or “improper” forms of sexual activity and drug use (Campbell et al., 2005; Castle, 2004; Kalichman & Simbayi, 2004; Muyinda et al., 1997; Nyblade et al., 2003; Ogden & Nyblade, 2005; Safman, 2004). According to a study conducted by Nyblade et al. (2003) in Ethiopia, Tanzania and Zambia, although people have a basic idea of how HIV and AIDS are transmitted (that is, they know that it is transmitted through having unprotected sex with an infected individual and through infected blood and needles, and that using a condom and avoiding casual sex helps to reduce their HIV risk), they lack in-depth knowledge of the disease and the transmission process. The authors found that majority of study participants had no idea that there is a difference between HIV and AIDS, and had no understanding of how AIDS progressed and had inaccurate perceptions of how long an HIV-infected individual can live, and what people with the infection looked like for the majority of the time they live with the disease. Even though people had a basic understanding of HIV transmission, many still had a fear of casual transmission. That is, they had a fear that the disease could be transmitted through ordinary, daily activities such as shaking hands and eating food prepared by those who are HIV positive. Study participants also had a fear that AIDS would lead to a slow, painful death and many even referred to the disease as the “killer disease”, and people living with the disease as “walking skeletons”. As a result of these fears, individuals, in an attempt to protect themselves, decrease their contact with known or suspected HIV positive individuals, thus resulting in stigmatization of these individuals (Nyblade et al. 2003). For example, a study in Zambia revealed that some respondents would not sell goods to an HIV-infected customer for fear that the association would put them at risk of acquiring the virus (Ogden & Nyblade, 2005). The fear of casual transmission and fear

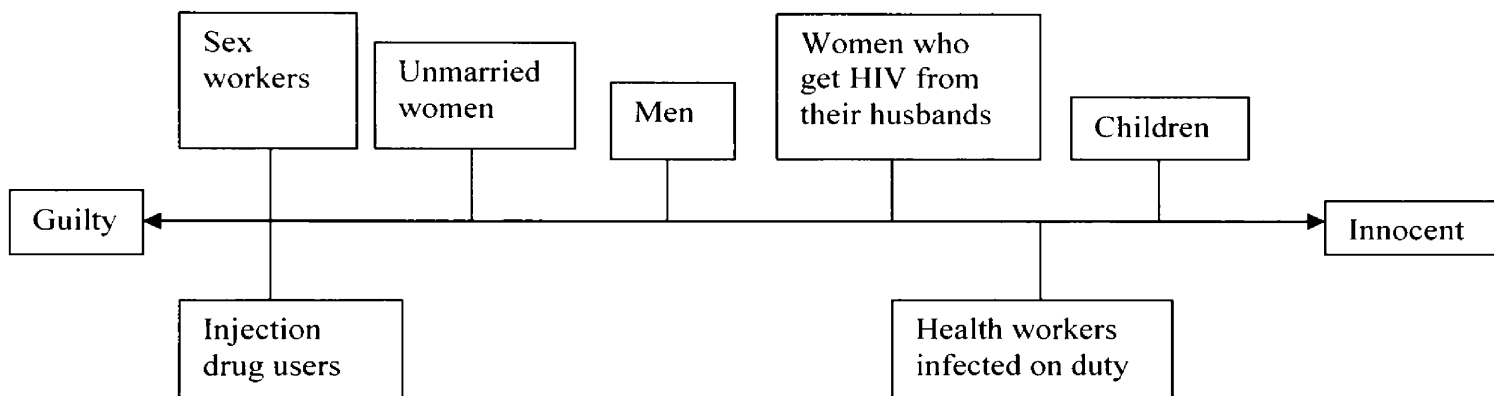
of imminent death is sometimes referred to as fear of contamination in AIDS-related stigma literature (Anderson et al., 2008).

HIV and AIDS is also often associated with socially undesirable or “immoral” behaviors such as sexual promiscuity, adultery, and drug use, which encourages stigmatization especially in African societies where sex is a taboo topic and is often linked with sin (Campbell et al., 2005; Nyblade et al., 2003; Ogden & Nyblade, 2005). This association with socially unacceptable behaviors facilitates the stigmatization of those infected due to the perception that HIV positive individuals brought the problem upon themselves (Castle, 2004). Religion plays an important role as often times people associate HIV and AIDS with sin and punishment from God (Nyblade et al., 2003; Ogden & Nyblade, 2005). Ogden & Nyblade (2005), in a study of AIDS-related stigma in Ethiopia, Tanzania, Zambia and Vietnam, identified 3 major factors linked to the association of HIV and AIDS with morals and values: the creation of a divide between “us” and “them”, the continuum between “innocence” and “guilt”, and shame, blame and gender.

In all four countries, the authors found that there was already a divide between “righteous”, “upstanding” citizens (“us”) and those considered to be deviant and immoral (“them”). This pre-existing divide served to reinforce stigma against HIV positive individuals as these individuals are placed in the “them” category for sinning against God and going against social norms. The general perception was that HIV and AIDS was a consequence of individuals “choosing” to engage in socially and morally unacceptable behaviors. This divide also allowed uninfected individuals to be self-righteous and believe that they were not at risk of acquiring the infection themselves because of their strong “moral values”. This association of HIV and AIDS with deviant behavior leads uninfected individuals to question the characters of infected individuals and speculate about how they became infected. For example, the authors found that in Ethiopia, Tanzania and Zambia, when people first learned that another person was HIV-positive, the assumption was that he/she was promiscuous. However, in all four countries, it was found that generally there was a distinction between those who became infected or were suspected to have become infected through immoral behaviors and those who were

viewed as innocent victims of someone else’s bad behavior (for example, children infected through their mothers or health care workers infected through patient contact). The authors point out that although all HIV-infected individuals face some degree of stigmatization, the extent to which each HIV-positive individual is stigmatized is dependent on his/her presumed “guilt” or “innocence”, as determined by the method with which he/she acquired the disease. Figure 2.2 outlines the continuum from presumed “innocence” to presumed “guilt”.

Figure 2.2: Schematic of “Innocence-to-Guilt” Continuum¹²



As Ogden & Nyblade (2005) point out, caution must be used in the application of this diagram since in practice the groups in which infected individuals are placed can differ greatly. For example, a married woman who gets HIV from her husband can be considered guilty if she does not get along well with her neighbors and they wish to isolate her. However, the diagram helps in creating a picture of how an infected individual may be perceived by his/her community. As the diagram shows, those who are perceived to have become infected by engaging in socially and morally unacceptable behaviors are considered guilty, while those who are believed to have become infected through no fault of their own are considered innocent. Some individuals are guiltier than others. For example, sex workers and injection drug users are considered to be guiltier than men because of the pre-existing stigma against sex workers and injection drug users. That is, groups such as sex workers, women and poor people who are already

¹² Adapted from Ogden & Nyblade, 2005

marginalized in society face increased marginalization and discrimination if they are also associated with HIV and AIDS, resulting in even more severe hardships (Nyblade et al., 2003). This problem when AIDS-related stigma is overlaid upon pre-existing stigmas is sometimes referred to as multiple stigma or double stigma (Nyblade et al., 2003; Ogden & Nyblade, 2005; Reidpath & Chan, 2005).

Lastly, Ogden & Nyblade (2005) found that AIDS-related stigma, moral judgment, shame and blame were interrelated with gender in all contexts, contributing to stigma based on morality. According to their study, a “proper” woman is expected to exhibit strong moral values and thus being HIV-positive implies that she has failed in this expectation. Although men are expected to be adventurous and explore sexually, women are expected to be sexually faithful and righteous. Thus an HIV-positive woman may be viewed as immoral and blamed for bringing disease and shame to her family or marriage. As a result, HIV-positive women are more heavily stigmatized than their male counterparts. For example, in Ethiopia and Zambia, an HIV positive man may be viewed as having become infected “accidentally”, while an HIV-positive woman would be accused of sexual promiscuity and seen as having disgraced herself and brought shame to her family (Ogden & Nyblade, 2005).

Fear of contamination and blame are some of the reasons why the families, friends and loved ones of those living with HIV and AIDS are also stigmatized. That is, secondary stigma is partly caused by the belief that by their close association with an HIV positive individual, the families, friends and loved ones of people living with HIV and AIDS could also be HIV positive (Safman, 2004), and thus could also infect others. A study conducted in Thailand reported that caregivers of children who had lost a parent to HIV and AIDS had difficulty finding childcare for these children as there was a general perception that OVC were also HIV positive and their contact with other children would also result in those other children becoming infected with the disease (Safman, 2004). Ogden & Nyblade (2005) also found that family members and loved ones of those living with HIV and AIDS could be blamed for their family member’s HIV positive status, and thus stigmatized as a result. For example, the authors found that in Ethiopia, Tanzania,

Zambia and Vietnam, parents of HIV positive individuals were often blamed and thus stigmatized for not raising their children properly, which resulted in them behaving “badly” and thus becoming infected. Participants in this study may experience either primary or secondary stigma, or both since it is possible for a caregiver to be HIV positive but not yet ill with AIDS, for a child to be HIV positive, for both caregiver and child to be HIV positive or for neither to be HIV positive, but the foster child is (that is, his/her biological parent(s) is either living with HIV and AIDS or died from the disease). Due to privacy concerns and the fear of increasing stigma towards a particular household, questionnaires for this study deliberately do not ask about participants’ HIV status. As a result, it is not possible to determine if children in the third category of the OVC definition are AIDS-affected. However, the non-governmental organizations from whom the study sampling frames were obtained were focused on particularly targeting AIDS-affected children. The term AIDS-related stigma will be used in this review to refer to both primary and secondary stigma, especially since literature shows that both primary and secondary stigma tend to have many of the same consequences. More information about the nature of the study will be provided in the data and methods section.

2.6.3 Expressions of Stigma

Stigma can manifest itself in many different ways. This section will briefly outline the various expressions of stigma, but how stigma is manifested in the lives of caregivers of OVC will be discussed in the next section. Ogden & Nyblade (2005), identify four main expressions of stigma that HIV and AIDS-infected/affected individuals may experience: physical stigma, social stigma, language or verbal stigma and institutional stigma. Physical stigma consists of physical isolation and violence. For example, people may refuse to sit next to a known or suspected HIV-infected individual on a bus, and household members may designate a special plate, cup and cutlery specifically for the sick individual. Physical violence, although not very common, does also sometimes occur, and HIV-infected individuals may have stones thrown at them or be beaten. For example, Ogden & Nyblade (2005), describe a situation where an HIV-positive woman in Tanzania was afraid that if her partner found out about her status, he would beat her for

bringing the disease into the marriage and household. In a study of OVC in Malawi, Mann (2002) also found that some OVC complained of other children throwing stones at them. Thurman et al. (2008) found that in Rwanda, one in five OVC was ill-treated by other children, possibly as a result of stigma.

Social stigma can be experienced by both HIV-infected and affected individuals. It has three components: isolation, voyeurism and loss of identity or role in the community. Isolation includes shunning from family, household and community members, decreased visits from friends and family, and a loss of social networks. For example, HIV-infected/affected individuals may suddenly not be invited to family ceremonies such as weddings or they may not be told of community meetings, and be left out of other community gatherings. Ogden & Nyblade (2005) found that voyeurism was one of the most frequently reported type of stigma in Ethiopia, Tanzania and Zambia. Households with HIV-infected individuals often reported suddenly receiving visits from neighbors, who would then leave to tell others in the community what they saw, thus contributing to gossip and further isolation. Loss of identity occurs when there is a loss of respect, especially since HIV-infected individuals are sometimes viewed as “sinners” who are paying for their transgressions against God and the society, and diminishing roles and responsibilities due to the perception of imminent death associated with HIV and AIDS.

Gossip, rumors, taunting, finger-pointing and insults all constitute verbal stigma. Very often, once an individual is suspected to be HIV-positive, rumors and gossip about how he/she acquired the disease surface. In their study, Ogden & Nyblade (2005) found that verbal stigma was the most significant form of stigma experienced by both HIV-infected and affected individuals, and particularly for women. For example in Ethiopia, some women reported experiencing vicious gossip because they were suspected of being HIV-positive, while men in the community also suspected of being HIV-positive did not face the same amount of gossip. Blaming is also a common form of verbal stigma, as those infected are seen as having become infected through their own “deviant” behaviors.

Finally, the last form of stigma is institutional stigma, which can lead to a loss of livelihood due to loss of customers or loss of employment, differential treatment in schools by teachers against HIV-infected/affected children, differential treatment in healthcare settings whereby health care workers can refuse to treat HIV-infected individuals, etc. For example, some HIV-infected individuals in Ethiopia reported having been refused treatment at a dental clinic because of their HIV-positive status.

2.6.4 Impact of AIDS-related stigma on caregivers and their households

AIDS-related stigma can have a very serious impact on caregivers' attitudes towards AIDS-affected foster children in their care. This next section reviews the impact of stigma on caregivers of OVC and their households, and provides an overview of how these consequences may affect their attitudes towards their foster children. However, before this overview, it is important to clarify the meaning of households. A household in this study consists of, at the time of interview, related or unrelated people who slept in that house at least two of the past seven nights, with the exclusion of special events such as weddings, funerals and other festivals that would call for overnight visitors and other house guests to be present. A household also consists of the wives of polygamous men and their children who live in separate houses in the same compound and who share in the daily chores of managing the household. However wives of the same man who live in different houses in different compounds are not considered as part of the same household¹³. Throughout the literature, varying definitions of households are used in different studies, and one issue worth mentioning is the fact that the term "family" is very often used in the research, but it may not necessarily equate to a household, as family members could live elsewhere in different households that do not qualify for the criteria outlined above. Nevertheless, information on the impact of AIDS-related stigma on families is still useful in this context as it sheds more light on how stigma and discrimination can impact groups of connected individuals.

¹³ This definition is similar to that used in Demographic Health Survey (DHS), in which a household is defined as a person or a group of persons, related or unrelated, who live together in the same house or compound, share the same housekeeping arrangements, and are catered for as one unit.

Literature shows that primary and secondary stigma have many of the same consequences, and these consequences indirectly affect caregivers' attitudes towards their foster children by negatively affecting their psychosocial well-being. There are various aspects of stigma that may impact caregiver psychosocial well-being. Nyblade et al. (2003) have reported that individuals associated with people living with HIV and AIDS, particularly children and other family members, experience social exclusion and gossip from others in the community. Caregivers of HIV-infected/affected individuals may experience decreased visits from friends and neighbors, thereby resulting in the loss of social networks. In Zimbabwe, caregivers responsible for AIDS-affected children as well as HIV-infected individuals experienced social exclusion from their friends and neighbors. One caregiver who was caring for three orphaned children was quoted as saying,

“People who used to be friendly to me have severed their ties. Now I feel very lonely and dirty” (WHO, 2002).

Sometimes, AIDS-related stigma in the community is so high that potential caregivers shy away from accepting AIDS-affected foster children into their households for fear of being shunned by community members (Ansell & van Blerk, 2004). Hosegood et al. (2007a) also found that in South Africa, members of AIDS-affected households felt that people viewed them as being “diseased” and “poor”, and believed that neighbors shunned them because of the assumption that because others in the household had died, everyone else in the household was also HIV-positive. Household members, particularly surviving spouses, also complained of feeling criticized, blamed and stigmatized by community members. According to UNAIDS (2008b), in Sukumaland in northern Tanzania, the belief that AIDS-related deaths are caused by witchcraft is ubiquitous. Witchcraft accusations can lead to intimidation and victimization of caregivers, particularly older women, including physical attack, destruction of property, eviction from family property and ostracism.

Caregivers may also experience reduced income due to loss of customers/clients for their businesses, leading to increased anxiety about how to cope. For instance, Ogden &

Nyblade (2005) describe a situation in Vietnam where the mother of an HIV positive woman lost her livelihood as a daycare provider when parents withdrew their children after her daughter's condition was discovered. Other consequences of AIDS-related stigma, such as limited job opportunities and even loss of housing can also result in increased stress and financial difficulties for caregivers and their households (Nyblade et al., 2003).

Loss of family reputation as a result of having a member who is HIV positive is another consequence of AIDS-related stigma. For example, a family with an HIV positive member may lose respect from neighbors and other community members, and this may result in the loss of social support at a time when family members, particularly caregivers of the sick individual or caregivers of OVC need it the most, and also possibly loss of economic support which can increase the financial pressure on caregivers and other family members (Ogden & Nyblade, 2005). There may also be a disruption in normal social relationships as interactions with other people may become embarrassing or awkward and family members may simply steer clear of other people in an attempt to avoid such situations (Crandall & Coleman, 1992).

Another less studied factor that compounds stigma towards caregivers and their households is the issue of jealousy. AIDS-affected households, particularly those in the developing world, sometimes receive material support in the form of food, clothing, etc. from non-governmental organizations (NGOs) trying to lessen the impact of HIV and AIDS on household members. However, there is some evidence in the literature that this support can induce jealousy from those in the community who are not receiving similar support and thus increasing stigmatization and marginalization of these households and their members (Thurman et al., 2008). However, insufficient information exists on this issue and further research is required before any firm conclusions can be drawn.

CHAPTER 3 – CONCEPTUAL FRAMEWORK, RESEARCH QUESTIONS & HYPOTHESES

3.1 Conceptual Framework

A pictorial representation of the conceptual framework for this study is presented in figure 3.1. It outlines the relationship between regional characteristics such as the regional HIV and AIDS prevalence level, community-level factors, household-level factors and individual-level factors, and how all these variables interact to influence and shape caregivers' attitudes towards OVC in their care. The main independent and dependent variables are shaded in gray. Not all the factors exhibited in the framework can be accounted for in this analysis due to limitations of the dataset. However, they are included here in the framework in order to provide the reader with an accurate view of the myriad of separate and interrelated factors that must be considered when examining caregiver attitudes towards their foster children in the context of HIV and AIDS in sub-Saharan Africa. Factors that will be measured in this study or for which suitable proxies are available are in bold.

The primary dependent variable is caregivers' attitudes towards OVC in their care. Caregivers' attitudes towards OVC in their care are directly influenced by their individual psychosocial well-being. However, this relationship is bi-directional, as indicated by the two-headed arrow, since, as outlined in the literature review, it can also be argued that the caregiver's attitude can influence his/her psychosocial well-being. In addition, there is also a bi-directional relationship between caregiver attitudes towards OVC in their care and child psychosocial well-being. Note that caregiver psychosocial well-being will be used both as an outcome and as an independent variable.

Caregivers' psychosocial well-being is also influenced by individual factors associated with AIDS-related stigma, and household-level factors. Perceived stigma is the primary independent variable of interest. As previously discussed, it has much of the same consequences as enacted stigma as it can cause individuals to isolate themselves from others and to stop engaging in activities that they normally would have participated in

either as a result of shame or for fear of being treated badly. By self-isolation, individuals can feel lonely and depressed. Perceived stigma can also affect a child's psychosocial well-being in much the same way as it affects a caregiver's psychosocial well-being, and thus this relationship is also included in the conceptual framework. Since this study is specifically concerned with caregivers whose lives are impacted by HIV and AIDS, the variable HIV/AIDS-affected is also included in caregiver-related factors.

Caregiver-related factors include the caregiver's age, gender, marital status, headship status, his/her biological relationship to the foster child, the number of biological children in the household, his/her education level and religiosity, the support network available, and their knowledge and understanding of HIV and AIDS transmission, as well as his/her reason for fostering. As previously outlined in the literature review, these factors may positively or negatively affect a caregiver's attitude towards foster OVC in his/her care.

Child-related factors such as the child's age and gender may also directly affect caregivers' attitudes towards OVC in their care. Caregivers may have more positive feelings towards a younger child as they may feel that such a child will have little memory of their biological parents, and thus he/she is more likely to have a stronger bond with them, as compared with older children who may find it difficult to adjust. Female children are sometimes also preferred as girls can be easily married off to wealthier men, thus benefiting the caregiver. Child-related factors also directly affect a child's psychosocial well-being as younger children may be better able to adapt to changing environments, as compared with older children who may have formed strong bonds with their parents before they died and thus will find it harder to recover from their deaths. Since girls are sometimes preferred as they can be married off and also because they can help with household chores such as cooking and caring for younger children, girls may be more easily accepted in foster environments than their male counterparts, and thus a child's gender can also affect psychosocial well-being.

Household-level factors also come into play, as they influence the foster care environment and thus can also impact both caregiver and child psychosocial well-being.

A household's socio-economic status is another independent variable of interest and is important because it is indicative of the resources available to individuals living in a household. Household socio-economic status interacts with remittances as households that receive money and other material goods from members who may be working elsewhere will have more resources available to them, as compared with households which do not. A household's socio-economic status and remittances also interact with household food security as limited household resources and the lack of remittances may imply limited access to sufficient food for all members of the household.

For this study, the burden of care consists of two elements: the child dependency ratio and the presence of chronically ill persons in the household. Due to nature of the dataset, the child dependency ratio cannot be measured directly. However, household size will be used as a proxy for the child dependency ratio (discussed in further detail in the data and methods section), as a large household, particularly one with many children and few adults, imposes many of the same problems on household food security and financial resources as the child dependency ratio. As previously outlined, the burden of care, depending on how much pressure it puts on the caregiver, can negatively impact the caregiver's psychosocial well-being. The burden of care also impacts OVC psychosocial well-being since the higher the pressure it places on the household, the harsher the conditions it imposes on the child's environment, and thus the more likely it is to create emotional turmoil in the child. A household's burden of care and access to support services are interrelated. This is because the burden of care will have a lower psychological impact on both a caregiver and a child living in a household that has access to support services such as counseling, home-based care and food support, by reducing the pressure on the caregiver to provide for the child and by improving the child's environment and making it more conducive for normal activities, such as going to school with other children in the community. The above-mentioned factors are included in the framework as a subset of location (rural versus urban areas) as this variable can impact individual livelihoods, thus influencing household socio-economic status and food security, and access to medical and support services, especially for very remote rural areas with poor roads, which make some populations difficult for health workers,

volunteers and others from both government and non-governmental agencies to reach and vice versa.

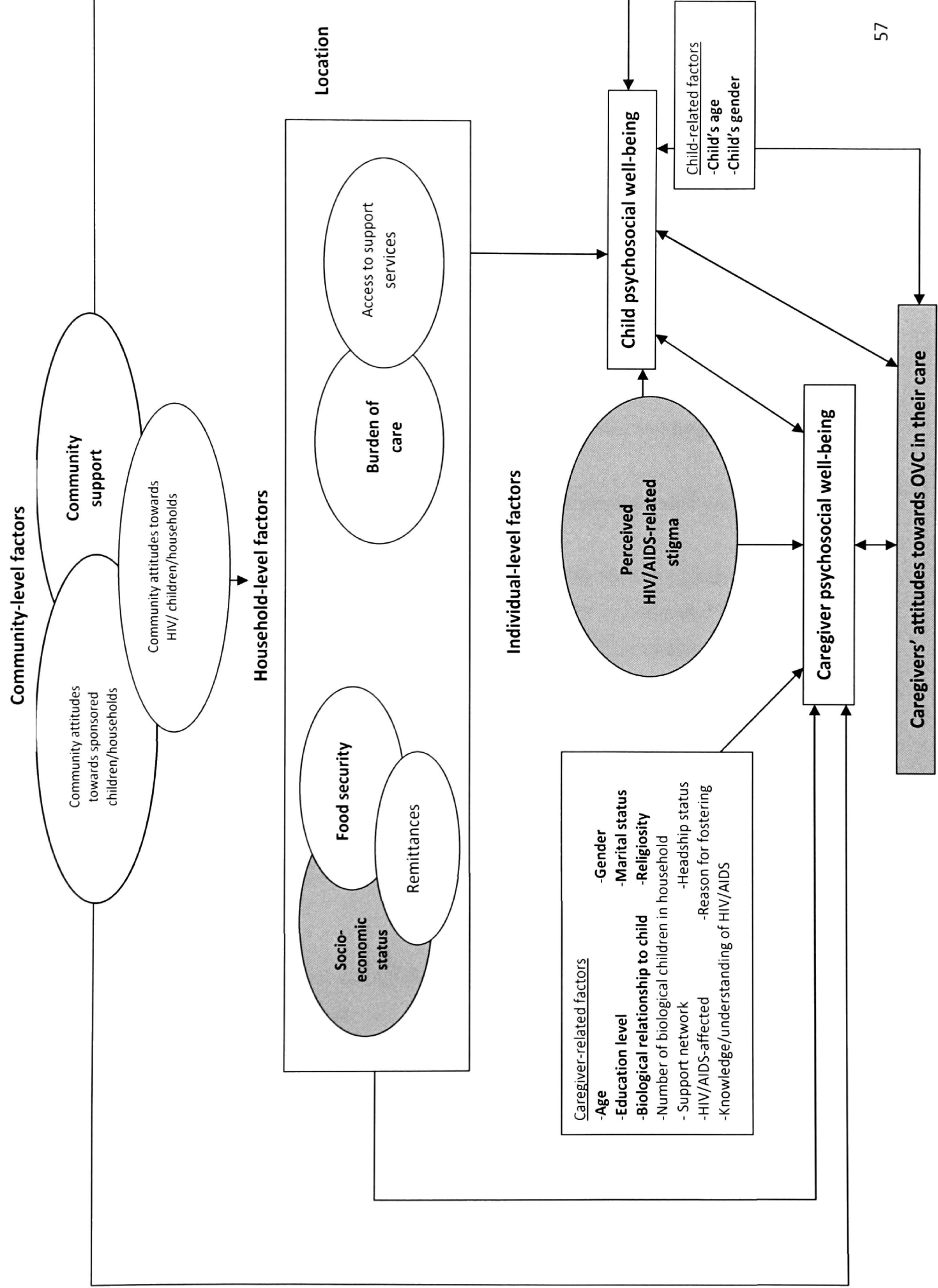
Community-level factors influence both household-level factors and caregiver and child psychosocial well-being. At the household level, negative community attitudes towards sponsored children and households (for example, jealousy and anger that those children and households receive support from aid organizations, while other children and households not similarly affected do not), and negative attitudes towards AIDS-affected children and households (that is, AIDS-related stigma from the community) can result in social exclusion and limited livelihood opportunities (for example, community members may stop buying from a caregiver who sells farm produce), which decrease household financial and food resources available. Community attitudes towards sponsored children and households is interlinked with community attitudes towards AIDS-affected children and households because AIDS-affected children and households may receive assistance from local and international organizations, which may induce further resentment among community members who are not receiving similar support. Both community attitudes towards sponsored children and households and community attitudes towards AIDS-affected children and households cannot be measured in this study due to the lack of community-level variables.

Community support is interlinked with community attitudes towards sponsored children and families and community attitudes towards AIDS-affected children and households since negative attitudes are likely to result in reduced support. Community support can help decrease the burden of care and improve access to support services (for example, if neighbors hear of NGOs in the area who are helping out OVC households, they are more likely to let caregivers in these households know). At the regional level, the HIV prevalence can have an overall impact at the community and household levels by influencing community attitudes towards HIV and AIDS, caregivers and their households, reducing overall productivity and negatively impacting economic activities in a particular area, which in turn can affect household-level factors such as household socio-economic status, food security and burden of care, and thus can also have an effect

at the individual level, by impacting psychosocial well-being and attitudes towards foster children.

Figure 3.1: Conceptual Framework

Regional HIV Prevalence



3.2 Research questions and hypotheses

The primary goal of this study is to determine the effect of perceived AIDS-related stigma on the relationship between caregiver psychosocial well-being and caregivers' feelings towards OVC in their care. A secondary goal is to ascertain the effect, if any, of household socio-economic status on the above-mentioned relationship. The study explores the effect of OVC psychosocial well-being on caregiver psychosocial well-being, as well as the effect of caregiver psychosocial well-being on caregiver feelings towards OVC in their care. The specific study research questions and hypotheses are outlined below:

1. Is OVC psychosocial well-being associated with the psychosocial well-being of their caregivers?

Hypothesis 1.1: OVC in poor psychosocial health are more likely to have caregivers who also have poor psychosocial health as compared with OVC in good psychosocial health, controlling for other relevant factors.

2. Is caregivers' psychosocial well-being associated with caregivers' attitudes toward OVC in their care?

Hypothesis 2.1: Caregivers' in poor psychosocial health are more likely to have negative attitudes towards OVC in their care as compared with caregivers in good psychosocial health, controlling for other relevant factors.

3. What is the role of perceived AIDS-related stigma in shaping caregivers' attitudes towards OVC in their care?

- 3.1.1 Is perceived AIDS-related stigma associated with the relationship between caregivers' psychosocial well-being and caregivers' feelings toward OVC in their care?

Hypothesis 3.1.1: Perceived AIDS-related stigma exacerbates the relationship between caregivers' psychosocial well-being and

caregivers' feelings towards OVC in their care, controlling for other relevant factors.

- 3.1.2 Does a household's socio-economic status modify the association between perceived AIDS-related stigma and the relationship between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care?

Hypothesis 3.1.2: At lower levels of household socio-economic status, the association between perceived AIDS-related stigma and the relationship between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care is further exacerbated (that is, the effect is stronger), controlling for other relevant factors.

CHAPTER 4 - DATA AND METHODS

4.1 Background

This study draws on data collected for the 2007-2008 evaluation of three interventions for orphans and vulnerable children in Tanzania, as part of the MEASURE Evaluation Orphans and Vulnerable Children (OVC) Targeted Evaluation (MEASURE Evaluation OVC TE) project funded by USAID/PEPFAR and carried out in collaboration with Tulane University School of Public Health and Tropical Medicine and Constella Futures. The primary goal of this project was to answer the question, “what is the effectiveness of interventions in terms of models, components, costs, and outcomes, in improving the well-being of OVC in resource poor settings?”. Using guidelines outlined in the Framework for the Protection, Care and Support of OVC Living in a World with HIV and AIDS (2004), the following three programs in Tanzania were selected to be evaluated: Mama Mkubwa and Kids Club Program run by The Salvation Army, Tumaini, Care and Allamano Project run by CARE Tanzania and Family Health International, and the Jali Watoto Program run by Pact Tanzania. The evaluation consisted of three components: case studies conducted to obtain in-depth information about how each program is run, outcome evaluation and costing to determine the effectiveness and cost of implementation of each program and data demand and utilization to disseminate information obtained from the overall evaluation so as to guide program and policy decisions. This study uses data from the outcome evaluations of The Salvation Army (TSA) Mama Mkubwa and Kids Club program and the Tumaini, Care and Allamano Project (referred to in this study as Allamano), which were carried out in Mbeya Region and Iringa Region, Tanzania from May to September 2007. Some of the outcomes used to assess the effects of the two programs include household food security, community support for OVC and their households, OVC psychosocial well-being, OVC perceived physical health status, OVC HIV and AIDS knowledge and understanding, and OVC formal education. A map of the study sites can be seen below in figure 4.1 shaded in dark green and light green.

Figure 4.1: Map of study sites



TSA is a Christian-based group that runs a kids' club program in conjunction with a Mama Mkubwa (meaning aunt in Kiswahili) Psychosocial Support program of OVC in various parts of Tanzania. The purpose of these conjoined programs are to strengthen community-based responses to meet the needs of OVC and to provide psychosocial support for OVC through the implementation of kids clubs and ongoing support to OVC and their households through the provision of regular home visiting via community volunteers, mainly women known as Mama Mkubwas. The program also facilitates the sensitization of the community to the plight of OVC in an attempt to reduce AIDS-related stigmatization and discrimination towards these children through community counseling in the form of meetings with community members and village leaders. Appendix B provides a brief overview of the TSA program.

Allamano is a Catholic-based group supervised by a group of Italian-based nuns known as the Consolata Sisters. Allamano runs a program that provides voluntary testing and counseling and HIV and AIDS treatment and home-based care for people living with HIV and AIDS, material (for example, payment of school fees, provision of bed nets, etc.) nutritional and emotional support for the children and households of people living with HIV and AIDS. Allamano has a registry of children, which contains the names and addresses of all children who are either HIV positive and receiving treatment from its clinic, or who are wards of HIV positive patients who are either currently receiving treatment or who were receiving treatment, but have now passed away. The study sample was drawn from this list. For more detailed information on Allamano's clients and activities, please refer to Appendix B.

4.2 Combating AIDS-related stigma in Tanzania

Specific efforts have been made to combat AIDS-related stigma in Tanzania. For example, in an attempt to decrease AIDS-related stigma, national policy requires that all HIV and AIDS patients be given the same quality of care as other patients (Mwakalobo, 2007). Other efforts to address stigma have also been made by local, national and international organizations in the country. For example, the International Center for

Research on Women (ICRW) designed and implemented an intervention intended to target stigma at the community-level by preventing and reducing stigma amongst communities of people living with HIV and AIDS in Kimara, Tanzania (Nyblade et al., 2008). The program used several techniques, including dissemination of simple brochures, training and education of community leaders about HIV and AIDS and stigma, counseling for people living with HIV and AIDS and integrating anti-stigma and discrimination messages into existing HIV and AIDS intervention activities. However, an evaluation of the program yielded mixed results as there was an indication that although the program may have had an effect at the individual level, there was no apparent effect at the community level (Nyblade et al., 2008; UNAIDS, 2007). The Tanzania Red Cross Association also began the implementation of their 2 year HIV and AIDS Program in 2008. This program is mainly focused on promoting safer sexual behaviors amongst the general population with a focus on condom use and HIV and AIDS education, as well as addressing stigma and discrimination through awareness, education and community mobilization activities¹⁴. A third intervention, implemented amongst young people living in northeastern Tanzania, focused on reducing student risk of HIV infection and decreasing AIDS-related stigma amongst this group by training local teachers and health workers to provide HIV and AIDS education to primary school children. After a year of implementation, the program was found to be successful at increasing children's knowledge of HIV and AIDS and improving their attitudes towards people living with HIV and AIDS (Klepp et al., 1997).

In spite of these efforts, it is worth pointing out several gaps and challenges. Firstly, many of these programs have been targeted towards reducing AIDS-related stigma against people living with HIV and AIDS. A search of HIV and AIDS interventions in Tanzania by this researcher yielded few interventions addressing AIDS-related stigma experienced by OVC and their caregivers. Although reducing stigma and discrimination against people living with HIV and AIDS (PLWHA) may also decrease the problem for caregivers of AIDS-infected/affected children, this group may also face some unique problems that PLWHA's may not face. For example, while community members may

¹⁴ <http://www.ifrc.org/Docs/Appeals/annual08/MAA64006TZ.pdf>

understand why a household with an ill person is receiving material support from non-governmental organizations in the area, they may not be as understanding of households with OVC that do not have ill members, but receive similar support. This jealousy, mentioned earlier in this review, may lead to marginalization of these households. Thus more interventions that specifically address stigma and discrimination against households caring for OVC are necessary. As Brown, Macintyre & Trujillo (2003) point out in their review of AIDS-related stigma interventions, this is a common problem everywhere as most AIDS-related stigma reduction programs generally focus on three main areas: interventions designed to target attitudes towards people living with HIV and AIDS, interventions designed to increase willingness to treat people living with HIV and AIDS among healthcare workers, and interventions designed to help people living with HIV and AIDS or those at risk of acquiring the infection cope with perceived stigma through education and counseling. Another issue is that although there were some interventions addressing perceived stigma on the part of people living with HIV and AIDS, there were very few interventions tackling perceived HIV and AIDS stigma on the part of caregivers of OVC or even OVC. Such interventions are important because perceived stigma may have some of the same effects as stigma from the community.

Mwakalobo (2007), in a study of the impact of HIV and AIDS on rural households, identified some other significant challenges faced by HIV and AIDS interventions and programs in general, some of which may also impact stigma reduction activities. The first problem is the low level of education, particularly in rural areas which have increased illiteracy levels. This makes it difficult to increase awareness via written messages such as pamphlets and brochures. This is a problem that may also affect AIDS-related stigma programs as education components of some of these programs may employ written material. Secondly, limited resources prevent the goals of programs and interventions to be fully reached across all levels of the population. That is, very often, programs and interventions are implemented only to a certain extent due to limitations imposed by diminishing resources. Thus although much has been done to fight the HIV and AIDS epidemic in Tanzania, much more still needs to be done to diminish its impact

on the average Tanzanian and households caring for HIV positive individuals and/or foster children.

4.3 Sampling Strategies

4.3.1 TSA program, Mbeya Region

In Mbeya, child-based sampling frames were used for both the intervention and comparison groups. The desired sample size for the evaluation was 600 children and their caregivers, as it was determined beforehand that this was the sample size required (500 children, plus an extra 100 children to account for children who cannot be located and non-response such as refusal, non-availability of respondent, incomplete interviews or duplication) to detect differences in prevalence of outcomes between the intervention and comparison groups of 0.1, assuming prevalence of the outcomes in one of the groups is 0.5 (most conservative estimate). This was based on a one sided probability of type I error of .05 and a power of 80%. For the intervention group, a list of OVC participating in TSA's Mama Mkubwa and Kids Club program was obtained from TSA program officials. This list contained the names, ages and contact information for slightly over 1000 children of all ages from two wards – Ilembo Ward (11 villages) and Isuto Ward (3 villages). This list was filtered out for all children aged 8 to 14 years as children of this age were the focus for the outcome evaluation of the original study, and children with 9 months or more exposure to the TSA program. Children with 9 months or more exposure were selected because of the evaluation nature of the original study. It was decided beforehand that in order for the intervention to have had any effect, children must have been enrolled for at least 9 months. A total of 683 children from 10 villages from Ilembo Ward and 3 villages from Isuto Ward were obtained. All 683 children were selected to be interviewed and caregiver questionnaires were administered to whoever in the child's household was identified as the child's primary caregiver. That is, children on this list were the primary focus of the study. A household was included in the study only if a child on the study list was aged 8 to 14 years and lived in that household (the child must have spent at least 2 of the past 7 nights in that household as per the study requirements for qualifying as a household member). A caregiver was selected to be interviewed based

on whether or not he or she was the primary caregiver for the child on the list. This applies to both TSA and Allamano data collection procedures. Data collection in Mbeya from both intervention and comparison groups occurred concurrently.

Unfortunately, initial data collection and preliminary data analysis showed the following:

1. There was an unexpectedly high rate of ineligibility. That is, children were older or younger than the age reported in the TSA documents, thus falling out of the 8 to 14 years range.
2. There was insufficient awareness of the TSA intervention program (not enough children had heard of the program or had participated in the program to allow for a good enough evaluation of the program).
3. Some participants were busy harvesting crops from their household farms at the time the interviewers visited and thus interviewers had to schedule appointments that were about a week or more after the time period allotted for data collection. Unfortunately, the exact numbers were not documented due to initial problems with the local research organization. However, all these participants were later interviewed during the second round of data collection, as outlined below.
4. Some children could not be located. This was particularly true for households with multiple children selected. Investigations indicated that in intervention areas, the primary reason for this was that the TSA sampling frame had been padded with extra children by TSA program volunteers who believed that by indicating that they were providing services for many more children than they actually were, they would receive extra materials such as books, pencils etc. to run their kids clubs. In comparison areas, the primary reason for children not being located was duplicate names, which had been badly misspelled, thereby appearing to be two or three different children, but was all only actually different variations of the same name for one child.
5. Some OVC and their caregivers only spoke Kimalia. This was not originally planned for in the study and thus a new team of Kimalia-speaking interviewers had to be recruited and trained, and study instruments had to be translated into Kimalia.

With the exception of the second issue, these problems were applicable to both the intervention and comparison groups. As a result of the above-mentioned issues, a second round of data collection occurred about a month and a half after the first round of data collection had been completed. For the second round of data collection, the original sampling frame of TSA children used to select participants for the first round of data collection was used again to select more children. However, this time, the intervention exposure criterion was dropped and all remaining children aged 8 to 14 years were selected to participate. Essentially, this means that all children aged 8 to 14 years from the original TSA sampling frame were selected to be interviewed. The only issue is that 683 of them were interviewed a month and a half earlier than the second group of 109 children. However this gap in data collection may affect the quality of the data collected in the second round, and this will be discussed further in the study limitations and strengths section.

The TSA comparison group was selected in a similar process as the intervention group and is outlined below in bullet-points for ease of clarity:

- A child-based sampling frame was used, allowing for the possibility of selecting multiple children from one household.
- A total of 5 villages (2 villages from Ilembu Ward and 3 villages from Isuto Ward) were selected as comparison group study areas partly because TSA had pre-selected those areas to receive future services, as preliminary work performed by TSA program officials showed that those areas contained a growing number of OVC in need of support. They were also selected for practical and logistical reasons such as ease of access (there were two villages that could only be accessed via very narrow mountain roads, which were, at the time of data collection, inaccessible via vehicles due to the start of the rainy season) and willingness of village leaders to cooperate in the study.
- A list of OVC in all 5 villages were obtained from community registries, which are log books used by village leaders to record births, deaths, movements in and out of village, marriages, etc.

- The list was filtered out for children aged 8 to 14 years. A total of 1309 children were obtained.
- The final sample of 650 kids was selected by the following method:
 - Stratification of children by village
 - Calculation of weight for each village (that is, total number of eligible kids in that village divided by 1309)
 - Multiplication of weight for each village by 650 (desired sample size) and then selected that number of children from each village through random selection using SPSS software
- The final sample contained 650 children from a total of 5 villages and in the 2 wards. 650 children, rather than 600 as initially mentioned, were selected because there was the fear that there may be duplication of children's names as was found in the intervention group, which may end up reducing the overall sample size.

4.3.2 Allamano program, Iringa Region

A child-based sampling frame was also used for this program. Researchers first obtained a comprehensive list of all children who were receiving services from the Allamano program or who were wards of Allamano patients. This list of over 1000 children was then filtered for children aged 8 to 14 years, as per the evaluation requirements. This resulted in a total of 795 children from 18 wards (2 wards in Iringa Rural and 16 wards in Iringa Urban). In order to account for those who may refuse to participate in the study, those who may not be located due to incorrect addresses, children who may have HIV and AIDS and who may be too ill to be interviewed, children whose ages may have been incorrectly reported in the registry, etc., all 795 children were selected to participate in the study.

The comparison group contained children aged 8 to 14 years who had been pre-selected by the Southern Highlands Participatory Organization or SHIPO¹⁵, an NGO similar to

¹⁵ Appendix B provides a brief overview of SHIPO's program. More information can also be found on SHIPO's website at <http://www.shipo-tz.org/>.

Allamano, but operating in neighboring Njombe District. A child-based sampling frame was also used here. The procedure outlined below was used in selecting the comparison study participants:

- 3 wards in neighboring Njombe District (Uwemba Ward, Ilembula Ward and Mtwango Ward) were selected for logistical and practical reasons, such as ease of access and ease of obtaining permission from Njombe District officials to collect data in those areas.
- A comprehensive list of OVC, regardless of age, from all 3 wards and who had been pre-selected by SHIPO to receive services similar to those provided by Allamano in the near future was obtained from SHIPO.
- This list was filtered for children aged 8 to 14 years, resulting in over 1000 OVC aged 8 to 14 years.
- 700 children aged 8-14 years were randomly selected from the list to participate in the study using SPSS software. Similar to that done for the TSA intervention, an initial sample size of 600 children was determined beforehand to be appropriate to detect differences in prevalence of 0.1. However, while in the field, researchers decided to add an extra 100 children to total 700 children as the information for locating children and their households provided by SHIPO was very unreliable and there was the fear that a large number of children may not be located, which would thus reduce the overall sample size.

Data collection in Iringa Region occurred one after the other due to the distance (about two hours drive) between Iringa District and Njombe District. Data was first collected in Iringa District, after which data collection in Njombe District began.

4.4 Study Instruments

A minimum of 4 questionnaires were administered per household. Depending on how many children were selected per household, and depending on whether these selected children each had different caregivers (very rare instances) or the same caregiver, multiple copies of questionnaires 2 to 4 could be administered per household. The first questionnaire, known as the household questionnaire, could be administered to either the

head of the household (as identified by household members) or to the selected child's caregiver. This questionnaire sought to obtain information on household assets and asked questions about material possessions, land ownership and dwelling infrastructure. The second questionnaire is the parent/caregiver/guardian questionnaire, which was administered only to the parent or caregiver or guardian of the selected child. This questionnaire solicited information such as the caregiver's demographic information (age, marital status, and formal education level), caregiver's perception of his/her own physical health and psychosocial well-being, food and nutrition in the household, community support and their perceptions of marginalization, etc. The third questionnaire, the parent/caregiver/guardian regarding child questionnaire, was focused on obtaining information about the selected child from the caregiver's perspective. Thus questions about the biological relationship between the caregiver and child, the whereabouts of the child's biological parents if the caregiver was not the child's biological parent, the child's school attendance, health and psychosocial well-being, as well as the caregiver's feelings towards the child were asked. The final questionnaire, the child questionnaire, was administered directly to the child him/herself and sought to obtain information on child demographic factors, child's own account of their school attendance, self-reported physical health and psychosocial well-being, support networks, knowledge and understanding of HIV and AIDS transmission, sexual risk behavior, etc. Each of the four questionnaires also contained modules that asked questions about the TSA or Allamano interventions for both the intervention and comparison groups. However, none of those modules will be used in these analyses since this study does not have an evaluation purpose.

4.5 Data Description

The data were obtained from a cross-sectional survey. The population of interest for the MEASURE Evaluation outcome evaluation study is children aged 8 to 14 years living in Mbeya or Iringa regions, Tanzania who are either receiving program services from TSA and Allamano (intervention groups) or who have been pre-selected to receive program

services in the near future by TSA in Mbeya region or by SHIPO (comparison groups) in Iringa Region. The population of interest for this particular study is the primary caregivers of fostered OVC aged 8 to 14 years, regardless of intervention status. Intervention status will be controlled for in all analyses as program participation can influence participants' responses. More information on variables used in this study and their definitions will be provided later on in this section in table 7. The unit of analyses is the individual caregiver, but data are linked via household identification number so that responses from caregivers can be linked to child-level variables such as child psychosocial well-being, child age and sex. To account for the variations in sampling strategy outlined in the previous section, the significance of the interactions between study sites and the primary variables of interest were assessed. These results are presented in table 2 in Appendix C. Since none of the interaction terms were significant, the combined dataset of TSA-and-Allamano supported OVC will be used. The sampling strategy will also be controlled for during multivariate regression analyses by adding this variable in all models. It is important to point out here that the variations in sampling strategy and the sampling frames limit the external validity of the study, but this will be discussed in further detail in the study limitations and strengths section.

After combining the TSA and Allamano datasets, a new dataset was created using a variable that identified the type of relationship between the caregiver and the child. Since this study is focused on foster care situations, all primary caregivers who were not the biological parents of the selected children in their care (that is, natural mother or natural father) were output into a new dataset for this analysis, and all caregivers who were natural parents were dropped. As previously mentioned, caregivers were linked to children via a unique household identification (household ID) number. More information on this variable is provided later on in this section. Table 4.1 below shows the distribution of foster versus non-foster caregivers in the combined dataset of TSA & Allamano evaluations.

Table 4.1: Percentage distribution of non-foster and foster caregivers in combined (TSA & Allamano) dataset

Caregiver relationship to child	n	Distribution (%)
Natural parents	1,448	63.07
Other caregivers	848	36.93
Total (N)	2296	100.00

There were a total of 848 foster households in the combined and filtered dataset.

With the exception of the intervention modules, which addressed each specific OVC intervention and used to evaluate the activities for each program, all questionnaires used were exactly the same, especially in terms of item wording, for both Mbeya and Iringa. The exact same team of interviewers was used to collect data for Kiswahili interviews in each evaluation in the two regions. In Mbeya region, a different set of interviewers were used to collect data from Kimalila speakers. All interviews in Iringa Region were conducted in Kiswahili. Table 3 shows the percentage distribution of Kiswahili and Kimalila speakers in the dataset. Variables that are relevant to this particular analysis are exactly the same for both datasets. Caregivers from Mbeya region were from Ilemba Ward and Isuto Ward specifically, while caregivers from Iringa were all resident in Iringa District, consisting of Iringa Rural and Iringa Urban, and Njombe District, consisting of Uwemba Ward, Illembula Ward and Mtwango Ward. Table 4.2 below shows the distribution of study households with regards to their location.

Table 4.2: Percentage distribution of study households according to location

Region	District	Sub-area	n	Distribution (%)
Mbeya	Mbeya Rural	Ilembo Ward	199	23.47
		Isuto Ward	96	11.32
Iringa	Iringa Rural		15	1.77
	Iringa Urban		231	27.24
	Njombe District	Uwemba Ward	152	17.92
		Ilembula Ward	84	9.91
		Mtwango Ward	71	8.37
Total (N)			848	100.00

Table 4.3: Percentage distribution of Kiswahili and Kimalila foster households in combined and filtered dataset

Language of Interview	n	Distribution (%)
Kiswahili	750	88.44
Kimalia	98	11.56
Total	848	100.00

Table 4.4 below shows the distribution of foster households by study site after the TSA and Allamano datasets were combined and non-foster households were filtered out so that only foster households remained. There were four main study sites and each site had a different sampling method as previously outlined. It is important to point out here that no effort was made during data collection to recruit children living in foster households as this was not related to the original evaluation study. Since the focus of the original

evaluation study was on children aged 8 to 14 years enrolled in the interventions and children aged 8 to 14 years soon to be enrolled in similar interventions, the sample sizes seen in the table below were not pre-determined.

Table 4.4: Percentage distribution of foster households according to study site

Study site	n	Distribution (%)
TSA intervention study sites	240	28.30
TSA comparison study sites	55	6.49
Allamano intervention study sites	246	29.01
Allamano comparison study sites	307	36.20
Total	848	100.00

Although interviews were completed for all 848 caregivers, interviews were completed for only 836 children. Table 4.5 below provides a brief summary of interview results for children.

Table 4.5: Summary of interview results for foster children

Interview Result	n
Interview completed	836
Child never at home	2
Child was physically disabled (for example, deafness)	5
Child was mentally disabled (for example, Down's syndrome)	3
Questionnaires missing (no information available on whether or not interviews were completed)	2
Total (N)	848

There were a total of 12 children for whom interviews could not be completed for various reasons as noted above. As a result there were 12 caregivers in the dataset who could not be linked with children. Since one of the objectives of these analyses is to determine the effect of child psychosocial well-being on caregiver psychosocial well-being, those caregivers who could not be linked with children were removed from subsequent analyses such that there were a total of 836 foster households, each with one caregiver and one foster child. Table 4.6 shows the percentage distribution of foster households according to study site after these 12 caregivers have been removed from the analysis.

Table 4.6: Percentage distribution of foster households according to study site

Study site	n	Distribution (%)
TSA intervention study sites	239	28.59
TSA comparison study sites	55	6.58
Allamano intervention study sites	243	29.07
Allamano comparison study sites	299	35.77
Total (N)	836	100.00

Calculation of sample weights

To account for unequal probabilities of selection, the data will be weighted as outlined in the table 4.7 below:

Table 4.7: Caregiver sample weights according to district

District	*2002 12-80+ years Population Estimates	n	Sample weights
Mbeya Rural	137533	294	21.6287
Iringa Rural	150857	15	100.2853
Iringa Urban	4682	228	4.5316
Njombe District	269711	299	30.0340

*These numbers represent the 2002 Tanzania census estimate¹⁶ for all those aged 12 to 80+ years in 2002 in the various districts. Caregivers in the dataset range in age from 12 years to 90 years, with a median age of 49 years and a mean age of 47.4 years. No estimates are available specifically for OVC caregiver population in the various districts or in the two regions. Thus sample weights are approximate. Sample weights are calculated by dividing the n's by the population estimates and finding the square root of this value. The square roots are used because the sample weights are very different compared to the relative sizes of the populations from which the samples were drawn, and thus using the square roots of the weights calculated to weight the data may help to minimize the big differences in weights.

4.6 Overview of variables in the analyses

Measuring attitudes towards foster children in the context of HIV and AIDS

Due to the limited number of studies regarding caregiver attitudes towards OVC in their care, there are no gold standard measures for examining attitudes towards OVC in foster care in the context of HIV and AIDS in sub-Saharan Africa. In fact, the majority of attitude measures in the HIV and AIDS literature are those geared mostly towards measuring attitudes towards people living with HIV and AIDS and to some extent their families, friends and loved ones, with little or no guidelines for measuring attitudes towards OVC in the context of HIV and AIDS. The existing AIDS attitude measures were mostly developed for use in the United States and have used likert-type scales (for example, 1=strongly disagree, 2=disagree, 3=agree, 4=strongly disagree) to target various sub-groups, particularly health care providers, volunteers and those in direct, regular contact with HIV positive individuals. They focused on categories such as blaming of the victim, fear of AIDS and fear of death (Blumfield et al., 1987; Bouton et al., 1987; Froman et al., 1992; Froman & Owen, 1997; Royse & Birge, 1987; Schondel & Shields, 1992). Some works also included categories such as homophobia, as AIDS was originally associated with homosexuals in the early days of the epidemic (Bouton et al., 1987; Froman et al., 1992; Royse & Birge, 1987; Schondel & Shields, 1992).

¹⁶ <http://www.tanzania.go.tz/census/regions.htm>

With regards to attitudes towards OVC, some studies that have examined caregivers' feelings towards their foster children have used qualitative techniques such as focus group discussions, in-depth interviews, and case studies to solicit information from these populations (Guest, 2001; Mann, 2002), while others using quantitative methods have used scale items (Ohnishi et al., 2008). Other non-HIV and AIDS-related literature that have sought to measure attitudes to foster care in general from the perspectives of street children and children in state custody in the developed world have also used a mixture of qualitative methods such as personal in-depth interviews with children and quantitative methods involving the use of scale items covering constructs such as family loyalty and peer influence, as past attitude studies have done (Fernandez, 2007; Holdaway & Ray, 1992).

Most likely the ideal method for measuring attitudes towards foster children in the context of HIV and AIDS would be to use a mixture of qualitative (case studies and in-depth personal interviews) as well as quantitative methods using likert-type scales as have been done in the past. Unfortunately due to limitations with this current dataset, this study will measure attitudes towards OVC using a few selected relevant items.

Definition of caregivers' attitudes towards OVC in their care variable: Caregiver's attitudes towards his/her foster children will be measured using caregiver's feelings towards his/her foster children, which consists of a score created from the following 3 scale items: NAME is much harder to take care of than most children, NAME does things that really bother me, and I feel angry with NAME. Response options include: strongly agree (1), agree (2), disagree (3) and strongly disagree (4). The Cronbach coefficient alpha for these items is 0.7126. A score was created by summing up the 3 scale items such that the higher the score, the more positive a caregiver's attitude is towards a foster child in his/her care and the lower the score, the more negative the attitude. This variable has no missing values. Table 4.8 below summarizes the properties of this variable.

Table 4.8: Caregivers' attitudes towards OVC in their care scale properties (n=836)

Property	Value
Range	3 - 12
Median	10
25 th percentile	9
75 th percentile	12
Mean (standard deviation)	9.9701 (1.8682)
Cronbach's alpha	0.7126

Based on the distribution of this variable, a dichotomous variable was constructed using the median score as the cutoff point so that all those with scores less than or equal to 10 were put into one category (1 = do not have positive feelings towards child) and all those with scores greater than 10 were put into a second category (0=have positive feelings towards child). Both versions of this variable will be used at different stages of the analyses. The scale items used to construct these variables were borrowed from the US Census Bureau, Survey of Income & Program Participation (SIPP). This is a longitudinal survey that collects information from US resident populations and sub-groups on issues such as poverty, health insurance coverage, income and employment.¹⁷ Note that there are limitations resulting from the use of items not validated for use in sub-Saharan Africa and these limitations will be discussed in more detail in the study limitations and strengths section.

Definition of caregivers' psychosocial well-being variable: Caregivers' psychosocial well-being will be measured using a score created from 5 scale items borrowed from the WHO Quality of Life-100. This is a set of 100 items designed for cross-cultural use with people living with HIV and AIDS to assess quality of life. The items are grouped into 7 domains: physical (assessing pain, discomfort, energy, etc.), psychological (assessing positive and negative feelings, self-esteem, etc.), level of independence (assessing

¹⁷

http://www.acf.hhs.gov/programs/opre/other_resrch/eval_data/reports/common_constructs/com_appb_sipp.html

mobility, activities of daily living, etc.), social relationships (assessing personal relationships, sexual activity, etc.), environment (assessing home environment, financial resources, etc.), spirituality, religion and personal beliefs, and finally a general domain assessing overall quality of life and general health perceptions (WHOQOL-HIV Group, 2003). The 5 items borrowed for this study ask about feelings of depression, sadness and anxiety, and form part of the positive and negative subscales of the psychological domain. They each have the following response options: 1= “not at all”, 2= “a little”, 3= “a moderate amount”, 4= “very much”, and 5= “an extreme amount”. Table 4.9 below provides information on the specific items used to create this scale.

Table 4.9: Caregivers’ psychosocial well-being scale items

Scale item	Response options
How much do you enjoy life?	Not at all (1); A little (2); A moderate amount (3); Very much (4); An extreme amount (5)
How much do you experience positive feelings in your life?	Not at all (1); A little (2); A moderate amount (3); Very much (4); An extreme amount (5)
How much do any feelings of sadness or depression interfere with your everyday functioning?	Not at all (1); A little (2); A moderate amount (3); Very much (4); An extreme amount (5)
How much do any feelings of depression bother you?	Not at all (1); A little (2); A moderate amount (3); Very much (4); An extreme amount (5)
How worried do you feel?	Not at all (1); A little (2); A moderate amount (3); Very much (4); An extreme amount (5)

The Cronbach coefficient alpha for this scale is 0.7654, and the score was created by summing up all the items. Reverse coded items were re-coded such that the higher the score, the better the caregiver’s psychosocial health and the lower the score, the worse it is. For example, a value of 5 represents the lowest level of psychosocial health (i.e. poor psychosocial health) and a value of 25 represents the highest level of psychosocial health

(i.e. good psychosocial health). There are no missing values for this variable. Table 4.10 below summarizes the properties of this variable for this study.

Table 4.10: Caregivers’ psychosocial well-being scale properties (n=836)

Property	Value
Range	5 - 24
Median	14
25 th percentile	11
75 th percentile	17
Mean (standard deviation)	14.014 (3.7582)
Cronbach’s alpha	0.7654

The distribution of this variable was examined and based on the median cut-off point, it was re-defined such that 1= poor psychosocial well-being (consisting of scores ranging from 5 to 14) and 0=average/good psychosocial well-being (consisting of scores ranging from 15 to 24). This dichotomized version of the variable will be used during univariate analyses; however, bivariate and multivariate analyses will make use of this variable as a continuous variable. Note that this variable will be used both as an outcome to address the first research question, and as an independent variable to address the subsequent research questions.

Definition of primary independent variables

Measuring AIDS-related stigma – evidence from the literature

Due to considerable variation in the definition of stigma and the fact that the concept itself is dynamic and dependent on the cultural and economic context, there are no gold standard measures for assessing stigma (Genberg et al., 2007; Mahendra et al, 2007). One prevailing issue contributing to the limited availability of reliable stigma measures is that instruments that have been used in past studies have either been not comprehensive enough to cover all aspects of this complex concept, or they have been overly detailed and thus impractical for regular use in the field (Genberg et al., 2007). An example of an

overly detailed instrument is the 101-item HIV and AIDS stigma scale developed by Berger, Ferrans & Lashley (2001), which covered constructs such as personalized stigma, disclosure concerns, negative self-image and concern with public attitudes towards persons with HIV and AIDS, and was tested amongst HIV-positive women.

On the whole, many studies on AIDS-related stigma have addressed the fear of casual transmission and imminent death – one of the main causes of stigma - through instruments that address knowledge and understanding of HIV and AIDS transmission, disease progression and the social exclusion of people living with HIV and AIDS (Nyblade et al., 2005). Other studies have addressed the second major cause of stigma – the association of HIV and AIDS with socially unacceptable behaviors – through the use of items assessing shame, blame and guilt with regards to people living with HIV and AIDS (PLHA). For example, some studies have examined the extent of the belief that PLHA are being punished by God for their sins (Blendon & Donelan, 1988; Boer & Emons, 2004). However, measures used have often been ambiguous and failed to capture the underlying reason behind stigmatizing actions (Nyblade et al., 2005). For example, items such as, “Would you be willing to share food with a person with HIV and AIDS?” is ambiguous because if an individual is unwilling to share food with an HIV/AIDS-infected person, the actual reason may be because he/she may feel that the sick individual is sick due to his/her own immoral actions, and thus does not deserve to eat with everyone else. However, according to Nyblade et al. (2005), many studies interpret this to mean that the individual is afraid of contracting the disease by sharing food with an infected person, although it is possible that the first reason may be the real motivation behind that attitude. The authors also identify other challenges to measuring stigma, such as sample selectivity, particularly amongst people living with HIV and AIDS, as the sampling frames for such studies are sometimes drawn from organizations serving these groups. HIV-infected individuals served by such organizations constitute a select group of people and are usually different from those not served by such organizations (for example, those who are afraid of being stigmatized may not participate in HIV and AIDS programs offered by such organizations). This issue is very applicable to this study as perceived AIDS-related stigma will be measured amongst caregivers

receiving support from NGOs, as well as caregivers slated to receive future services. Other challenges include difficulty collecting data on stigmatizing attitudes due to the tendency of respondents to give socially acceptable answers, and ethical issues related to asking an individual if he/she has experienced AIDS-related stigma.

Also the majority of stigma tools available for use were actually developed in the United States – only a few were actually developed for use in sub-Saharan Africa and other areas with high HIV and AIDS prevalence (Holzemer & Uys, 2004; Mahendra et al., 2007). Holzemer & Uys (2004), in a study exploring how healthcare providers can help manage stigma, identified five major instruments reported in the literature for measuring AIDS-related stigma, and all of these were developed for use in countries such as the US. For example, they identify a 10-item scale by Herek & Capitano (1993), developed to assess stigma amongst the American public. The instrument assessed four aspects of stigma: negative feelings towards persons with AIDS, support for coercive AIDS-related policies, blame of persons with AIDS and intentions to avoid a person with AIDS. Other measures identified by the authors also covered constructs such as social rejection, internalized shame, and social isolation. Due to the cultural and religious undertones often associated with stigma, measures developed in Western cultures may be inappropriate for use in non-Western cultures.

In recent years, several studies exploring AIDS-related stigma outside of Western culture have been carried out. Some have focused on the use of qualitative measures - for example, work done by Hong, Anh & Ogden (2004) in Vietnam and by researchers for UNAIDS (2000b) in Uganda and India - such as in-depth interviews and focus group discussions amongst target populations. Other studies have endeavored to measure stigma quantitatively. For example, Yang et al. (2006), in an investigation of factors influencing willingness to disclose one's HIV-positive status in China used a 4-item scale to measure AIDS-related stigma. The scale was composed of the following items: "HIV infected people should be ostracized by their spouse and family members", "HIV infected people should be kicked out of their villages", "I would keep a normal relationship with my HIV-infected friends", and "HIV infected people should have the same rights of

education and employment as others”, and was based on a 4-point agreement scale. The authors used a composite score to assess the level of stigma. However, the internal consistency was relatively low, as the Cronbach coefficient alpha for this scale ranged from 0.60 to 0.62. In another study amongst truckers in Brazil, AIDS-related stigma was assessed quantitatively using a 15-item scale that was developed based on a literature review and formative research in Brazil. The scale covered the main domains of stigma and discrimination, which included fear of casual transmission, blame towards people living with HIV and AIDS and fear of enacted stigma (Chinaglia et al., 2007). Bao et al. (2003), in a comparison of two HIV prevention programs amongst workers in Vietnam, measured AIDS-related stigma through the use of two instruments: an additive score created from 8 true or false statements assessing participants knowledge and understanding of HIV and AIDS transmission, and an index of stigmatizing attitudes constructed from 5 items (for example, “If you knew that a co-worker had HIV and AIDS, would you be willing to work with him/her in the same place?”, etc.) borrowed from well-established surveys such as the Demographic and Health Surveys (DHS). The Cronbach coefficient alpha for this index was 0.79.

A thorough search of the literature unveiled several studies focusing on the development of a reliable and valid scale for quantitative stigma assessment in sub-Saharan Africa. Nyblade & MacQuarrie (2006), in an exploration of quantitative measures for stigma in developing countries, identified promising indicators for measuring stigma, developed and tested amongst community and health providers in Tanzania. These indicators measure actual fear of contracting the disease, capture behavior that results from the fear of causal transmission and assess shame, blame and judgment of people living with HIV and AIDS. Scales performed well on tests of reliability and validity. Kalichman et al. (2005) also developed an AIDS-Related Stigma Scale, which was tested in five South African communities, consisted of nine items and was based on previous stigma measures developed in developed countries, as well as on current knowledge of the dynamics of AIDS-related stigma in southern Africa. It covered well-documented stigmatizing actions such as repulsion, avoidance and persecution of people living with

HIV and AIDS. The scale was found to be internally consistent and reliable in three languages (English, Xhosa and Afrikaans).

Currently, there are insufficient reliable measures to assess multiple stigmas, which cannot be ignored because they can impact the degree and intensity of stigmatization and lead to increased marginalization and discrimination (Nyblade et al., 2003; Nyblade, 2006; Reidpath & Chan, 2005). Nyblade (2006), in a review of literature on stigma assessment and measurement, identified three major categories of literature: studies assessing stigma in the general population, studies assessing perceived and experienced stigma from the perspective of people living with HIV and AIDS and studies comparing AIDS-related stigma to the stigma of other diseases. While these are all important, one noticeable missing category is the assessment of perceived and experienced stigma from friends, families and loved ones of people living with HIV and AIDS. Although secondary stigma has been identified and acknowledged, it has not been as widely studied as primary stigma, and there is relatively little to no information on ways in which perceived stigma from the perspective of those closely associated with HIV positive individuals can be assessed and measured. However, information on how perceived stigma from the perspective of people living with HIV and AIDS has been assessed and measured in past studies can guide how perceived stigma from the perspective of those closely associated with people living with HIV and AIDS can be measured.

Nyblade (2006) found that studies measuring perceived stigma from the perspective of people living with HIV and AIDS focused on two main issues: the fear that people living with HIV and AIDS have about those closely associated with them (for example partners, family members, friends, etc) and those in the community such as neighbors finding out that they are HIV positive (for example, they may be afraid of losing friends, being blamed for their condition, being socially isolated, etc.) and on their expectations of how these people would react to that knowledge (be supportive, be unsupportive, etc.). OVC and their caregivers are likely to experience similar fears in that they may be afraid that people will find out that they have a family member who is HIV positive and thus discriminate against them by avoiding them for example, or that they may think that

people who do know that they have a family member who is HIV positive will be unsupportive. This study will measure perceived AIDS-related stigma using items that attempt to get at what OVC and their caregivers expect others in their community to think about them because they are closely associated with someone who is either living with the disease or has died from it.

Definition of perceived AIDS-related stigma variable

Caregiver perception of AIDS-related stigma: Due to a poor Cronbach alpha coefficient, this variable will be measured using two likert items assessing gossip and feelings of social isolation– “People speak badly about you or your family” and “You feel isolated from others in the community”. Response options for these both of these items are strongly agree (1), agree (2), disagree (3) and strongly disagree (4). The distributions of the responses for these two items are shown in the tables below:

Table 4.11: Distribution of 1st stigma measure (“People speak badly about you or your family”)

People speak badly about you or your family	Distribution (%)	Weighted %	n
Strongly agree	12.31	13.26	98
Agree	21.23	20.70	169
Disagree	39.70	37.66	316
Strongly disagree	26.76	28.37	213
Total	100.00	100.00	796

There are a total of 40 missing values for this variable (N=836). This variable was dichotomized based on the median cut-off point of the distribution and the distribution of this dichotomized variable has been presented in table 4.12 below. This is the variable that will be used in subsequent analyses.

Table 4.12: Distribution of dichotomized stigma measure (“People speak badly about you or your family”)

People speak badly about you or your family	Distribution (%)	Weighted %	n
Agree	33.54	33.97	267
Disagree	66.46	66.03	529

Total	100.00	100.00	796
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The next table below shows the distribution of the second stigma measure, “You feel isolated from others in the community”.

Table 4.13: Distribution of 2nd stigma measure (“You feel isolated from others in the community”)

You feel isolated from others in the community	Distribution (%)	Weighted %	n
Strongly agree	7.78	8.63	65
Agree	15.33	14.00	128
Disagree	41.68	40.07	348
Strongly disagree	35.21	37.30	294
Total	100.00	100.00	835

There is one missing value for this variable (N=836). Based on the median cut-off point of the distribution, this variable was dichotomized and the distribution of this dichotomized variable is shown below in table 4.14. This is the variable that will be used in subsequent analyses.

Table 4.14: Distribution of dichotomized stigma measure (“You feel isolated from others in the community”)

You feel isolated from others in the community	Distribution (%)	Weighted %	n
Agree	23.11	22.63	193
Disagree	76.89	77.37	642
Total	100.00	100.00	835

These two items are independently associated with each other ($p < 0.05$) as can be seen from table 4.15 below. This means that caregivers who report feeling isolated from the community are also more likely to report that people speak badly about them or their families.

Table 4.15: Results from cross-tabulation between “People speak badly about you or your family” and “You feel isolated from others in the community” (n = 796)

You feel isolated from others in the community	People speak badly about you or your family		Total %
	Agree	Disagree	
Agree	17.17	6.17	23.34
Disagree	16.80	59.86	76.66
Total %	33.97	66.03	100.00

p-value=0.0000

Child perception of AIDS-related stigma: There is also a child version of this variable as the goal is to measure perceived stigma. A child’s perception of AIDS-related stigma will be measured using the following item: “How often do you play alone because no one wants to play with you?”

Response options: Never (1), almost never (2), sometimes (3), almost always (4), always (5)

Table 4.16 below shows the distribution of this item.

Table 4.16: Distribution of item, “How often do you play alone because no one wants to play with you?”

How often do you play alone because no one wants to play with you?	Distribution (%)	Weighted %	n
Never	65.39	65.62	546
Almost never	22.28	20.87	186
Sometimes	5.15	4.95	43
Almost always	4.55	5.27	38
Always	2.63	3.29	22
Total	100.00	100.00	835

As can be seen from the table above, this variable has one missing value. This variable was categorized such that the following three categories were obtained: 1 = never (consists of the “never” category), 2 = sometimes (consists of the “almost never” and “sometimes” categories), and 3 = frequently (consists of the “almost always” and

“always” categories). The distribution of this categorical variable is shown in table 4.17. This is the variable that will be used in subsequent analyses.

Table 4.17: Distribution of child perception of AIDS-related stigma

How often do you play alone because no one wants to play with you?	Distribution (%)	Weighted %	n
Never	65.39	65.62	546
Sometimes	27.43	25.82	229
Frequently	7.19	8.56	60
Total	100.00	100.00	835

Note that there are some limitations associated with the use of single items rather than a scale item to measure perceived stigma. These limitations will be discussed in the study limitations and strengths section of this document.

Definition of household socio-economic status variable: Principal component analysis was used to construct the index of economic status of a household using the following items from the household questionnaire: floor material, main source of drinking water, toilet facility, possession of assets such as radios, televisions, paraffin lamps, iron, refrigerators, car/truck and a bank account, presence of electricity in the home, number of rooms used for sleeping and animals owned. Twenty-one options were available for main source of drinking water and these included water from ponds/lakes, spring water, rivers, dams, protected and unprotected wells, boreholes, etc. This variable was thus dichotomized into two categories – improved water sources and unimproved water sources – based on the WHO’s criteria for improved and unimproved water sources.¹⁸ According to the WHO, improved water sources include household connections, public standpipes, boreholes, protected dug wells, protected springs, and rainwater collections, while unimproved water sources include unprotected wells, unprotected springs, vendor-provided water, bottled water and tanker-truck provided water. To obtain the number of people per room used for sleeping, a new variable was constructed by dividing the total number of household members by the number of rooms used for sleeping. This new

¹⁸ <http://www.who.int/whosis/whostat2006ImprovedWaterImprovedSanitation.pdf>

variable, together with the other variables, was used to create the household socio-economic status variable.

Principal component analysis first standardized the individual variables that made up the index by calculating z-scores. Then the factor loadings were calculated and the indicator values were multiplied by the loadings and summed to produce the household's economic status index value. Only the first of the factors with an eigen value greater than 1 was used to represent the economic status index. The result was a standardized score with a mean of zero and a standard deviation of one (Rutstein, Shea & Johnson, 2004). This standardized score was then recoded into quintiles such that 1= "poorest", 2= "poorer", 3= "middle", 4 = "richer" and 5= "richest". This procedure is similar to that used by the Demographic and Health Survey (DHS) to calculate the wealth index. The distribution of this variable is presented in table 4.18 below. There were 3 missing values.

Table 4.18: Distribution of household socio-economic status variable

Income level	Household socio-economic status (n=833)		
	%	Weighted %	n
Poorest	20.17	21.55	168
Poorer	19.93	21.10	166
Middle	20.05	25.06	167
Richer	19.93	19.02	166
Richest	19.93	13.27	166

During analyses, this variable was re-coded into 3 main levels: 1 = poor (poorest and poorer categories combined), 2 = middle (middle income category), and 3 = rich (richer and richest categories).

Definition of child's psychosocial well-being variable: A child's psychosocial well-being will be measured using a score created from 8 scale items borrowed from items in the global self-esteem and family relationships subscales, which is based on the Rosenberg

Self-Esteem scale – a 10-item scale originally developed to assess self-esteem among adolescents (Crandal, 1973; Rosenberg, 1965; Wylie, 1974). Table 4.19 below provides information on the specific items used to create this scale.

Table 4.19: Child’s psychosocial well-being scale items

Scale item	Response options
You are happy with the way you can do most things	Strongly agree (1); Agree (2); Disagree (3); Strongly disagree (4)
You sometimes think you are a failure	Strongly agree (1); Agree (2); Disagree (3); Strongly disagree (4)
You are happy with yourself as a person	Strongly agree (1); Agree (2); Disagree (3); Strongly disagree (4)
You like being just the way you are	Strongly agree (1); Agree (2); Disagree (3); Strongly disagree (4)
You are as good a person as you want to be	Strongly agree (1); Agree (2); Disagree (3); Strongly disagree (4)
You are happy about how much your family likes you	Strongly agree (1); Agree (2); Disagree (3); Strongly disagree (4)
You are too much trouble to your family	Strongly agree (1); Agree (2); Disagree (3); Strongly disagree (4)
You get along as well as you would like with your family	Strongly agree (1); Agree (2); Disagree (3); Strongly disagree (4)

The Cronbach coefficient alpha for this scale was 0.7007, and the score was also constructed by summing up all the items such that the higher the score, the better the child’s psychosocial health and the lower the score, the worse it is. The properties for this variable have been summarized in the table below.

Table 4.20: Child’s psychosocial well-being scale properties (n=836)

Property	Value
Range	8 – 32
Median	24
25 th percentile	22
75 th percentile	27
Mean (standard deviation)	24.2512 (4.0074)
Cronbach’s alpha	0.7007

As was done for caregivers’ psychosocial well-being, a binary variable was created using the median score as the cut-off point such that 1 = poor psychosocial health (scores ranging from 8 to 24) and 0 = average/good psychosocial health (scores greater than 24). This dichotomized version of the variable will be used during univariate analyses; however, bivariate and multivariate analyses will make use of this variable as a continuous variable.

Definition of other relevant variables

Other relevant variables used in this study and how they are defined are presented below in Table 4.21.

Table 4.21: Definitions of other relevant variables used in this study

Variable	Items to be used	Variable definition
<p>Community support</p> <p>-This question was posed only and directly to the caregiver and will be used as a proxy variable to measure community support from the community.</p> <p>-Response options are yes/no, with yes given a value of 1 and no given a value of 0.</p>	<p>*In the past 6 months, did your household receive help from friends, relatives or neighbors?</p>	<p>This factor will be measured using the following question posed directly and only to the caregiver of the child: "In the past 6 months, did your household receive help from friends, relatives or neighbors?". This is a yes/no binary variable. "Help" refers to both material support such as provision of food, clothing, money, etc. as well as counseling/emotional support, as response options for the follow up to this question include these categories. Thus community support in this sense refers to actual community support and not perceived community support. This question was asked of caregivers in both the intervention and comparison groups. Thus caregivers who answered yes could either be referring to services received from participating in any one of the two interventions, or they could be referring to non-program related help received from friends, neighbors, etc. Caregivers who reported not receiving any community support were not asked the follow up question about the type of help received since it was not applicable.</p>
<p>Food security</p> <p>-This is a series of questions posed to the caregiver about food in the household and the ways in which the caregiver manages the family's needs for food.</p> <p>-Source: Food and Nutritional Technical Assistance (FANTA) Household Food Security Access Scale.</p>	<p>*In the past 4 weeks, did you worry that your household would not have enough food?</p> <p>* In the past 4 weeks, were you or any household member not able to eat the kinds of foods you preferred because of lack of resources?</p> <p>*In the past 4 weeks, did you or any household member eat a limited variety of foods due to lack of resources?</p> <p>*In the past 4 weeks, did you or any household member eat food that you preferred not to eat because of a lack of resources to</p>	<p>The items making up the household food security variable are taken from the FANTA food security scale and measure 3 main domains of food insecurity: anxiety and uncertainty about household food supply, insufficient quality and insufficient food intake and its physical consequences (Coates, Swindale & Bilinsky, 2007). To determine the prevalence of household food insecurity, households were categorized into four levels: food secure, mild food insecurity, moderate food insecurity and severe food insecurity according to the criteria laid out by the FANTA food security access scale (Coates, Swindale & Bilinsky, 2007).</p>

	<p>obtain other types of food?</p> <p>*In the past 4 weeks, did you or any household member eat a smaller meal than you felt you needed because there was not enough food?</p> <p>*In the past 4 weeks, did you or any other household member eat fewer meals in a day because there was not enough food?</p> <p>* In the past 4 weeks, was there ever no food at all in your household because there were not resources to get more?</p> <p>*In the past 4 weeks, did you or any household member go to sleep at night hungry because there was not enough food?</p> <p>*In the past 4 weeks, did you or any household member go a whole day and night without eating anything because there was not enough food?</p> <p>The following question was asked after each item indicated above:</p> <p>*How often did this happen?</p> <p>Response options for this question are 1 (rarely – once or twice), 2(sometimes – 3 to 10 times), and 3(often – more than 10 times).</p>	
Variable	Items to be used	Variable definition
Presence of ill persons in	*In this home, are there any	This variable was first summed up such that 0=no ill persons in

<p>the household</p> <ul style="list-style-type: none"> -These questions are asked of the caregiver only. - Response options: "yes" (1) and "no" (0) for both questions. 	<p>children who are severely sick or physically disabled? *Has any adult in the household been sick 3 months in a row or longer?</p>	<p>household, 1 = at least 1 ill child or 1 ill adult in household & 3 = at least 1 ill child and 1 ill adult in household. It was then dichotomized into the following 2 levels: 0 = no ill person in the household, 1 = one or more ill persons in the household. This is a binary variable.</p>
<p>Household size</p> <ul style="list-style-type: none"> -Due to the nature of the dataset available, household dependency ratio cannot be measured directly. However, household size has been selected as a suitable proxy for this variable as household size can give an indication of how much pressure is imposed on household resources such as food and finances. 	<p>*Total members of households</p>	<p>This variable is continuous and represents the total number of people living in one household.</p>
<p>Caregiver's age</p> <ul style="list-style-type: none"> -This question is posed directly to the caregiver. 	<p>*How old are you now?</p>	<p>This variable is continuous and will be used in this form.</p>
<p>Caregiver's marital status</p> <ul style="list-style-type: none"> -This question is posed directly to the caregiver. Response options are: 1 = Yes, currently married; 2 = Yes, living with a man/woman; 0 = No, not in union 	<p>*Are you currently married or living together with a man/woman as if married?</p>	<p>This variable was re-defined such that those who reported were currently married or living together with a man/woman as if married were in one category (1) and those not in unions were in the second category (0).</p>

Variable	Items to be used	Variable definition
<p>Caregiver's biological relationship to child</p> <p>-This question is posed directly and only to the caregiver.</p> <p>-Response options include natural grandmother, natural grandfather, aunt, uncle, older brother, older sister and other.</p>	<p>*What is your relation to name?</p>	<p>In this new dataset, this variable now only has the following categories available since the "natural parents" category was filtered out: natural grandmother, natural grandfather, aunt, uncle, older brother, older sister, other. A frequency was run to examine the distribution and the decision was made to redefine this variable such that 1 = "natural grandparents" (combining natural grandmother/grandfather), 2 = "other related caregivers" (combining aunt, uncle and older siblings), and 3 = "other non-related caregivers" (other category, which consisted of step-parents, step-siblings, in-laws, family friends, neighbors, etc. acting as caregivers). Natural grandparents are the reference category for this variable.</p>
<p>Caregiver's educational level</p>	<p>*Have you ever attended school? (yes/no)</p> <p>*What is the highest level of school you attended: pre-primary, primary, post-primary, secondary, post-secondary, university?</p>	<p>A frequency was first run to determine the distribution of these two variables. They were both then re-coded such that an ordered variable was produced: 1 = "no education", 2 = "primary education", and 3 = "post-primary education" (this includes post-primary, secondary, post-secondary and university – educated caregivers). "Post-primary education" is the reference category for this variable.</p>
<p>Caregiver's religiosity</p> <p>-Response options are: 1 = "strongly agree", 2 = "agree", 3 = "disagree", 4 = "strongly disagree".</p>	<p>*Religion is an important part of my life.</p>	<p>This likert-item was first dichotomized into 2 groups: 1 = "religious" (includes those who strongly agree and agree to the statement) and 2 = "not religious" (includes those who strongly agree and agree to the statement) and then a frequency was run to determine its distribution.</p>
<p>Caregiver's sex</p> <p>-This is an observation the interviewer is required to make when speaking with the caregiver of the child.</p>	<p>*Record sex of respondent</p>	<p>This is a dichotomized variable such that 1 = male and 0 = female.</p>
<p>Child's age</p> <p>-This question is posed</p>	<p>*How old were you at your last birthday?</p>	<p>This variable is continuous.</p>

directly to the child.			
Child's sex -This is not a question, but rather an observation on the part of the interviewer speaking with the child.	*Record sex of child	This is a categorical variable, with females coded with a value of 1 and males coded with a value of 0.	
Location (rural vs. urban)	*Ward/location name	A dichotomized variable was created such that 1=rural areas (consisting of Iringa Rural, Ilembo Ward, Isuto Ward and Mtwango Ward) and 0=urban areas (consisting of Iringa Urban, Uwemba Ward and Ilembula Ward).	
Household identification number (Household ID)	*Household ID	Due to the hierarchical nature of the data, this unique household identification number was used to link caregivers and their foster children. However this variable is not included in the either the univariate, bivariate or multivariate analyses.	
Intervention status/Study site -This variable will be used to control for the different sample strategies used at the study sites as well as be used to control for the fact that some participants are receiving services from TSA and Allamano, while some are not receiving any services at all.	*Study ID *Group ID	Due to variations in sampling strategies for the different groups, sampling variation will be controlled for by using a variable created from the study and group IDs. This variable will essentially be coded such that 1=TSA intervention group, 2=TSA comparison group, 3=Allamano intervention group and 4=Allamano comparison group. This way, the sampling strategies used in the 4 sites and participants' intervention status can be controlled for during multivariate regression.	

4.7 Statistical methods

4.7.1 Univariate and Bivariate Analyses

Univariate, bivariate and multivariate analyses were conducted. For all statistical tests, p-values less than 0.05 are used to determine statistical significance, although p-values less than 0.10 are also reported. For the bivariate and multivariate analyses, caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care were used as continuous outcomes. Stata/SE 10.1 was used for the univariate, bivariate and multivariate linear regression analyses.

Univariate analyses

The results of the univariate analyses are presented in chapter 5 in tables 5.1 and 5.2, and they provide information on sample characteristics (distributions of individual variables), as well as information on missing data for each variable. For this portion of the analysis, the two main outcomes, caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care, were used as binary outcomes in order to obtain statistics on the distribution of caregivers with poor psychosocial well-being and the distribution of caregivers with negative feelings towards OVC in their care. However, for the bivariate and multivariate analyses, these variables were used as continuous outcomes.

Bivariate analyses

Linear regression was used to examine the unadjusted associations between the outcome variables (caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care) and continuous independent variables. For discrete/categorical independent variables, ANOVA F-tests were used to determine the associations between these variables and the two outcomes. Results of the bivariate analyses are also presented in chapter 5 in tables 5.3a, 5.3b and 5.4.

4.7.2 Multivariate Analyses

Linear regression analyses

First, a correlation matrix between the dependent variables and all independent variables was run to ensure that none of the correlation coefficients were above tolerable levels (that is, 0.50 and above), which would suggest collinearity. The results of the correlation matrix are shown in table 2 in Appendix C. Linear regression analyses were then conducted to determine adjusted associations between the two main outcome variables, independent variables and any theoretically appropriate interaction terms. Model building was conducted by first entering the primary variables of interest into the model, while controlling for intervention status, and then adding other individual-level variables, and then household-level and community-level factors, as well as appropriate interaction terms individually into the respective models as outline below, while simultaneously monitoring results for multi-collinearity between the variables. The variance inflation factor (VIF) was used as a test for multi-collinearity, and if this factor between two variables was greater than 10, this implied collinearity, meaning that both variables are highly related. If this happened, one of the two variables was dropped from the analyses. Variables and interactions that were entered into the models were guided by the literature and also by the results of the bivariate analyses. All results are presented in full in chapter 6. The general model specification for the analyses is shown below:

General model specification:

$$\text{yhat} = \beta_0 + \beta_1 * \text{intervention status} + \alpha * \text{primary independent variables of interest} + \delta * \text{individual-level factors} + \gamma * \text{household-level factors} + \lambda * \text{community-level factors} + \theta * \text{interaction terms if applicable} + \epsilon$$

yhat = outcome variable of interest (caregivers' psychosocial well-being or caregivers' attitudes towards OVC in their care)

β_0 = model intercept

ϵ = error term

The following models represent initial models that were run to test each research hypothesis. Final models obtained are presented in chapter 6.

Hypothesis 1.1: Poor OVC psychosocial health negatively affects the psychosocial well-being of their caregivers, controlling for other relevant factors.

Initial model 1:

$$\hat{y} = \beta_0 + \beta_1 * \text{child psychosocial well-being} + \beta_2 * \text{caregiver age} + \beta_3 * \text{caregiver education level} + \beta_4 * \text{caregiver marital status} + \beta_5 * \text{caregiver biological relationship to child} + \beta_6 * \text{caregiver perception of AIDS-related stigma} + \beta_7 * \text{OVC perception of AIDS-related stigma} + \beta_8 * \text{caregivers' feelings towards OVC in their care} + \beta_9 * \text{household socio-economic status} + \beta_{10} * \text{household food security} + \beta_{11} * \text{presence of ill persons in household} + \beta_{12} * \text{household size} + \beta_{13} * \text{community support} + \beta_{14} * \text{location} + \beta_{15} * \text{intervention status} + \epsilon$$

where \hat{y} = caregivers' psychosocial well-being (continuous outcome)

Dummy variables were created and used for the following variables:

1. Caregivers' education level (post-primary education used as reference level)
2. Caregivers' biological relationship to child (grandparents used as reference level)
3. OVC perception of stigma ("OVC never play alone because no one else wants to play with them" used as reference level)
4. Household socio-economic status (rich households used as reference level)

Caregivers' perception of stigma was measured using the two variables previously discussed ("You feel isolated from others in your community", and "People speak badly about you or your family").

Hypothesis 2.1: Caregivers' in poor psychosocial health are more likely to have negative feelings towards OVC in their care as compared with caregivers' in good psychosocial health, controlling for other relevant factors.

Initial model 2:

$$\text{yhat} = \beta_0 + \beta_1 * \text{caregiver psychosocial well-being} + \beta_2 * \text{OVC psychosocial well-being} + \beta_3 * \text{caregiver age} + \beta_4 * \text{caregiver education level} + \beta_5 * \text{caregiver marital status} + \beta_6 * \text{caregiver biological relationship to child} + \beta_7 * \text{caregiver perception of AIDS-related stigma} + \beta_8 * \text{OVC perception of AIDS-related stigma} + \beta_9 * \text{child's age} + \beta_{10} * \text{child's sex} + \beta_{11} * \text{household socio-economic status} + \beta_{12} * \text{household food security} + \beta_{13} * \text{presence of ill persons in household} + \beta_{14} * \text{household size} + \beta_{15} * \text{community support} + \beta_{16} * \text{location} + \beta_{17} * \text{intervention status} + \epsilon$$

where yhat = caregivers' feelings towards OVC in their care

The same dummy variables created for initial model 1 were also used here, and caregivers' perception of stigma was assessed using the same two measures. This was also done for initial models 3 and 4 below.

Hypothesis 3.1.1: Perceived AIDS-related stigma exacerbates the relationship between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care, controlling for other relevant factors.

Initial model 3:

$$\text{yhat} = \beta_0 + \beta_1 * \text{caregiver psychosocial well-being} + \beta_2 * \text{OVC psychosocial well-being} + \beta_3 * \text{caregiver age} + \beta_4 * \text{caregiver education level} + \beta_5 * \text{caregiver marital status} + \beta_6 * \text{caregiver biological relationship to child} + \beta_7 * \text{caregiver perception of AIDS-related stigma} + \beta_8 * \text{OVC perception of AIDS-related stigma} + \beta_9 * \text{child's age} + \beta_{10} * \text{child's sex} + \beta_{11} * \text{household socio-economic status} + \beta_{12} * \text{household food security} + \beta_{13} * \text{presence of ill persons in household} + \beta_{14} * \text{household size} + \beta_{15} * \text{community support} + \beta_{16} * \text{location} + \beta_{17} * \text{intervention status} + \beta_{18} * I + \epsilon$$

where yhat=caregivers' feelings towards OVC in their care

I = interaction terms between caregivers' psychosocial well-being and caregivers' perceptions of AIDS-related stigma (1 interaction term was created for each measure of stigma for a total of two interaction terms)

Hypothesis 3.1.2: At lower levels of household socio-economic status, the effect of perceived AIDS-related stigma on the relationship between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care is further exacerbated (that is, the effect is stronger), controlling for other relevant factors.

Initial model 4:

$$\text{yhat} = \beta_0 + \beta_1 * \text{caregiver psychosocial well-being} + \beta_2 * \text{OVC psychosocial well-being} + \beta_3 * \text{caregiver age} + \beta_4 * \text{caregiver education level} + \beta_5 * \text{caregiver marital status} + \beta_6 * \text{caregiver biological relationship to child} + \beta_7 * \text{caregiver perception of AIDS-related stigma} + \beta_8 * \text{OVC perception of AIDS-related stigma} + \beta_9 * \text{child's age} + \beta_{10} * \text{child's sex} + \beta_{11} * \text{household socio-economic status} + \beta_{12} * \text{household food security} + \beta_{13} * \text{presence of ill persons in household} + \beta_{14} * \text{household size} + \beta_{15} * \text{community support} + \beta_{16} * \text{location} + \beta_{17} * \text{intervention status} + \beta_{18} * J + \epsilon$$

where yhat = caregivers' feelings towards OVC in their care

J = two-way and three-way interaction terms between caregivers' psychosocial well-being, caregivers' perception of AIDS-related stigma and household socio-economic status (more information provided in chapter.

Examining possible bi-directional associations

As outlined in the conceptual framework guiding this study, there are several possible bi-directional associations:

1. Between caregivers' psychosocial well-being and child psychosocial well-being,
2. Between caregivers' psychosocial well-being and caregivers' attitudes towards OVC in their care
3. Between child psychosocial well-being and caregivers' attitudes towards OVC in their care.

To determine the exact nature of these relationships so that a decision on whether structural equation modeling (SEM) would be necessary could be made, first simple linear regressions and then multivariate linear regressions were conducted using one variable as an outcome and the other as the primary variable of interest and then

reversing the roles. The results of these regression analyses are presented in table 6.5 in section 6.1.5. Due to the lack of insufficient evidence of bi-directionality on majority of the relationships tested, it was determined that SEM would not be necessary and multivariate linear regression was sufficient to test all the hypotheses.

Endogeneity

After a final selection of variables and final models were obtained from the multivariate linear regression analyses, potential endogenous variables, as guided by the literature, were identified. These potential endogenous variables are:

1. Household-level factors
 - a. Household socio-economic status (categorical)
 - b. Household food security (binary)
 - c. Presence of chronically ill persons in the household (binary)
 - d. Household size (continuous)
2. Individual-level factors
 - a. OVC psychosocial well-being (continuous)
 - b. Caregivers' psychosocial well-being (continuous)

Using the literature, possible instruments were identified in the database for caregivers' psychosocial well-being. Unfortunately, no suitable instruments (a suitable instrument must be correlated with the endogenous variable, but not correlated with the outcome variable) could be identified for any of the other potential endogenous variables. The Hausman test for endogeneity was used to determine if caregivers' psychosocial well-being was truly endogenous. The results of the Hausman test are presented in chapter 6.

CHAPTER 5 – SPECIFIC FINDINGS/RESULTS – UNIVARIATE AND BIVARIATE ANALYSES

5.1 Univariate Analyses – Sample characteristics

5.1.1 Individual-level factors

Foster caregiver characteristics

The majority of caregivers in this study are grandparents who make up 42.61%, with other relatives such as aunts, uncles and older siblings making up close to 29%, while the remaining 29% are step-parents, step-siblings, in-laws, neighbors, family friends and other un-related caregivers. The mean caregiver age is 47.40 years (standard deviation = 17.79), with a median of 49 years. The majority of these caregivers, 91.68%, are female. A large proportion of caregivers, roughly 47% have no education at all, while 48.91% have only a primary school education. A small minority, 3.67%, have a post-primary school education. Only 5.82% of caregivers are not religious; the majority, 94.18% reported that religion was an important part of their lives. On the whole, the psychosocial well-being of the majority of these caregivers is poor (52.48% have poor psychosocial health as compared with 47.52% who have average to good psychosocial health). With regards to the primary independent variables of interest, about 34% of caregivers believe that people speak badly about them or their families, while 66.03% disagree with this statement. Approximately 23% also feel isolated from others in the community, while the majority, 77.37%, disagrees with this statement. 56.20% of caregivers have negative feelings towards OVC in their care, while the remaining 43.80% have positive feelings towards these children. Table 5.1 below provides more detail on these caregiver characteristics.

With regards to relevant child-related factors which will be accounted for in this study, but which are not shown in table 5.1 below, the average age of a child is 11.5 years (standard deviation = 1.85; median age = 12 years), and there are no missing values for this variable (n=836). Approximately 50% of children in the dataset were males (no missing values for this variable; n=836), and with regards to child psychosocial well-

being, 43.62% of OVC were in average to good psychosocial health, while the remaining 56.38% were in poor psychosocial health (no missing values; n=836).

Table 5.1: Characteristics of foster caregivers

Variable	Caregiver Characteristics (N=836)			
	%	Weighted %	n	Missing data n (%)
Sex	-	-	836	0 (0.00)
Female	92.70	91.68	775	-
Male	7.30	8.32	61	-
Marital status	-	-	836	0 (0.00)
Married or living with a partner	47.37	47.98	396	-
Not married or living with a partner	52.63	52.02	440	-
Religiosity	-	-	834	2 (0.24)
Religious	94.12	94.18	785	-
Not religious	5.88	5.82	49	-
Education level	-	-	835	1 (0.12)
No education	45.99	47.41	384	-
Primary education only	48.86	48.91	408	-
Post-primary education	5.15	3.67	43	-
Biological relationship to child	-	-	836	0 (0.00)
Natural grandparents	44.98	42.61	376	-
Other relatives	31.82	28.56	266	-
Non-related caregivers	23.21	28.83	194	-
People speak badly about you or your family	-	-	796	40 (4.78)
Agree	33.54	33.97	267	-
Disagree	66.46	66.03	529	-

You feel isolated from others in the community	-	-	835	1 (0.12)
Agree	23.11	22.63	193	-
Disagree	76.89	77.37	642	-
Caregivers' psychosocial well-being	-	-	836	0 (0.00)
Poor	54.19	52.48	453	-
Average to good	45.81	47.52	383	-
Feelings towards foster child	-	-	836	0 (0.00)
Negative	57.42	56.20	480	-
Positive	42.58	43.80	356	-

The variable in bold is analyzed as the main outcome in this study.

Due to insufficient variation associated with the caregiver sex and religiosity, these two variables will be dropped from bivariate and multivariate regression analyses as it will be difficult to detect differences if they exist.

5.1.2 Household and community-level factors

36.54% of foster households have at least one or more chronically ill persons in the household, in addition to having OVC, and 67.71% of households fall into the poor to middle economic index categories, as compared with 32.28% of households that fall into the rich economic index category. The majority of households, 74.20%, have severe food insecurity, and only 22.19% of households reported receiving material support in the form of food, clothing, education expenses, etc. from the community, while 77.81% received no support at all. 55.58% of foster households are located in rural areas, while the remaining 44.42% are in urban areas. Table 5.2 provides more information on these characteristics. Median household size is 5 members per household, with a mean of 5.44 (standard deviation = 2.30; not shown tables below). This variable has no missing values (n=836).

Table 5.2: Characteristics of foster households

Variable	Household characteristics (N=836)			
	%	Weighted %	n	Missing data n (%)
Location	-	-	836	0 (0.00)
Rural	45.33	55.58	379	-
Urban	54.67	44.42	457	-
Presence of ill persons in household	-	-	836	0 (0.00)
None	62.68	63.46	524	-
At least one or more	37.32	36.54	312	-
Household socio-economic status	-	-	833	3 (0.36)
Poor	40.10	42.65	334	-
Middle	20.05	25.06	167	-
Rich	39.86	32.28	332	-
Food security	-	-	836	0 (0.00)
Secure	8.01	7.33	67	-
Mild food insecurity	2.03	2.10	17	-
Moderate food insecurity	16.15	16.36	135	-
Severe food insecurity	73.80	74.20	617	-
Community support	-	-	836	0 (0.00)
Yes	22.97	22.19	192	-
No	77.03	77.81	644	-

With regards to household food security, as an overwhelming majority of households are experiencing severe household food insecurity, this variable was dichotomized such that 1 = households experiencing severe household food insecurity (includes “severe food insecurity” category), and 0 = households not experiencing severe food insecurity

(includes the other 3 categories). This was done so as to avoid problems with small cell sizes for the other categories in subsequent analyses.

5.2 Bivariate Associations

Preliminary analyses were conducted to determine bivariate associations between outcome variables, both of which are continuous variables, and independent variables. The relationship between continuous predictors and the two outcome variables, caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care, were examined using linear regression to obtain unadjusted associations. ANOVA F-tests were used to examine the associations between the discrete/categorical predictors and the outcome variables. Tables 5.3 and 5.4 below provide information on whether the primary independent variables of interest were independently associated with the outcomes, as well as which other variables were independently associated with the outcomes (unadjusted associations).

Results from table 5.3 show that, at the 5% significance level, OVC psychosocial well-being was independently associated with caregivers' psychosocial well-being ($p=0.036$) as well as with caregivers' feelings towards OVC in their care ($p=0.000$). The difference in average caregivers' psychosocial well-being score associated with a one unit increase in OVC psychosocial well-being score was 0.09832. Since higher scores for both OVC psychosocial well-being and caregivers' psychosocial well-being represent improved psychosocial health, this result suggests that improved OVC psychosocial well-being is associated with improved caregivers' psychosocial well-being. This preliminary finding supports the first hypothesis that poor OVC psychosocial well-being is associated with poor caregivers' psychosocial well-being, however further analysis is required before any conclusions can be drawn.

According to the second research hypothesis, caregivers' in poor psychosocial health are more likely to have negative feelings towards OVC in their care, as compared with caregivers in good psychosocial health, controlling for other relevant factors. However,

as can be seen from the bivariate results in table 5.3, caregivers' psychosocial well-being was not independently associated with the outcome, caregivers' feelings towards OVC in their care. On the other hand, the results show a one unit increase in OVC psychosocial well-being score was associated with an average increase of 0.0788 in the score for caregivers' feelings towards OVC in their care. Again, since higher scores for both OVC psychosocial well-being and caregivers' feelings towards OVC in their care represent improved psychosocial health and more positive feelings, this result suggested that improved OVC psychosocial well-being was independently associated with more positive caregiver feelings towards OVC. Thus from these initial results, it appears that it is rather OVC psychosocial well-being, and not caregivers' psychosocial well-being as hypothesized, that is associated with caregivers' feelings towards OVC in their care.

Table 5.3 also shows that caregivers' feelings towards OVC in their care was not independently associated with caregivers' psychosocial well-being ($p=0.106$). Caregivers' age was independently associated with caregivers' psychosocial well-being ($p=0.005$), but not with caregivers' feelings towards OVC in their care ($p=0.608$). A one year increase in a caregiver's age was associated with an average decrease of 0.0270 in caregivers' psychosocial well-being score, thus suggesting that older caregivers were more likely to suffer from poor psychosocial health as compared with younger caregivers. A child's age and a household's size were both not independently associated with either caregivers' psychosocial well-being or caregivers' feelings towards OVC in their care.

From table 5.4, it can be seen that several other factors were independently associated with caregivers' psychosocial well-being. At the 5% significance level, community support was independently associated with caregivers' psychosocial well-being ($p=0.0034$), and at the 10% significance level, was independently associated with caregivers' feelings towards OVC in their care ($p=0.0599$). With regards to caregivers' psychosocial well-being, the direction of the association implied that caregivers who received community support were more likely to suffer from poor psychosocial health (mean = 13.3177; SD = 3.4228) as compared with those who did not receive community

support (mean = 14.2221; SD = 3.8306). With regards to caregivers' feelings towards OVC in their care, the direction of the association shows the opposite effect. That is, caregivers who received community support were more likely to have positive feelings towards OVC in their care (mean = 10.1927; SD = 1.5584) compared with caregivers who did not receive community support (mean=9.9037; SD = 1.9472). However, this was a weak association, and required further investigation in the form multivariate analyses, where other factors were accounted for in the models presented in chapter 6.

Household socioeconomic status was independently associated with caregivers' psychosocial well-being ($p=0.0005$), but not associated with caregivers' feelings towards OVC in their care ($p=0.2175$). With regards to caregivers' psychosocial well-being, the results showed that caregivers' in richer households were more likely to have better psychosocial well-being as compared with caregivers in poorer households. Caregivers living in households experiencing severe food insecurity were also more likely to suffer from poor psychosocial health ($p=0.0000$) as compared with those who were not living in households suffering from food insecurity [mean=13.2885 (SD=3.5745) vs. mean=16.0594 (3.5077)]. Household food security was also weakly associated with caregivers' feelings towards OVC in their care ($p=0.0802$), as caregivers in households experiencing severe food insecurity were more likely to have more negative feelings towards OVC in their care.

Caregivers with at least one or more chronically ill individual in their households were more likely to suffer from poor psychosocial health ($p=0.0001$) as compared with those with no chronically ill members [mean=13.3621 (SD=3.4706) vs. mean=14.4027 (SD=3.8708)]. With regards to caregivers' feelings towards OVC in their care, there was no significant difference in mean score between those caregivers who had at least one or more chronically ill household member and those who did not ($p=0.7987$).

While location was only weakly associated with caregivers' psychosocial well-being ($p=0.0773$), there was a highly significant difference in mean caregivers' feelings towards OVC score between caregivers living in rural areas (mean=9.5989; SD = 1.7825)

compared with caregivers living in urban areas (mean = 10.2779; SD = 1.8835). That is, caregivers living in rural areas were significantly more likely to have more negative feelings towards OVC in their care as compared with caregivers living in urban areas. Caregivers' education level was not independently associated with either caregivers' psychosocial well-being ($p=0.1556$) or caregivers' feelings towards OVC in their care ($p=0.2190$).

There was a significant difference in mean caregivers' psychosocial well-being score amongst grandparents, other relatives and non-related caregivers ($p=0.0000$). That is, the type of biological relationship between a caregiver and a child was independently associated with caregivers' psychosocial well-being. The direction of the association suggested that grandparents were more likely to have poorer psychosocial well-being in comparison with other related caregivers such as aunts/uncles/older siblings and non-related caregivers such as in-laws, stepparents, step-siblings and neighbors. However, with regards to caregivers' feelings towards OVC in their care, there was no significant relationship.

There was highly significant difference in mean caregivers' psychosocial well-being score between caregivers who were married or living with a partner and caregivers who were single ($p=0.0000$). The direction of the association implied that caregivers who were single were more likely to have poor psychosocial health (mean = 13.4046; SD = 3.6523) as compared with caregivers who were married or living with a partner (mean = 14.6920; SD = 3.7627). On the other hand, although this was a weak association ($p=0.0629$), caregivers who were single were more likely to have more positive feelings towards OVC in their as compared to their married counterparts [mean=10.0841 (SD = 1.7921) vs. mean=9.8434 (SD=1.9437)].

A child's sex was not independently associated with a caregiver's psychosocial well-being ($p=0.2318$). However, it was independently associated with a caregiver's feelings towards that child ($p=0.043$). The direction of the association implied that caregivers had

more positive feelings towards female OVC as compared with male OVC [mean=10.1005 (SD = 1.7546) vs. mean=9.8397 (SD = 1.9687)].

At the 5% significance level caregivers' perception of stigma (both measures) was independently associated with both caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care. With regards to caregivers' psychosocial well-being, the results suggested that caregivers who feel isolated from their communities and who believe that people gossip about them or their families were more likely to suffer from poor psychosocial well-being as compared with those caregivers who did not feel isolated from their communities or who did not believe that their neighbors gossiped about them. A child's perception of AIDS-related stigma was not independently associated with caregivers' psychosocial well-being, and was only weakly associated with caregivers' feelings towards that child ($p=0.0733$). The direction of the association suggested that caregivers were more likely to have positive feelings towards OVC who reported never playing alone because no one else wanted to play with them as compared with OVC who sometimes or frequently played alone.

Table 5.3: Bivariate associations between continuous independent variables and outcomes (caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care)

Variable	Caregivers' psychosocial well-being		Caregivers' feeling towards OVC in their care	
	Coefficient (*SE)	p-value	Coefficient (*SE)	p-value
OVC psychosocial well-being	0.09832 (0.0468)	0.036**	0.0788 (0.0182)	0.000**
Caregivers' psychosocial well-being			0.0318 (0.0198)	0.109
Caregivers' feelings towards OVC in their care	0.1376 (0.0850)	0.106		
Caregivers' age	-0.0270 (0.0096)	0.005**	0.0022 (0.0043)	0.608
OVC age	-0.0191 (0.0920)	0.835	0.0216 (0.0405)	0.595
Household size	0.0807 (0.0824)	0.328	0.0150 (0.0329)	0.649

*Linearized standard errors
**p<0.05

Table 5.4: Bivariate associations between discrete independent variables and outcome variables (caregivers' psychosocial well-being and caregivers feelings towards OVC in their care)

Variable	Mean (SD)	Test statistic	p-value	Mean (SD)	Test statistic	p-value
Community support		F(1, 834) = 8.64	0.0034**		F(1, 834) = 3.55	0.0599*
Yes	13.3177 (3.4228)			10.1927 (1.5584)		
No	14.2221 (3.8306)			9.9037 (1.9472)		
Household socio-economic status		F(2, 830) = 7.58	0.0005**		F(2, 830) = 1.53	0.2175
Poor	13.4731 (3.5171)			9.8892 (1.8215)		
Middle	13.9880 (3.9101)			10.1916 (1.8463)		
Rich	14.5904 (3.7819)			9.9398 (1.9283)		
Household food security		F(1, 834) = 98.07	0.0000**		F(1, 834) = 3.07	0.0802*
Severe food insecurity	13.2885 (3.5745)			9.9026 (1.9374)		
Not experiencing severe food insecurity	16.0594 (3.5077)			10.1598 (1.6471)		
Presence of ill persons in household		F(1, 834) = 15.25	0.0001**		F(1, 834) = 0.07	0.7987
At least one or more	13.3621 (3.4706)			9.9487 (1.8628)		
None	14.4027 (3.8708)			9.9828 (1.8730)		
Location		F(1, 834) = 3.13	0.0773*		F(1, 834)=28.26	0.0000**
Urban	13.8053 (3.7492)			10.2779 (1.8835)		
Rural	14.2665 (3.7586)			9.5989 (1.7825)		
Caregivers' education level		F(2, 832) = 1.86	0.1556		F(2, 832) = 1.52	0.2190
No education	13.7708 (3.5238)			9.8568 (1.8389)		
Some primary	14.1691 (3.9454)			10.0735 (1.8874)		
Post-primary education	14.6977 (3.9312)			10.1395 (1.7124)		
Biological relationship between caregiver and child		F(2, 833) = 12.63	0.0000**		F(2, 833) = 0.14	0.8685
Grandparents	13.3910 (3.5408)			10.0080 (1.8540)		
Other relatives	14.8835 (3.6047)			9.9361 (1.7654)		
Non-related caregivers	14.0309 (4.1362)			9.9433 (2.0338)		
Caregivers' marital status		F(1, 834) = 25.16	0.0000**		F(1, 834) = 3.47	0.0629*

Married or living with a partner	14.6920 (3.7627)		9.8434 (1.9437)	
Single	13.4046 (3.6523)		10.0841 (1.7921)	
Child sex		F(1, 834) = 1.43		F(1, 834) = 4.09
Female	13.8589 (3.6101)	0.2318	10.1005 (1.7546)	0.0435**
Male	14.1699 (3.8989)		9.8397 (1.9687)	
You feel isolated from others in your community (caregiver)		F(1, 833) = 21.29		F(1, 833) = 7.58
Agree	12.9430 (3.4569)	0.0000**	9.6477 (2.2127)	0.0060**
Disagree	14.3474 (3.7797)			
People speak badly about you or your family (caregiver)		F(1, 794) = 30.81		F(1, 794) = 10.23
Agree	13.0787 (3.5937)	0.0000**	9.6704 (2.0874)	0.0014**
Disagree	14.6049 (3.6970)		10.1115 (1.6969)	
How often do you play alone because no one wants to play with you? (child)		F(2, 832) = 0.11		F(2, 832) = 2.62
Never	13.9817 (3.8197)	0.8984	10.0678 (1.9053)	0.0733*
Sometimes	14.0218 (3.6436)		9.8254 (1.6872)	
Frequently	14.2167 (3.6735)		9.600 (2.1169)	

*p<0.10; **p<0.05

To summarize the above results, the following variables were independently associated with poor caregivers' psychosocial well-being (that is, lower caregivers' psychosocial well-being score):

At the 5% significance level:

1. Poor OVC psychosocial well-being (provides preliminary support for first research hypothesis)
2. Older caregivers
3. Receiving community support
4. Poorer household socio-economic status
5. Severe household food insecurity
6. Presence of at least one or more ill persons in the household
7. Being a grandparent caregiver as opposed to other relative or other non-related caregivers such as in-laws, step-family members and neighbors
8. Caregiver not being married or living with a partner
9. Caregiver perceiving him/herself to be stigmatized (both measures of stigma)

At the 10% significance level:

1. Living in an urban area

The following variables were not independently associated with caregivers' psychosocial well-being:

1. Caregivers' feelings towards OVC in their care
2. OVC age
3. Household size
4. Caregivers' education level
5. Child's sex
6. OVC perception of AIDS-related stigma

The following variables were independently associated with negative caregivers' feelings towards OVC in their care (that is, lower caregivers' feelings towards OVC in their care score):

At the 5% significance level:

1. Poor OVC psychosocial well-being
2. Living in a rural area
3. Female OVC
4. Caregiver perceiving him/herself to be stigmatized (both measures of stigma)

At the 10% significance level:

1. Not receiving community support
2. Severe household food insecurity
3. Caregiver being married or living with a partner
4. OVC perceiving themselves to be stigmatized

The following variables were not independently associated with caregivers' feelings towards OVC in their care:

1. Caregivers' psychosocial well-being (contradicts second research hypothesis)
2. Caregivers' age
3. OVC age
4. Household size
5. Household socio-economic status
6. Presence of ill persons in the household
7. Caregivers' education level
8. Type of biological relationship between caregiver and child

Since caregivers' psychosocial well-being was not associated with caregivers' feelings towards OVC in their care and the second research hypothesis is that poor caregivers' psychosocial well-being is associated with negative caregivers' feelings towards OVC in their care, stratified bivariate analyses were also conducted to determine if this relationship was significant amongst certain populations. These analyses were conducted for the primary independent variables of

interest, household socio-economic status, household food security, caregivers' perception of stigma, and also for caregivers' biological relationship to the child, caregivers' marital status and household location. Significant results were obtained only for the following variables – household socioeconomic status, household food security, type of biological relationship between caregiver and child, and location. The results for the significant findings have been tabulated in table 5.5 below.

The results show that amongst middle income households, there was a significant association between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care ($p=0.0001$). However, this association was not significant for either poor or rich households so it is possible that the observed significant association was a random effect. This association was further investigated through the creation of an interaction term during multivariate regression analyses. Amongst households not experiencing severe household food security, caregivers' psychosocial well-being was weakly associated with the outcome ($p=0.064$), thus suggesting that caregivers' psychosocial well-being may be a more significant predictor of caregivers' feelings towards OVC in their care amongst these households in comparison with households experiencing severe household food insecurity. Caregivers' psychosocial well-being was a significant predictor of caregivers' feelings towards OVC in their care amongst households located in rural areas ($p=0.003$) in comparison with households located in urban areas. That is, caregivers' psychosocial well-being appeared to have a stronger influence on caregivers' feelings towards OVC in their care amongst rural households than it did amongst urban households. Amongst non-related caregivers such as in-laws, stepparents and neighbors, caregivers' psychosocial well-being was independently associated with caregivers' feelings towards OVC in their care ($p=0.003$). However this association was not significant amongst grandparent caregivers and aunt/uncle caregivers. During multivariate regression analyses, these associations were further tested through the creation of appropriate interaction terms and the results are reported in chapter 6.

With regards to the third and fourth research hypotheses, these were tested during multivariate regression analyses, the results of which have also been provided in chapter 6.

Table 5.5: Associations between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care (outcome) by household socio-economic status, household food security, type of biological relationship between caregiver and child, and household location

Caregivers' feelings towards OVC in their care					
Household socio-economic status					
Variable	Poor households	Middle income households	Rich households		
	Coefficient (~SE)	Coefficient (~SE)	Coefficient (~SE)	p-value	p-value
Caregivers' psychosocial well-being	-0.0030 (0.0338)	0.1293 (0.0380)	-0.0147 (0.0308)	0.001**	0.633
Household food security					
Variable	Households experiencing severe food insecurity	Households not experiencing severe food insecurity			
	Coefficient (~SE)	Coefficient (~SE)	p-value	p-value	
Caregivers' psychosocial well-being	0.0122 (0.0251)	0.0721 (0.0387)	0.626	0.064*	
Location					
Variable	Rural area	Urban area			
	Coefficient (~SE)	Coefficient (~SE)	p-value	p-value	
Caregivers' psychosocial well-being	0.0858 (0.0287)	-0.0197 (0.0257)	0.003**	0.444	
Type of biological relationship between caregiver and child					
Variable	Grandparents	Other relatives	Other non-related caregivers		
	Coefficient (~SE)	Coefficient (~SE)	Coefficient (~SE)	p-value	p-value
Caregivers' psychosocial well-being	-0.0395 (0.0329)	0.0124 (0.0318)	0.1164 (0.0391)	0.231	0.003**

Notes

~Linearized standard errors

*p<0.10; **p<0.05

CHAPTER 6 – SPECIFIC FINDINGS/RESULTS – MULTIVARIATE ANALYSES

6.1 Linear regression analyses

As previously described in chapter 4, a correlation matrix between the dependent and independent variables in the analyses was first run to determine the size of the correlation coefficients between these variables. The results of the correlation matrix have been tabulated in table 2 in Appendix C. Results from the correlation matrix indicated that none of the correlation coefficients between the variables in the analyses were above tolerable levels (that is, above 0.50), which would have suggested a possible collinearity issue.

Multivariate linear regression analyses were then conducted to further investigate the relationships between the outcomes and the independent variables of interest, while adjusting for other relevant factors. As previously outlined in chapter 4, it was important to control for intervention status as some caregivers and OVC were enrolled in programs aimed at improving their quality of life, while other caregivers and OVC were not yet enrolled in such programs. Model building was carried out as described in section 4.7.2.

6.1.1 Testing Hypothesis 1.1

To address the first research hypothesis that poor OVC psychosocial well-being (primary independent variable of interest) is negatively associated with poor caregivers' psychosocial well-being (outcome), caregivers' psychosocial well-being was first regressed on OVC psychosocial well-being, while adjusting for intervention status (model 1 in table 6.1). Then the initial model 1 described in section 4.7.2, which controls for other factors, such as other individual, household and community-level factors, as well as intervention status, was also run (results shown as model 2 in table 6.1). Also for this model, OVC age and sex were not included as not only were these variables not significant in the bivariate analyses, but there is also very little evidence in the literature linking these two variables to caregivers' psychosocial well-being. This was done so as

to avoid having too many irrelevant variables in the model, which would decrease the likelihood of obtaining statistically significant results where appropriate.

Results related to hypothesis: Model 1 in table 6.1 shows that adjusted for intervention status only, OVC psychosocial well-being was significantly associated with caregivers' psychosocial well-being ($p=0.049$). A 1-unit increase in OVC psychosocial well-being was associated with an average increase of 0.0879 units in caregivers' psychosocial well-being score, adjusting for intervention status, thus suggesting that improved OVC psychosocial well-being was associated with improved caregivers' psychosocial well-being, controlling for intervention status. This result was similar to results seen in the bivariate analyses. However, when adjusted for factors such as caregivers' socio-demographic characteristics, type of biological relationship between caregiver and child, caregivers' and OVC perceptions of stigma, household-level factors and community support, the association between OVC psychosocial well-being and caregivers' psychosocial well-being was no longer significant ($p=0.287$). By examining the size of the coefficient associated with OVC psychosocial well-being, it can also be seen that when other individual, household and community-level factors were controlled for in model 2, the size of the coefficient associated with OVC psychosocial well-being decreased from 0.0879 units in model 1 to 0.0407 in model 2, which is equivalent to an approximately 53% decrease. The implications of these results are discussed further in chapter 7.

Other relevant results: Model 2 also shows other factors that are associated with caregivers' psychosocial well-being. These include caregivers' education level, caregivers' marital status, caregivers' perception of stigma (both measures), household food security, community support and household location. Adjusted for all other variables in the model, the mean difference in caregivers' psychosocial well-being score between caregivers with no education compared with caregivers with a post-primary education (reference level for analysis) was 1.6678. Note that the p-value for this association was only weakly significant at the 10% significance level ($p=0.095$). However these results do imply that caregivers with no education may have a higher

psychosocial well-being score, and therefore better psychosocial health as compared with caregivers with a post-primary education, adjusting for all variables in the model. Further research is required to verify these results.

Being married was a significant predictor of improved caregivers' psychosocial well-being, adjusted for other variables in the model ($p=0.006$), while being single was associated with diminished caregivers' psychosocial well-being. From model 2 in table 6.1, it can be seen that the mean difference in caregivers' psychosocial well-being score between caregivers who were married or living with a partner and caregivers who were single was 0.8420. These results show that being married resulted in an average increase of 0.8420 units in caregivers' psychosocial well-being score, and therefore improved caregivers' psychosocial well-being. Caregivers' who perceive themselves to be stigmatized were also more likely to suffer from poor psychosocial health – both measures of perceived stigma (feelings of isolation and perceived gossip) were significantly associated with the outcome ($p=0.014$ and 0.000 respectively). The results show that, adjusting for all other variables in the model, caregivers feeling isolated from others in their communities (as compared with those who did not feel isolated) was associated with an average decrease of 0.9964 units in caregivers' psychosocial well-being score, thus implying poor psychosocial health. Caregivers believing that people spoke badly about them (as compared with those who did not believe this) was also associated with an average decrease of 1.1819 units in caregivers' psychosocial well-being score, adjusting for all other variables in the model.

Adjusting for all other variables in the model, living in a household experiencing severe food insecurity, as compared with living in a household not experiencing severe food insecurity, was associated with poor caregivers' psychosocial well-being ($p=0.000$). Living in a household that is experiencing severe food insecurity was associated with an average decrease of 2.2185 units in caregivers' psychosocial well-being score, adjusting for all other variables in the model. Receiving community support was also associated with an average decrease of 0.7251 units in caregivers' psychosocial well-being score, adjusting for all other variables in the model. Living in a rural area was associated with

improved caregivers' psychosocial well-being, as the results show that living in a rural area, compared to living in an urban area, was associated with an average increase of 1.0004 units in caregivers' psychosocial well-being score, adjusting for all other variables in the model.

The results below also show that caregivers' in the Allamano intervention group were more likely to have improved psychosocial well-being, as compared with caregivers in the TSA intervention group (reference level for analysis), adjusting for all other variables in the model.

Summary of relevant results: After adjusting for other relevant factors and amongst variables significant only at the 5% level, the following were found to be the strongest predictors of caregivers' psychosocial well-being (that is, they resulted in the greatest amount of change in caregivers' psychosocial well score):

1. Household food security - change of 2.2185 units
2. Caregivers' perception of stigma ("People speak badly about you or your family") – change of 1.1819 units
3. Location (rural vs. urban) – change of 1.0004 units
4. Caregivers' perception of stigma ("You feel isolated from others in the community") – change of 0.9964 units
5. Caregivers' marital status – change of 0.8420 units
6. Community support – change of 0.7251 units

Adjusting for all other variables in the model, the following variables were found not to be significant (neither at the 5% significance level, nor at the 10% significance level) predictors of caregivers' psychosocial well-being:

1. OVC psychosocial well-being (contradicts Hypothesis 1.1)
2. Caregivers' age
3. Type of biological relationship between caregiver and child

4. OVC perception of AIDS-related stigma
5. Caregivers' feelings towards OVC in their care
6. Household socio-economic status
7. Presence of chronically ill household member
8. Household size

Table 6.1: Association between caregivers' psychosocial well-being (outcome), OVC psychosocial well-being, and other selected characteristics - results from linear regression analyses

Variable	Model 1		Model 2	
	Coefficient (~SE)	p-value	Coefficient (~SE)	p-value
OVC psychosocial well-being	0.0879 (0.0446)	0.049**	0.0407 (0.0382)	0.287
Caregivers' age			-0.0175 (0.0140)	0.211
Caregiver has no education			1.6678 (0.9974)	0.095*
Caregiver has some primary education			1.0346 (0.9622)	0.283
Caregiver married/living with partner			0.8420 (0.3069)	0.006**
Other relatives			0.6993 (0.4688)	0.136
Other non-related caregivers			0.2513 (0.6202)	0.685
Caregiver feels isolated			-0.9964 (0.4033)	0.014**
Caregiver believes people speak badly about them			-1.1819 (0.3255)	0.000**
OVC sometimes play alone			-0.0396 (0.3087)	0.898
OVC frequently play alone			0.2331 (0.5006)	0.642
Caregivers' feelings towards OVC in their care scale			0.0682 (0.0755)	0.367
Caregiver lives in poor household			-0.6246 (0.3563)	0.080
Caregiver lives in middle income household			-0.1384 (0.4156)	0.739
Caregiver lives in household with severe food insecurity			-2.2185 (0.3318)	0.000**
Caregiver lives in household with 1 or more ill member			-0.1388 (0.3030)	0.647
Household size			-0.0251 (0.0644)	0.697
Caregiver lives in household receiving community support			-0.7251 (0.3648)	0.047**
Caregiver lives in household located in rural area			1.0004 (0.4503)	0.027**
Constant	11.9133(1.0272)	0.000**	13.0314 (2.0313)	0.000**
TSA control group	1.4377 (0.5274)	0.007**	0.7552 (0.4967)	0.129
Allamano intervention group	1.4209 (0.6793)	0.037**	2.1901 (0.6466)	0.001**
Allamano control group			0.6649 (0.4557)	0.145

Notes

~Linearized standard errors

*p<0.10; **p<0.05

6.1.2 Testing Hypothesis 2.1

To test the second research hypothesis that caregivers in poor psychosocial health are more likely to have negative attitudes towards OVC in their care as compared with caregivers in good psychosocial health, controlling for other relevant factors, the outcome, caregivers' feelings towards OVC in their care, was first regressed only on the primary independent variable of interest, caregivers' psychosocial well-being, while controlling for intervention status. The results of this simple linear model are presented as model 1 in table 6.2. Then a second model was run but this time controlling for other individual-level factors, household-level and community-level factors, as well as intervention status, as described in section 4.7.2. These results are presented as model 2 in table 6.2.

Results related to hypothesis: From model 1 in table 6.2, it can be seen that when only intervention status was controlled for, caregivers' psychosocial well-being was significantly associated with caregivers' feelings towards OVC in their care at the 5% significance level ($p=0.047$). That is, a 1-unit increase in caregivers' psychosocial well-being score resulted in an average increase of 0.0362 units in caregivers' feelings towards OVC in their care score, controlling for intervention status. Since higher scores are associated with improved caregivers' psychosocial well-being and more positive caregivers' attitudes towards OVC in their care and vice versa, this preliminary result provided support for the second research hypothesis, and contradicted the results from the bivariate analyses where no significant association was found. However, as can be seen from model 2 in table 6.2, when socio-economic variables as well as intervention status were controlled for, caregivers' psychosocial well-being was no longer significantly associated with caregivers' feelings towards OVC in their care ($p=0.347$). By comparing the sizes of the coefficients associated with caregivers' psychosocial well-being in models 1 and 2 in the table, it can also be seen that when individual, household, and

community-level factors were controlled for, the size of the coefficient decreased by more than 10% of its value as compared to when those factors were not controlled for in the model (that is, there was a drop from 0.0362 to 0.0182). The implications of these results are discussed further in chapter 7.

Other relevant results: On the other hand, several other variables were associated with the outcome as can be seen from the table. OVC psychosocial well-being, for example, was significantly associated with the outcome ($p=0.009$). Adjusting for all other variables in the model, a one unit increase in OVC psychosocial well-being score was associated with an average increase of 0.0500 units in caregivers' feelings towards OVC in their care score, thus implying that improved OVC psychosocial well-being was associated with positive caregivers' feelings towards OVC in their care. Caregivers believing that people spoke badly about them or their families, in comparison with those who did not believe that people gossiped about them, was associated with an average decrease of 0.4207 units in caregivers' feelings towards OVC, adjusting for all other variables in the model, thus implying an association with negative attitudes towards OVC. This association was significant at the 5% significance level ($p=0.025$). The other stigma measure, "You feel isolated from others in the community", although significant at the bivariate stage, was not found to be significantly associated with the outcome, adjusting for other relevant factors.

OVC perception of stigma was weakly associated with caregivers' feelings towards OVC in their care ($p=0.081$). The results suggested that OVC who frequently play alone because no one else wants to play with them, compared with OVC who never play alone because no one else wants to play with them (reference level for analysis) were more likely to have caregivers with negative feelings towards them (average decrease of 0.0602 units in caregivers' feelings towards OVC score), adjusting for all other variables in the model. Although household socio-economic status was not independently associated with caregivers' feelings towards OVC in their care at the bivariate stage, the multivariate regression results showed that caregivers living in middle income households, as compared with those living in rich households (reference level), were

more likely to have positive feelings towards OVC in their care (average increase of 0.3907 units in caregivers' feelings towards OVC score; $p=0.048$), adjusting for all other variables in the model. However, since none of the other categories were associated with the outcome (lack of a clear trend), it is possible that this is a random association that may not have any real-life significance.

Results in table 6.2 show that caregivers living in a household with at least one or more ill member were more likely to have positive feelings towards OVC in their care, as compared with those who do not have an ill member present in the household ($p=0.019$). With regards to intervention status, caregivers in the Allamano intervention and control groups, adjusting for all other variables in the model, were also more likely to have positive attitudes towards OVC in their care.

Summary of relevant results: After adjusting for other relevant factors and amongst variables significant at the 5% significance level, the following were found to be the strongest predictors of caregivers' feelings towards OVC in their care (that is, they resulted in the greatest amount of change in caregivers' feelings towards OVC in their care score):

1. Caregivers' perception of stigma ("People speak badly about you or your family") – change of 0.4207 units
2. Household socio-economic status (middle income households) – change of 0.3907 units
3. Presence of chronically ill household members – change of 0.3541 units
4. OVC psychosocial well-being – change of 0.0500 units

After adjusting for other relevant factors, the following are a list of variables that were not associated with caregivers' feelings towards OVC in their care:

1. Caregivers' psychosocial well-being (contradicts Hypothesis 2.1)
2. Caregivers' age
3. Caregivers' education level

4. Caregivers' feelings of isolation
5. Type of biological relationship between caregiver and child
6. OVC age
7. OVC sex
8. Household food security
9. Household size
10. Community support
11. Location

Table 6.2: Association between caregivers' feelings towards OVC in their care (outcome), caregivers' psychosocial well-being and other selected characteristics- results from preliminary linear regression analyses

Variable	Model 1		Model 2	
	Coefficient (~SE)	p-value	Coefficient (~SE)	p-value
Caregivers' psychosocial well-being	0.0362 (0.0182)	0.047**	0.0182 (0.0193)	0.347
OVC psychosocial well-being			0.0500 (0.0190)	0.009**
Caregivers' age			0.0007 (0.0071)	0.921
Caregiver has no education			-0.0332 (0.4153)	0.936
Caregiver has some primary education			0.2983 (0.4048)	0.461
Caregiver married/living with partner			-0.2494 (0.1550)	0.108
Other relatives			-0.0322 (0.2220)	0.885
Other non-related caregivers			0.0165 (0.3130)	0.958
Caregiver feels isolated			-0.2027 (0.2069)	0.328
Caregiver believes people speak badly about them			-0.4207 (0.1871)	0.025**
OVC sometimes play alone			-0.0130 (0.1498)	0.931
OVC frequently play alone			-0.0602 (0.3447)	0.081*
OVC age			0.0322 (0.0392)	0.412
Female OVC			0.2143 (0.1444)	0.138
Caregiver lives in poor household			0.0668 (0.1936)	0.730
Caregiver lives in middle income household			0.3907 (0.1977)	0.048**
Caregiver lives in household with severe food insecurity			-0.2319 (0.1672)	0.166
Caregiver lives in household with 1 or more ill member			0.3541 (0.1511)	0.019**

Household size			0.0244 (0.0295)	0.409
Caregiver lives in household receiving community support			0.1635 (0.1658)	0.325
Caregiver lives in household located in rural area			0.2956 (0.2202)	0.180
Constant	8.8150 (0.2871)	0.000**	7.1725 (1.0259)	0.000**
TSA control group	-0.1369 (0.2833)	0.629	-0.2334 (0.2802)	0.405
Allamano intervention group	0.9863 (0.2993)	0.001**	0.7309 (0.3398)	0.032**
Allamano control group	1.1026 (0.1483)	0.000**	1.1846 (0.2125)	0.000**
<u>Notes</u>				
~Linearized standard errors				
*p<0.10; **p<0.05				

Assessing significance of relevant interaction terms: As suggested by the results from the stratified bivariate analyses in table 5.5, the following interaction terms were then included one at a time in the above model, while simultaneously checking for multi-collinearity and monitoring the size and significance of the coefficient for the primary variable of interest (caregivers' psychosocial well-being): interaction between household socio-economic status and caregivers' psychosocial well-being, interaction between household food security and caregivers' psychosocial well-being, interaction between the type of biological relationship between a caregiver and a child and caregivers' psychosocial well-being and the interaction between location and caregivers' psychosocial well-being. However, table 6.2 above only shows results from the reduced model (model without the interaction terms), as inclusion of the interaction terms in the model resulted in variance inflation factors for those interaction terms and the main effects used to create those terms greater than 10, suggesting a serious problem of multi-collinearity.

Multi-collinearity suggests that several variables in a model are all highly related and therefore measuring the same concept/construct. It is an issue because it results in inflated standard errors, which decrease the precision of the estimates obtained from the model. Having many highly related variables in a model also decreases the likelihood of

obtaining statistically significant results. Since the only way to resolve multi-collinearity is to remove one of each pair of collinear variables from the model, and in order to have an interaction term in a model, the main effects used to create that interaction term must also be in the model, all interaction terms were subsequently dropped from the analyses, resulting in the original reduced model.

Stratified regression analyses: Thus, in order to examine these relationships, stratified regression analyses were conducted, and the sizes and p-values of the coefficients associated with caregivers' psychosocial well-being were monitored. Models stratified by household socio-economic status were not run at this stage as the influence of household socio-economic status is examined in more detail in section 6.1.4 below. All models were controlled for intervention status and individual-level, household and community-level factors as shown in model 2, table 6.2. However, table 6.3 only show the results obtained for caregivers' psychosocial well-being as these results are the only results of interest for this portion of the analyses.

As can be seen from table 6.3, there were no significant associations between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care amongst households experiencing severe food insecurity, and amongst those not experiencing severe food insecurity, controlling for other relevant factors ($p=0.733$ and $p=0.626$ respectively). Amongst rural households, there was a weakly significant association between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care. The results show that a 1-unit increase in caregivers' psychosocial well-being score was associated with an average increase of 0.0505 units in caregivers' feelings towards OVC in their care score, thus implying that improved caregivers' psychosocial well-being was associated with improved caregivers' feelings towards OVC in their care, controlling for other relevant factors. Although caution must be used when interpreting this finding since interaction terms could not be assessed for significance, the results do suggest that psychosocial well-being may be associated caregivers' attitudes towards OVC in their care amongst those caregivers living in rural areas, as compared with those living in urban areas.

With regards to the type of biological relationship between the caregiver and child, amongst grandparents and other relatives, there were no significant associations between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care. However, amongst other non-related caregivers, such as step-family members, in-laws, neighbors, etc., there was a significant association between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care ($p=0.014$). The results show that amongst these other caregivers, a 1-unit increase in caregivers' psychosocial well-being score was associated with an average increase of 0.0987 units in caregivers' feelings towards OVC in their care score, controlling for other relevant factors. This implied that improved caregivers' psychosocial well-being was associated with improved caregivers' feelings towards OVC in their care, controlling for other relevant factors. Again, although interaction terms could not be assessed and therefore caution must be used in the interpretation of this result, the finding nonetheless suggests that psychosocial well-being may be a stronger predictor of caregivers' feelings towards OVC in their care amongst non-related caregivers as compared with related caregivers. These results are further discussed in chapter 7.

Table 6.3: Assessing the association between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care (outcome), by household food security, location and type of biological relationship between caregiver and child

		Household food security					
		Model 1 (experiencing severe household food insecurity)		Model 2 (not experiencing severe household food insecurity)			
Variable		Coefficient (~SE)	p-value	Coefficient (~SE)	p-value		
Caregivers' psychosocial well-being		-0.0076 (0.0223)	0.733	0.0205 (0.0419)	0.626		
Location							
		Model 1 (Rural area)		Model 2 (Urban area)			
Variable		Coefficient (~SE)	p-value	Coefficient (~SE)	p-value		
Caregivers' psychosocial well-being		0.0505 (0.0261)	0.054*	-0.0398 (0.0279)	0.155		
Type of biological relationship between caregiver and child							
		Model 1 (Grandparents)		Model 2 (Other relatives [±])		Model 3 (Other non-related caregivers ^{±‡})	
Variable		Coefficient (~SE)	p-value	Coefficient (~SE)	p-value	Coefficient (~SE)	p-value
Caregivers' psychosocial well-being		-0.0433 (0.0300)	0.150	0.0086 (0.0305)	0.779	0.0987 (0.0397)	0.014 **
<u>Notes</u>							
~Linearized standard errors; *p<0.10; **p<0.05							
±Other relatives = aunts, uncles and older siblings							
± ±Other non-related caregivers = step-family members, in-laws, neighbors, family friends, etc.							

6.1.3 Testing Hypothesis 3.1.1

In order to test hypothesis 3.1.1 (perceived AIDS-related stigma exacerbates the relationship between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care, controlling for other relevant factors), the procedures outlined in section 4.7.2 for the preliminary linear regression analyses were followed. The following interaction terms were created and separately entered into the model, testing for multi-collinearity with each addition: interaction between caregivers' feelings of isolation and caregivers' psychosocial well-being, and interaction between caregivers' belief that people speak badly about them or their families and caregivers' psychosocial well-being. However, as was seen with previous interaction terms, the variance inflation factors for these interaction terms and the main effects were far greater than 10, again implying serious multi-collinearity. As a result the two interaction terms had to be dropped from the model.

So in order to assess the influence, if any, of perceived AIDS-related stigma on the relationship between caregivers' psychosocial well-being and the outcome, a different method had to be used. First, the outcome, caregivers' feelings towards OVC in their care, was regressed on caregivers' psychosocial well-being, controlling for intervention status and other individual-level factors, household and community-level factors. However both measures for caregivers' perception of AIDS-related stigma were not included in this model (shown as model 1 in table 6.4). The value of the coefficient and the p-value associated with caregivers' psychosocial well-being were monitored. Then a second model was run, which included all variables that were present in model 1, and also one measure of AIDS-related stigma (shown as model 2). A third model was run (shown as model 3) also containing all the variables that were present in model 1, but this time including the second measure of stigma, and excluding the first measure of stigma in model 2. Model 2 in table 6.2 was used as the last comparison model as it contains all the variables present in model 1, table 6.4 and both measures of stigma. In all instances, the sizes and p-values of the coefficients associated with the primary variable of interest, caregivers' psychosocial well-being, were noted. The results are shown below in table 6.4 below.

From model 1, table 6.4, it can be seen that when perceived AIDS-related stigma was not controlled for in the analysis, there was a slightly significant association between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care ($p=0.067$). The results show that a 1-unit increase in caregivers' psychosocial well-being score resulted in an average increase of 0.0341 units in caregivers' feelings towards OVC in their care score (that is improved caregivers' psychosocial well-being resulted in more positive feelings towards OVC in their care), controlling for other relevant factors. However, when the isolation variable (caregiver feelings of isolation from the community) was added to the model, the association between the two variables was no longer significant ($p=0.147$). Similarly, when the isolation variable was replaced with the gossip variable (caregiver believes people speak badly about him or her) the relationship between the two variables was even less significant – the p-value increased from 0.147 to 0.291. Model 2 in table 6.2 shows that when both measures of stigma was added to the model, while controlling for other relevant factors, the relationship between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care was also not significant (further increase in p-value; $p=0.347$).

Table 6. 4: Assessing the influence of perceived AIDS-related stigma on the association between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care (outcome)

Variable	Model 1 (no stigma measures)			Model 2 (isolation stigma measure)			Model 3 (gossip stigma measure)		
	Coefficient (~SE)	p-value		Coefficient (~SE)	p-value		Coefficient (~SE)	p-value	
Caregivers' psychosocial well-being	0.0341 (0.0186)	0.067*		0.0270 (0.0186)	0.147		0.0205 (0.0194)	0.291	
OVC psychosocial well-being	0.0412 (0.0192)	0.0032**		0.0384 (0.0190)	0.044**		0.0515 (0.0191)	0.007**	
Caregivers' age	0.0054 (0.0071)	0.450		0.0035 (0.0070)	0.623		0.0013 (0.0072)	0.859	
Caregiver has no education	0.1309 (0.3911)	0.738		0.1548 (0.4012)	0.700		-0.0310 (0.4072)	0.939	
Caregiver has some primary education	0.5609 (0.3744)	0.134		0.5650 (0.3863)	0.144		0.3137 (0.3959)	0.428	
Caregiver married/living with partner	-0.2121 (0.1561)	0.175		-0.1991 (0.1551)	0.200		-0.2587 (0.1548)	0.095*	
Other relatives	-0.0586 (0.2312)	0.800		-0.0753 (0.2286)	0.742		-0.0284 (0.225)	0.899	
Other non-related caregivers	-0.0988 (0.3147)	0.754		-0.0902 (0.3146)	0.774		0.0084 (0.3145)	0.979	
Caregiver feels isolated				-0.3788 (0.1829)	0.039**				
Caregiver believes people speak badly about him/her							-0.4960 (0.1658)	0.003**	
OVC sometimes play alone	0.0010 (0.1508)	0.994		0.0082 (0.1492)	0.956		-0.0142 (0.1499)	0.925	
OVC frequently play alone	-0.6037 (0.3631)	0.097*		-0.5973 (0.3677)	0.105		-0.5980 (0.3427)	0.081*	
OVC age	0.0397 (0.0391)	0.310		0.0377 (0.0386)	0.329		0.0335 (0.0392)	0.393	
Female OVC	0.2187 (0.1420)	0.124		0.2586 (0.1447)	0.074*		0.1957 (0.1408)	0.165	
Caregiver lives in poor household	0.0801 (0.1921)	0.677		0.0942 (0.1911)	0.622		0.0597 (0.1932)	0.757	
Caregiver lives in middle income household	0.3782 (0.1975)	0.056*		0.3778 (0.1966)	0.055*		0.3887 (0.1983)	0.050*	
Caregiver lives in household with severe food insecurity	-0.2482 (0.1629)	0.128		-0.2285 (0.1644)	0.165		-0.2463 (0.1649)	0.136	
Caregiver lives in household with 1 or more ill member	0.2288 (0.1500)	0.127		0.2625 (0.1500)	0.081*		0.3362 (0.1515)	0.027**	
Household size	0.0230 (0.0306)	0.453		0.0231 (0.0305)	0.449		0.0258 (0.0294)	0.381	
Caregiver lives in household receiving community support	0.1722 (0.1617)	0.287		0.1264 (0.1631)	0.439		0.1922 (0.1617)	0.235	135
Caregiver lives in household located in rural area	0.3458 (0.2175)	0.112		0.3348 (0.2177)	0.124		0.2902 (0.2180)	0.184	

Constant	6.4328 (0.9997)	0.000**	6.7580 (0.9927)	0.000**	7.0556 (1.0269)	0.000**
TSA control group	-0.0564 (0.2829)	0.842	-0.1149 (0.2827)	0.684	-0.2137 (0.2802)	0.446
Allamano intervention group	0.9346 (0.3549)	0.009**	0.9426 (0.3557)	0.008**	0.7195 (0.3327)	0.031**
Allamano control group	1.2710 (0.2172)	0.000**	1.2457 (0.2168)	0.000**	1.1870 (0.2120)	0.000**

Notes

~Linearized standard errors

*p<0.10; **p<0.05

Stratified regression analyses: In order to determine if there were any changes in the association between the two variables, caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care, stratified regression analyses (stratified by perceived AIDS-related stigma) were also conducted. The sizes and significance of the coefficients associated with caregivers' psychosocial well-being were monitored for each stratified analysis. All models were controlled for by intervention status, individual, household and community-level factors as seen in previous models. However, table 6.5 below only shows the results pertaining to caregivers' psychosocial well-being as these are the results that are pertinent for this portion of the analyses.

From the results obtained in table 6.5 below, it can be seen that regardless of the sub-population, there was no significant association between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care (all p-values >0.10).

Table 6. 5: Association between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care (outcome), stratified by perceived AIDS-related stigma

Variable	Model 1 - caregivers who feel isolated (n=193)		Model 2 - caregivers who do not feel isolated (n=642)	
	Coefficient (~SE)	p-value	Coefficient (~SE)	p-value
Caregivers' psychosocial well-being	0.0346 (0.0422)	0.414	0.0230 (0.0213)	0.281
Variable	Model 1 - caregivers who agree that others gossip about them (n=267)		Model 2 - caregivers who do not agree that others gossip about them (n=529)	
	Coefficient (~SE)	p-value	Coefficient (~SE)	p-value
Caregivers' psychosocial well-being	0.0472 (0.0387)	0.224	-0.0042 (0.0230)	0.856

Notes
~Linearized standard errors
*p<0.10; **p<0.05

6.1.4 Testing Hypothesis 3.1.2

In order to test hypothesis 3.1.2 (at lower levels of household socio-economic status, the association between perceived AIDS-related stigma and the relationship between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care is further exacerbated, controlling for other relevant factors), the following three-way interaction terms were created:

1. Interaction between caregivers living in poor households, caregivers' feelings of isolation, and caregivers' psychosocial well-being
2. Interaction between caregivers living in middle income households, caregivers' feelings of isolation, and caregivers' psychosocial well-being
3. Interaction between caregivers living in poor households, caregivers' belief that people speak badly about them, and caregivers' psychosocial well-being
4. Interaction between caregivers living in middle income households, caregivers' belief that people speak badly about them, and caregivers' psychosocial well-being

In order to test a three-way interaction term in a model, a model must also contain the 3 main effects as well as 3 two-way interaction terms. Thus a total 8 two-way interactions had to be created and included in the model:

1. Interaction between caregivers living in poor households and caregivers' feelings of isolation
2. Interaction between caregivers living in poor households and caregivers' psychosocial well-being
3. Interaction between caregivers' feelings of isolation and caregivers' psychosocial well-being
4. Interaction caregivers living in middle income households and caregivers' feelings of isolation
5. Interaction caregivers living in middle income households and caregivers' psychosocial well-being
6. Interaction between caregivers living in poor households and caregivers' belief that people speak badly about them

7. Interaction between caregivers' belief that people speak badly about them and caregivers' psychosocial well-being
8. Interaction between caregivers living in middle income households and caregivers' belief that people speak badly about them

Model 2 (estimates for model 2 have been reported in table 6.4) was used as the reduced model (model with no interaction) and the model containing all the 4 three-way interaction terms and 8 two-way interaction terms was used as the full model. Interaction terms were entered separately into the model and the VIF was noted with each addition. Unfortunately, inclusion of the two-way interaction terms resulted in high VIF values greater than 10 for the main effects as well as all of the two-way interaction terms. As a result, the two-way interaction terms had to be removed from the model. However, it is not possible to have three-way interaction terms in a model without the corresponding two-way interaction terms as it would be difficult to interpret the three-way interaction terms without them, and thus the three-way interaction terms also had to be removed from the model. Also, generally models cannot tolerate more than two interaction terms at a time, and therefore this method could not be used to test the final research hypothesis, and a different method had to be used.

Thus a stratified linear regression analyses was conducted in order to test the final hypothesis by re-running models 1, 2 and 3 in table 6.4, and model 2 in table 6.2 while stratifying by household socio-economic status (poor, middle, and rich households), instead of controlling for it. Models stratified by both perceived AIDS-related stigma and household socio-economic status could not be run due to small cell sizes (small sample sizes result in increases in standard errors). The sizes of the coefficients and p-values associated with caregivers' psychosocial well-being obtained from this stratified analysis were noted and compared with those obtained from the models previously mentioned. The results of the stratified analyses are presented in table 6.4 below. Only the coefficients and p-values associated with caregivers' psychosocial well-being are shown in the table, as these are the only results of interest in order to test hypothesis 3.1.2.

However, all models were controlled for intervention status, and other relevant factors as in models 1, 2 and 3 in table 6.4, and model 2 in table 6.2.

From the table it can be seen that amongst poor households, there was a significant association ($p=0.003$) between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care only when the gossip stigma measure is controlled for (that is, caregiver believes that people speak badly about him/her or their family). The results show that a 1-unit increase in caregivers' psychosocial well-being score was associated with an average increase of 0.0955 units in caregivers' feelings towards OVC in their care score. Amongst middle income households, when no stigma measures were controlled for in the model (model 1), a 1-unit increase in caregivers' psychosocial well-being score was significantly ($p=0.000$) associated with an average increase of 0.1185 increase in caregivers' feelings towards OVC in their care score. When the isolation stigma measure and both stigma measures were controlled for in the model, no significant results were obtained. However, when only the gossip stigma measure was controlled for in the model (model 3), a 1-unit increase in caregivers' psychosocial well-being was significantly ($p=0.010$) associated with an average increase of 0.0832 units in caregivers' feelings towards OVC in their care score. Amongst rich households, a significant association between the two variables was obtained only when the gossip stigma measure was controlled for in the model. However this association was only weakly significant ($p=0.050$). Amongst these households, a 1-unit increase in caregivers' psychosocial well-being was associated with an average increase of 0.0661 units in caregivers' feelings towards OVC in their care score.

Although the models in table 6.4 showed that there was no significant association between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care (with the exception of model 1 which showed a weak association when no stigma measures were controlled for), the models in table 6.4 showed that this association differed amongst households of varying socio-economic status. By examining p-values and sizes of the coefficients associated with caregivers' psychosocial well-being in table 6.6, it can be seen that amongst poor households, when the gossip stigma measure was

controlled for in the model (model 3), caregivers' psychosocial well-being score was most strongly associated with the outcome, caregivers' feelings towards OVC in their care score. The size of the coefficient associated with caregivers' psychosocial well-being decreased and the associated p-values increased from poor households to middle income households to rich households, thus implying that gossip may have had a stronger influence on the psychosocial well-being of caregivers living in the poorest households. However, caution must be used in interpreting the relevance of these results as the significance of relevant interaction terms could not be assessed.

Table 6.6: Assessing the influence of perceived AIDS-related stigma on the association between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care (outcome), by household socio-economic status

Poor households (n=334)							
Model 1 (no stigma measures)		Model 2 (isolation stigma measure)		Model 3 (gossip stigma measure)		Model 4 (both stigma measures)	
Variable	Coefficient (~SE)	p-value	Coefficient (~SE)	p-value	Coefficient (~SE)	p-value	p-value
Caregivers' psychosocial well-being	-0.0127 (0.0282)	0.654	-0.0167 (0.0275)	0.544	0.0955 (0.0317)	0.003**	-0.0095 (0.0331) 0.774
Middle income households (n=167)							
Model 1 (no stigma measures)		Model 2 (isolation stigma measure)		Model 3 (gossip stigma measure)		Model 4 (both stigma measures)	
Variable	Coefficient (~SE)	p-value	Coefficient (~SE)	p-value	Coefficient (~SE)	p-value	p-value
Caregivers' psychosocial well-being	0.1185 (0.0311)	0.000**	-0.0135 (0.0279)	0.629	0.0832 (0.0322)	0.010**	-0.0236 (0.0351) 0.502
Rich households (n=332)							
Model 1 (no stigma measures)		Model 2 (isolation stigma measure)		Model 3 (gossip stigma measure)		Model 4 (both stigma measures)	
Variable	Coefficient (~SE)	p-value	Coefficient (~SE)	p-value	Coefficient (~SE)	p-value	p-value
Caregivers' psychosocial well-being	-0.0077 (0.0332)	0.817	-0.0145 (0.0274)	0.597	0.0661 (0.0337)	0.050*	-0.0230 (0.0347) 0.509
<u>Notes</u>							
~Linearized standard errors							
*p<0.10; **p<0.05							

6.1.5 Examining possible bi-directional associations

As previously outlined in the literature review and conceptual framework, there are several possible bi-directional associations (association between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care, association between caregivers' psychosocial well-being and OVC psychosocial well-being, and association between OVC psychosocial well-being and caregivers' feelings towards OVC in their care) that may need to be accounted for in these analyses through the use of SEM. In order to determine if SEM was necessary, simple linear regression and multivariate linear regression analyses (that is, unadjusted and adjusted associations) were used to determine if these bi-directional associations were really significant by first using one variable as the outcome and the other variable as the primary independent variable of interest, and then reversing this and noting the significance of the coefficients associated with these variables. Table 6.7 below presents the results from these analyses.

Table 6.7: Examining possible bi-directional associations by assessing significance of coefficients associated with each variable

Outcome variable	
Caregivers' feelings towards OVC in their care	
1 ^o Independent variable of interest	Significance of coefficients
Caregivers' psychosocial well-being	Not Significant ⁺ Not Significant ⁺⁺
OVC psychosocial well-being	p=0.007 ⁺ p=0.009 ⁺⁺
Caregivers' psychosocial well-being	
1 ^o Independent variable of interest	Significance of coefficients
Caregivers' feelings towards OVC in their care	p=0.044 ⁺ Not Significant ⁺⁺
OVC psychosocial well-being	p=0.049 ⁺ Not Significant ⁺⁺
OVC psychosocial well-being	
1 ^o Independent variable of interest	Significance of coefficients
Caregivers' psychosocial well-being	p=0.059 ⁺ Not Significant ⁺⁺

Caregivers' feelings towards OVC in their care	p=0.005 [±] p=0.007 ^{±±}
<u>Notes</u>	
±Unadjusted associations; ±± Adjusted associations	
Not Significant = p>0.10	

From the table, it can be seen that when caregivers' feelings towards OVC in their care was the outcome, both the unadjusted and adjusted associations between this variable and caregivers' psychosocial well-being was not significant (that is, p-values associated with the coefficients >0.10). When the roles of the variables were reversed and caregivers' psychosocial well-being was the outcome and caregivers' feelings towards OVC in their care was the primary independent variable of interest, the unadjusted association between the two variables was significant at the 5% level (p=0.044). However, when the model was adjusted for other relevant factors (individual, household and community-level factors), the association was no longer significant (p>0.10). This suggested that when other relevant factors were controlled for, there was no significant bi-directional relationship between caregivers' feelings towards OVC in their care and caregivers' psychosocial well-being.

When caregivers' feelings towards OVC in their care was the outcome and OVC psychosocial well-being was the primary independent variable of interest, both the unadjusted and adjusted associations were significant (p=0.007 and p=0.009 respectively). When the roles of the variables were reversed, again both the unadjusted and adjusted associations were significant (p=0.005 and p=0.007 respectively). This suggested that there was a significant bi-directional relationship between caregivers' feelings towards OVC in their care and OVC psychosocial well-being.

With regards to the relationship between caregivers' psychosocial well-being and OVC psychosocial well-being, the unadjusted associations in both instances were significant. However, when the models were adjusted for other relevant variables, the associations were no longer significant. This implied that when other relevant factors were controlled for in the model, there was no significant bi-directional relationship between these two variables.

From the above results, the only significant bi-directional association obtained was that between caregivers' feelings towards OVC in their care and OVC psychosocial well-being. Since the research hypotheses for this study are mainly addressing the associations between caregivers' psychosocial well-being and OVC psychosocial well-being, and between caregivers' feelings towards OVC in their care and caregivers' psychosocial well-being, and since no significant bi-directional relationships regarding these associations were found, a decision was made not to conduct any structural equation modeling.

6.1.6 Endogeneity

As previously discussed in section 4.7.2 of chapter 4, there are a total of 6 possible known endogenous variables in this study:

1. Household-level factors
 - a. Household socio-economic status (categorical)
 - b. Household food security (binary)
 - c. Presence of chronically ill persons in the household (binary)
 - d. Household size (continuous)
2. Individual-level factors
 - a. OVC psychosocial well-being (continuous)
 - b. Caregivers' psychosocial well-being (continuous)

However, as previously outlined, suitable instruments could only be found for caregivers' psychosocial well-being. The inability to find appropriate instruments for these other suspected endogenous variables and thus test whether or not they were endogenous meant that endogeneity could not be controlled for in these analyses. As a result, there are several limitations that have been discussed in the study limitations section found in chapter 7.

The Hausman test for endogeneity was used to determine if caregivers' psychosocial well-being was truly endogenous. The following variables were found to be suitable

instruments for caregivers' psychosocial well-being: caregiver sick for 3 months in a row or longer (response options: yes/no), and caregivers' relatives who do not live in the household visit to see how the caregiver is doing (response options: strongly agree, agree, disagree, and strongly disagree). Tables 3 and 4 in appendix C provide more information on the definitions of these variables and their distributions in the dataset. These variables were chosen as possible instruments because they were not correlated with the outcome variable (caregivers' feelings towards OVC in their care), but were correlated with the suspected endogenous variable, caregivers' psychosocial well-being. The results of the Hausman test for endogeneity are shown below:

$$F(1, 793) = 0.78$$

$$p\text{-value} = 0.379$$

The null hypothesis for the Hausman test is that the variable being tested is not endogenous and since the p-value obtained was less than 0.05, the null hypothesis was accepted, and it was concluded that caregivers' psychosocial well-being was not endogenous. This result was expected because the linear regression analyses showed that there was no bi-directional association between caregivers' feelings towards OVC in their care and caregivers' psychosocial well-being, and it was this suspected bi-directional association that made caregivers' psychosocial well-being appear endogenous.

CHAPTER 7 – DISCUSSION

7.1 Discussion of results

In line with literature that reports that majority of foster parents in the context of HIV and AIDS in sub-Saharan Africa are grandparents, particularly grandmothers (Reddy et al., 2005; Atwine et al., 2004; Muula et al., 2003; Nyambedha et al., 2003; Safman, 2003), the majority of Tanzanian caregivers in this study are also grandparents, with their median age nearing 50 years. Most of them are also female, and the data shows that more than 80% of these caregivers have either no education at all or only some primary education. These results are validated by a recent United Nations report that suggests that due to gender inequalities, Tanzanian women are less likely to be educated as compared with men, and less likely to have completed higher level education as compared with men¹⁹. They are also consistent with other research in sub-Saharan Africa indicating that due to social and cultural norms, women tend to be the primary caregivers in households (Kipp et al., 2006; Kipp et al., 2007; Ssengonzi, 2007; UNAIDS, 2004). The evidence also suggests that the majority of these foster caregivers have poor psychosocial health, which is consistent with literature reporting increased stress, anxiety levels, loneliness and depression amongst those caring for children affected by HIV and AIDS in sub-Saharan Africa (Kipp et al., 2006; Kipp et al., 2007; Mann, 2002). More than a third of these caregivers are also caring for chronically ill members in the household, in addition to OVC and, as suggested by Bor et al. (1993), this may partly account for the increased stress levels amongst these caregivers. Similarly, the majority of foster OVC in this study also have poor psychosocial health, and this is corroborated by other OVC studies in Tanzania (Makame et al, 2002), Uganda (Atwine et al., 2005) and South Africa (Cluver & Gardner, 2006). Perceived stigma is also prevalent as about a third of caregivers in this study believe that their neighbors gossip about them or their families, while almost a quarter feel isolated from others in the community in which they live. An alarming 56% of caregivers also reported negative feelings towards OVC in their care.

¹⁹ <http://www.un.org/ecosocdev/geninfo/afrec/vol14no2/enrol.htm>

The majority of caregivers and their foster children in this study live in households located in rural areas, and only a third fall into the rich economic index category – the majority fall into the poor and middle economic index categories. These results are similar to those from other research on orphan households that indicate difficult financial circumstances for such households (Ainsworth & Filmer, 2002; Foster et al., 1996; UNAIDS, 2004; UNICEF, 2003). Many of these OVC households are large (median household size for those in this study is 5 members per household), and as reported by other studies elsewhere in sub-Saharan Africa (Bukusuba et al., 2007; FAO, 2003; Juma et al., 2004; UNAIDS, 2008b), household food insecurity is a serious problem. In this study, more than two-thirds of caregivers reported severe household food insecurity, and less than a quarter of these households receive any kind of community support in the form of clothing, food, education expenses or even psychosocial support.

This section of the dissertation will provide an overview of the main findings obtained from the analyses of these OVC households and their caregivers, and compare them with other studies where appropriate. Other relevant findings that also contribute to the existing literature on OVC and their caregivers will also be discussed.

Hypothesis 1.1: Association between OVC psychosocial well-being and caregivers' psychosocial well-being

One of the hypotheses of this study was that OVC in poor psychosocial health were more likely to have caregivers who also had poor psychosocial health, as compared with OVC in good psychosocial health, controlling for other relevant factors. While qualitative data from Malawi has suggested that poor OVC psychosocial well-being is associated with poor caregivers' psychosocial well-being (Mann, 2002), one of the main findings of this study is that OVC psychosocial well-being is not associated with caregivers' psychosocial well-being when socio-economic variables are controlled for in the models. In the Malawi study, the author suggested that poor OVC psychosocial well-being could possibly result in OVC becoming moody and disobedient because of lack of the appropriate attention they need to recover from their parents' deaths, and to adapt to their

new home environment. This bad behavior could then result in OVC being difficult to care for and caregivers' perceiving these children to be difficult to manage. The author hypothesized that having to deal with a difficult child on a daily basis could also negatively affect the caregiver's psychosocial well-being, and thus poor OVC psychosocial well-being was associated with poor caregivers' psychosocial well-being. However, this study was unable to corroborate these findings, and one of the reasons could be that because the Malawi study was a qualitative one, other relevant factors that may affect the association between OVC psychosocial well-being and caregivers' psychosocial well-being could not be taken into account. On the other hand, the study findings are similar to quantitative research conducted in the developed world, which found no significant association between parental psychosocial well-being and child psychosocial well-being in AIDS-affected households (Lester et al., 2006). However it is important to mention here that Lester et al.'s (2006) study was conducted amongst HIV-positive biological parents and their children, while this study focused on foster parents (non-biological parents) and their foster children. The relevance of this difference is the implication that regardless of the biological relationship between AIDS-affected children and their caregivers, there is still no association between OVC psychosocial well-being and caregivers' psychosocial well-being.

Mann (2002) also suggested that there may be a bi-directional association between the two variables. That is, the author intimated that caregivers' with poor psychosocial well-being may either treat OVC badly or pay even less attention to these children, which would further exacerbate OVC sadness and depression, and thus lead back to poor OVC psychosocial well-being, and poor OVC psychosocial well-being would further diminish caregivers' psychosocial well-being. However, this study was unable to establish a bi-directional association between OVC psychosocial well-being and caregivers' psychosocial well-being. Another major finding is that the association between OVC and caregivers' psychosocial well-being is mediated by socio-economic variables (that is, other individual-level, household-level and community-level factors), as the results showed that even though OVC psychosocial well-being was significantly associated with caregivers' psychosocial well-being when only intervention status is controlled for, once

socio-economic variables were controlled for, the association was not only no longer significant, but there was a more than 10% decrease in the resulting coefficient for OVC psychosocial well-being. This may have program implications and will be further discussed in section 7.2.

Other relevant findings: Other findings from this analysis also show that the following variables are strong predictors of poor caregivers' psychosocial well-being:

1. Living in a household experiencing severe food insecurity
2. Caregivers perceiving themselves to be stigmatized (feelings of isolation and gossip)
3. Living in an urban area
4. Being single (as opposed to being married or living with a partner)
5. Receiving community support (material support in the form of food, clothing, payment of children's school fees, etc., as well as emotional support in the form of visitation by neighbors and other community members)

There is much literature in sub-Saharan Africa that substantiate the association between poor caregivers' psychosocial well-being and household food insecurity (Juma et al., 2004), as well as the association between poor caregivers' psychosocial well-being and AIDS-related stigma (Ansell & van Berk, 2004; Nyblade et al., 2003; WHO, 2002). However, not much is known about the associations between poor caregivers' psychosocial well-being and living in an urban area, single motherhood, and receiving community support. With regards to the association between poor caregivers' psychosocial well-being and living in an urban area, it is possible that caregivers living in urban areas may be more isolated from their neighbors due to the lack of community in urban areas, unlike in rural areas where neighbors tend to have closer ties to each other. This lack of social support may contribute to poor caregivers' psychosocial well-being.

There are several possible reasons why single caregivers are more likely to have poor psychosocial health as compared with their married counterparts or those living with their partners. First of all, being single implies an inability to share the burden of caring for

OVC with another individual, which results in increased stress and worry. Secondly, single caregivers are likely to also be heads of their own households and literature suggests that not only do female-headed households tend to have a greater number of orphans than male-headed households (Horizons, 2004; UNICEF, 2003), but they also have higher levels of food insecurity (UNAIDS, 2006). These issues may also contribute to increased stress and anxiety levels for caregivers.

With regards to the association between poor caregivers' psychosocial well-being and receiving community support, this finding is surprising as it contradicts evidence from the literature that suggest the exact opposite. Currently, research indicates that poor caregivers' psychosocial well-being is associated with not receiving community support, while improved caregivers' psychosocial well-being is associated with receiving community support (Adepoju & Mbugua, 1997; Howard et al., 2006; Oburu & Palmerus, 2005; Ross & Aday, 2006). It is possible that this contradictory result was obtained in this study because the data was obtained from evaluation data in which study participants were enrolled or about to be enrolled in interventions targeting struggling AIDS-affected households. It may be that those households that received community support in this study were those that were the worst off in terms of household food security, socio-economic status, etc., and thus caregivers in these households may have had very poor psychosocial well-being, as compared with those households who did not receive community support. As a result, further examination of this relationship is required before any firm conclusions can be drawn about this finding.

Surprisingly, while other studies have suggested a possible link between household socio-economic status and caregivers' psychosocial well-being (Hosegood et al., 2007a; Rajaraman et al., 2006), this study found no significant association between the two variables. It may be that household socio-economic status has an indirect, rather than a direct association with caregivers' psychosocial well-being in the sense that socio-economic status is associated with household food security, and household food insecurity has been shown to be negatively associated with caregivers' psychosocial well-

being. That is, household food insecurity may be a pathway through which household socio-economic status influences caregivers' psychosocial well-being.

Hypothesis 2.1: Association between caregivers' psychosocial well-being and caregivers' attitudes towards OVC in their care

Another goal of this study was to determine if there was a significant association between poor caregivers' psychosocial well-being and negative caregivers' attitudes towards OVC. The hypothesis was that poor caregivers' psychosocial well-being was associated with negative caregivers' attitudes towards OVC in their care, controlling for other relevant factors. However, similarly to the association between OVC psychosocial well-being and caregivers' psychosocial well-being, while caregivers' psychosocial well-being is associated with caregivers' feelings towards OVC in their care when only intervention status is controlled for, it is not significantly associated with this outcome when other relevant factors such as individual, household and community-level factors are taken into account. Also, the association between the two variables is mediated by socio-economic variables, as when these variables were added to the model, not only was the association no longer significant, but the coefficient associated with caregivers' psychosocial well-being decreased by more than 10% of its original value. These findings are surprising as it was hypothesized that caregivers in poor psychosocial health would be more likely to take out the stress and frustrations associated with their daily caregiving activities on any OVC in the household, and thus would be more likely to have negative attitudes towards OVC in their care.

However, amongst specific sub-populations, the association between the two variables appears to be significant. This study found that amongst caregivers living in rural areas, caregivers' psychosocial well-being was associated with caregivers' attitudes towards OVC in their care, but not associated for caregivers living in urban areas. However, this association was weakly significant ($p < 0.10$) and further research is required before any conclusions can be drawn, as it may be possible that the association is random. The association between caregivers' psychosocial well-being and caregivers' attitudes towards OVC in their care was also significant amongst non-related caregivers (that is,

caregivers who were not grandparents or aunts/uncles/older siblings of the OVC in their care). This may be because non-related caregivers may be more likely to view non-related OVC as not their responsibility. Thus if such caregivers are suffering from poor psychosocial well-being, they may be more likely to be resentful of these children and blame them for their problems and thus have negative attitudes towards these children. However more research is required before any firm conclusions can be drawn about the association between caregivers' psychosocial well-being and their attitudes towards OVC in their care among non-related caregivers.

Other relevant findings: Other factors that were found to be most strongly associated with negative caregivers' attitudes towards OVC include:

1. Perceived gossip
2. Caregivers living in middle income households
3. Living in a household with no chronically ill members
4. Poor OVC psychosocial well-being

Although caregivers' feeling of isolation from their communities was not associated with their attitudes towards OVC in their care, caregivers' perception that their neighbors gossiped about them or their families was associated with negative attitudes. This may be because caregivers may associate gossip with the presence of an AIDS-affected child in the household. According to Ogden & Nyblade (2005), verbal stigma in the form of gossip, rumors, blaming, etc., is the most significant form of stigma experienced by both HIV-infected and affected individuals. Thus it would not be unusual for caregivers of AIDS-affected children to feel that the presence of these children in their households would instigate gossip among their neighbors (perhaps about the whereabouts of the children's parents, what they died of if they have passed away, and the HIV status of the children), and thus cause them to resent the presence of these children in their households. Thurman et al. (2008) also found that jealousy is sometimes directed towards orphan households due to the attention and support such households receive from both local and international organizations. This kind of jealousy can also stimulate malicious gossip, and thus make caregivers in such households more likely to believe that

their neighbors are gossiping about them and blame the source of this perceived gossip on OVC in the household. Although such caregivers may also feel isolated from the community as a result of this perceived gossip, they may be more likely to associate the gossip with the presence of the AIDS-affected child, and thus have negative attitudes towards that child, rather than associate the feelings of isolation with that child.

With regards to household socio-economic status, it was expected that caregivers living in poorer households would be more likely to have negative attitudes towards OVC in their care. However, this study found that only caregivers living in middle income households were more likely to have negative attitudes towards OVC in their care, as compared with caregivers living in rich households. There may be several reasons for this finding. Firstly, it could be that this was just a random association, particularly since the association was not observed for caregivers living in poor households (no clear trend), and therefore further testing is required before any firm conclusions can be drawn. Or it is possible that poor orphan households in this study may have received extra help from the interventions because they were so needy and thus the association between poverty and caregivers' attitudes towards OVC in their care may have been confounded by this, even though intervention status was controlled for in these analyses. Both middle income and rich households may not have received any help or as much help because they were not as needy as the poor households. While rich households may have been better able to cope with the presence of extra mouths in the household, caregivers in middle income households may have struggled to get by and this may have translated to negative attitudes towards the OVC in their care.

Surprisingly, living in a household with no chronically ill members was associated with negative attitudes towards OVC. Research shows that the presence of a chronically ill household member represents increasing stress less levels for both caregivers and other household members (Bor et al., 1993), and caregivers may sometimes experience guilt and resentment (Frierson et al., 1987). It was expected that caregivers who have to provide for OVC as well as chronically ill household members would be more likely to have negative attitudes towards these children, as opposed to those living in households

with no chronically ill households. It is possible that caregivers who take in both OVC and their ill parents view OVC as “innocent victims” of their parents’ behavior (Ogden & Nyblade, 2005), and therefore even if they blame the parents for having become infected, they may be more likely to feel sympathy for the children and hence have positive attitudes towards them. Caregivers may also feel sympathy for a child in anticipation of the loss that they and the child will soon face. Further research may be required to determine the exact nature of this relationship. With regards to the association between OVC psychosocial well-being and caregivers’ attitudes towards OVC in their care, children in poor psychosocial health are more likely to be moody, disobedient and generally difficult to manage (Mann, 2002; Nyambedha et al., 2007). Caregivers of such children may be more likely to have negative attitudes towards them, especially if they are acting out.

Hypotheses 3.1.1 & 3.1.2: Role of household socio-economic status and the influence of perceived AIDS-related stigma on the association between caregivers’ psychosocial well-being and caregivers’ feelings towards OVC in their care

The last two hypotheses of this study postulate that perceived AIDS-related stigma exacerbates the relationship between caregivers’ psychosocial well-being and caregivers’ feelings towards OVC in their care and that in poor households, as compared with richer households, this relationship is further exacerbated. With regards to the influence of perceived stigma on the association between caregivers’ psychosocial health and caregivers’ feelings towards OVC in their care, study results suggest that perceived stigma alone has no influence on the association between the two variables, which is inconsistent with hypothesis 3.1.1. This may be because although stigma is significantly associated with caregivers’ psychosocial well-being, psychosocial well-being itself does not influence caregivers’ attitudes, the exception possibly being in certain specific sub-populations such as caregivers living in rural areas and non-biologically related caregivers. However, the results show that in poorer households that have caregivers who are in poorer psychosocial health, perceived stigma does exacerbate the association between the two variables, which is consistent with hypothesis 3.1.2. In particular, in

these poor households, stigma channeled as gossip, rather than feelings of isolation from the community, is more likely to worsen the attitudes of caregivers who are in poorer psychosocial health, as compared to caregivers who are in better psychosocial health. However, since interaction terms could not be tested and analyses stratified by both perceived stigma and household socio-economic status could not be conducted, further research is required before any conclusions can be drawn about the influence of perceived gossip and poverty on the association between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care.

7.2 Study limitations and strengths

7.2.1 Study Design & Sampling Issues

Firstly, the data are cross-sectional, and therefore no cause-effect relationships could be determined, although associations between variables could be established. Secondly, sampling frames used were created from lists of beneficiaries of OVC interventions and lists of future beneficiaries of OVC intervention programs. This limits the external validity of the study as results cannot be extrapolated to caregivers of OVC who did not make it onto the lists used, as well as to caregivers of OVC in general. This is because there may be a significant difference between caregivers and OVC who participate or are willing to participate in HIV and AIDS interventions and those who are not. For example, those who do not participate in such programs may not do so for fear of being stigmatized by community members because of their association with an HIV and AIDS program.

Thirdly, there was considerable variation in sampling strategies used for selecting study participants. For both the TSA comparison group and the Allamano comparison group, some study areas were selected first for logistical and practical reasons and sampling frames of children living in those areas who had been pre-selected to receive future services were obtained. However for both the intervention groups, the sampling frames contained participants receiving services from all possible program areas. Thus study areas for the intervention group had equal probability of selection, while some study

areas in comparison groups did not. This creates a selection bias and could be important as program participants in study areas that could not be accessed or that were not selected for logistical reasons may be significantly different from those in study areas that were selected. An assessment of the interaction terms between study sites and primary variables of interest showed that they were not significant; however this was also controlled for in the regression analyses, which helped minimize the effect of the differences.

Lastly, the TSA sampling frame was padded with extra children, suggesting that the sampling frame was not accurate. This may have created a selection bias. There was also a gap of about a month in data collection between the first phase and second phase of interviews for the TSA intervention sample, and this may also decrease data quality as those who were interviewed in the second phase may already be aware that other people have been interviewed, may have an idea of some of the questions asked and thus may give different answers than they would have had they been interviewed the first time around.

7.2.2 Measurement Weaknesses

Caregivers' attitudes towards their foster children was measured with instruments and scales that have not been validated for use in sub-Saharan Africa. This is a major limitation to the study as it is difficult to ascertain whether the selected outcome – caregivers' feelings towards OVC in their care - is accurately measuring what it is intended to measure. However, as previously outlined, there have been to date very few studies examining caregiver attitudes towards OVC in their care, and those that have been conducted have relied mainly on qualitative measures. To the best of the author's knowledge, there are no validated quantitative measures for capturing caregiver attitudes towards OVC in sub-Saharan Africa.

Another major issue is the use of single-items to assess perceived AIDS-related stigma, rather than multiple-item scales. Single-item assessments generally tend to be less precise than multiple-items scales as they do not measure sufficient aspects of the

concept and may be more likely to change over time. However, it is important to keep in mind that the purpose of this study is to shed some light on an issue which to date, very little information is available. The purpose is not to make broad generalizations about caregivers' attitudes, but to explore associations and identify possible factors that may affect these attitudes.

Thirdly, household socio-economic status was assessed using an asset index that may not be capturing all aspects of socio-economic status. One problem with this asset index is that it does not distinguish between items that can be purchased, such as battery-operated radios and bicycles, and those that cannot be purchased or those that an individual has no control over as they are more a function of the area where one lives (for example, electricity and access to clean water). This may explain why household food security was a better indicator of caregivers' psychosocial health, as compared with household socio-economic status.

7.2.3 Statistical Issues

Shared method variance is also a potential limitation of the study. Shared-method variance refers to an association between variables at least partially due to similar methods of measurement (that is, covariation among items from the same scale that may be attributed to the method of measurement employed)²⁰. While this may not be a problem where the lack of an association between variables occurs, shared-method variance may account for significant associations between variables.

Another limitation is the possibility of endogeneity. Endogeneity is problematic because it results in biased parameter estimates. Biased parameter estimates mean that in repeated samples, the average of the estimates will not equal the true population parameters. As previously discussed, endogeneity could not be tested for or controlled for and thus the reported parameter estimates may be biased. Not being able to test the significance of appropriate interaction terms due to multi-collinearity is also an issue, as more accurate

²⁰Tepper, B., & Tepper, K. (1993). The effects of method variance between measures. *The Journal of Psychology*, 127 (3): 293-302.

information regarding the nature of hypothesized associations could therefore not be obtained.

7.2.4 Inability to control for other relevant factors

It is also possible for caregivers in this study to have multiple foster OVC in their care. However this information was not captured with the questionnaires and thus intra-caregiver variations in attitudes towards foster OVC in their care cannot be accounted for in this study. This is also another limitation of the study as a caregiver can have different feelings towards different children in their care. Caregivers were also not asked about why they were fostering in children, and thus fostering could be possibly due to other reasons (such as migration of parents for work, better access to schooling, improved living conditions for the children, etc.) apart from parental illness or death from HIV and AIDS. However, given the high HIV prevalence in both Mbeya and Iringa regions and given that the two programs in the original evaluation study were focused specifically on children identified by program volunteers and community leaders as affected by HIV and AIDS, this issue should have only a limited impact on the current analyses, since it is almost certain that majority of the children are affected by HIV and AIDS in some shape or form. This study was also unable to control for how long a child has lived in a particular foster care environment, which further limits the results as this factor influences how well adjusted both caregiver and child are to each other. For example, children who have been living in their foster households for several years are more likely to have adjusted to their environments and thus be more likely to be in better psychosocial health, as compared with children who have been recently orphaned or who have just moved into the household. Caregivers are also more likely to be used to having these children in their households and this could influence their attitudes towards them.

7.2.5 Data collection issues

Interviewer bias is also a possibility in this study since two separate data collection teams were used for Kiswahili households and Kimalia households in Mbeya Region. However, to reduce the impact of interviewer bias, both teams were given the exact kind of training, using the same training materials, and the same amount of training time.

Teams were also tested to make sure that they understood all data collection protocols. During data collection, researchers monitored both data collection teams to ensure that all protocols were strictly adhered to. Thus although there may be some interviewer bias, its impact will be limited.

There is also the possibility of information bias as some participants thought that data collection teams were collecting information about needy families so that extra material support could be provided for them. This was even after interviewers explained that respondents would not receive any compensation for agreeing to participate in the study. Thus some information may have been exaggerated by participants in anticipation of material support. For example, inaccurate information about household assets may have been provided in an effort to appear poor, resulting in a larger number of households falling into the lower levels of household socio-economic status, although in reality, that may not be the case. This is problematic as it increases the likelihood of associating negative caregiver attitudes with poorer households. Also, although the data is weighted, the denominator estimates used are approximate as no estimates were available for the population of caregivers of OVC in the study districts.

7.2.6 Strengths

Although there are some limitations that may impact any conclusions drawn from results obtained, the analysis is guided by a theoretical framework, with linkages and associations explained by available literature in the subject area. Other strengths include a well-trained data collection team and quality control implemented by the researcher herself to ensure that all questionnaires were completed accurately (skip patterns, etc. were properly followed, limited missing information, etc.). There was also double-data entry to limit some of the worst data entry errors.

CHAPTER 8 – CONCLUSIONS AND RECOMMENDATIONS FOR FUTURE RESEARCH

8.1 Conclusions

The focus of this study was to examine the relationship between OVC psychosocial well-being and caregivers' psychosocial well-being, as well as the relationship between caregivers' psychosocial well-being and caregivers' feelings towards OVC in their care, and how perceived AIDS-related stigma and household socio-economic status may influence this relationship. The main findings from this study are as follows:

Caregivers' psychosocial well-being

1. The association between OVC psychosocial well-being and caregivers' psychosocial well-being is mediated by socio-economic variables. That is, when socio-economic factors are accounted for, there is no significant association between OVC psychosocial well-being and caregivers' psychosocial well-being.
2. Household food insecurity, perceived AIDS-related stigma, living in an urban area and single motherhood most strongly contribute to poor caregivers' psychosocial well-being.
3. There is no bi-directional association between OVC psychosocial well-being and caregivers' psychosocial well-being.

Caregivers' attitudes towards OVC in their care

1. There is evidence to suggest that the association between caregivers' psychosocial well-being and caregivers' attitudes towards OVC in their care is also mediated by socio-economic variables.
2. Caregivers' psychosocial well-being is not a pathway through which other individual-level, household, and community level factors influence caregivers' attitudes towards OVC in their care, and perceived AIDS-related stigma and household socio-economic status appear to do little to change the nature of this relationship.

3. There is no statistical evidence of a bi-directional association between caregivers' psychosocial well-being and caregivers' attitudes towards OVC in their care.
4. Amongst certain specific sub-populations such as caregivers living in rural areas and non-biologically related caregivers of OVC, poor caregivers' psychosocial well-being may be associated with negative caregivers' attitudes towards OVC.
5. Perceived AIDS-related stigma in the form of gossip is a strong predictor of negative caregivers' attitudes towards OVC in their care.
6. OVC in poor psychosocial health are more likely to have caregivers who have negative attitudes towards them, as compared with OVC in good psychosocial health.
7. There is also evidence of a bi-directional association between OVC psychosocial well-being and their caregivers' attitudes towards them.

8.2 Program implications

Firstly, findings from this study suggest that the provision of continued food support needs to be a major component of programs intended to address diminished caregivers' psychosocial well-being, as this study shows that household food insecurity strongly contributes to poorer caregivers' psychosocial well-being. Secondly, perceived stigma on the part of either OVC or caregivers is rarely addressed in stigma interventions, as the focus has been on targeting enacted stigma directed towards AIDS-infected individuals, and to a smaller extent, on perceived stigma on the part of AIDS-infected individuals. However this study also highlights the importance of the role of perceived stigma on the part of caregivers, particularly perceived gossip, in shaping their attitudes towards OVC in their care. There is the need for interventions addressing the fact that the presence of AIDS-affected children in households may cause caregivers to believe that other community members are stigmatizing them, and make specific efforts to tackle this issue.

Continued attention to the psychosocial needs of OVC is critical. This study helps provide a better understanding of the relationship between OVC psychosocial well-being and their caregivers' attitudes towards them by revealing a bi-directional association

between the two variables. This finding also highlights the need for multi-pronged interventions that focus on addressing both issues simultaneously in order to obtain the best outcome. That is, to improve both OVC psychosocial well-being and caregivers' psychosocial well-being, interventions must simultaneously address factors such as household food insecurity, and perceived AIDS-related stigma, as well as specifically target single caregivers for further assistance, such as counseling.

Finally, there is also the need for program developers to target specific caregiver socio-demographic and socio-economic characteristics, such as caregivers' age, educational level, marital status, etc., in the design of programs aimed at improving both the psychosocial well-being of AIDS-affected children, and that of their caregivers. Although household socio-economic status was not significantly associated with caregivers' psychosocial well-being, the introduction of income-generating activities in poorer households can help improve their socio-economic status, and improve their access to food.

Overall, recommendations based on this study for improving both caregivers' psychosocial well-being and OVC psychosocial well-being, as well as caregivers' attitudes towards OVC in their care include the following:

1. Continued food support to reduce household food insecurity as this factor was found to be strongly associated with poorer caregivers' psychosocial well-being
2. A reduction in gossip through education of communities about HIV and AIDS. This is important as this study found that stigma, particularly stigma channeled as gossip, is a strong predictor of negative caregivers' attitudes towards OVC in their care, and perceived stigma in general also contributes to poorer caregivers' psychosocial well-being.
3. Addressing factors that influence OVC psychosocial well-being and their caregivers' attitudes towards them simultaneously due to the bi-directional nature of the association between these two variables

4. Introduction of income-generating activities for caregivers living in poor households as this will further help improve access to food
5. Provision of counseling, particularly for single caregivers, as this study found that single motherhood was also strongly associated with poorer caregivers' psychosocial well-being.

8.3 Recommendations for future research

There is much more that needs to be understood about factors influencing both OVC and caregivers' psychosocial well-being, as well as factors influencing caregivers' attitudes towards OVC in their care. Due to limitations of this dataset, this study was unable to control for the length of time a child had been living in his/her foster care situation, and since this information is pertinent in determining how well-adjusted both the child and caregiver are in their new living situation, further research on how this factor may affect both OVC psychosocial well-being and caregivers' attitudes towards OVC in their care is encouraged. Further research that takes into account caregivers' motivations for fostering OVC, as well as intra-caregiver attitudes towards OVC would also help provide a clearer picture of the factors that influence their attitudes towards these children in their care. The need for more research on appropriate instruments for assessing caregivers' attitudes towards OVC in their care in an African setting cannot be understated as this is critical in improving the validity and reliability of future work in this area. Future studies in this area also need to focus on qualitative research targeted towards caregivers themselves, rather than towards community members as has been done in the past, in order to better understand the motivations behind caregivers' fostering of OVC, and their feelings towards such children in their care.

More research is also required into determining whether or not the relationship between caregivers' psychosocial well-being and caregivers' attitudes towards OVC in their care is significant amongst certain sub-populations and if so, why, so that these issues can be specifically targeted for intervention. Although the majority of OVC in sub-Saharan Africa are cared for by extended family members (Ankrah, 1993; UNAIDS, 2004), information on any differences in caregiver attitudes between related and non-related

caregivers could also shed more light on foster care situations. The bi-directional association between OVC psychosocial well-being and their caregivers' attitudes towards them also needs to be further explored, as any additional information can help improve the living experiences of both OVC and foster caregivers. Also, more information is needed on why the presence of a chronically ill person in a household appears to be associated positive caregiver attitudes towards OVC.

Results from this analysis show that caregivers' education level is weakly associated with their psychosocial well-being, suggesting that caregivers with no education were more likely to have improved psychosocial well-being, as compared with caregivers with a post-primary education. However, literature indicates that having more education leads to better economic opportunities (UNAIDS, 2008ab), and therefore improved household food security, as compared with having no education at all. Thus it was expected that better-educated caregivers would have improved psychosocial well-being as compared with their illiterate counterparts. This unexpected finding may be explained by the fact that only approximately 5% of caregivers in this study have a post-primary education as compared with approximately 47% of caregivers with no education at all. Since the disparity between the numbers educated may be driving this result, further research is required for clarification.

Results from this study also suggested that OVC who perceived themselves to be stigmatized were more likely to have caregivers with negative attitudes towards them, as compared with OVC who did not perceive themselves to be stigmatized. However this association was weakly significant at the 10% significance level ($p=0.081$), and therefore further research is required for clarification. Finally, results from this study on the relationship between household socio-economic status and caregivers' attitudes are inconclusive and thus more research is required in order to clarify this association.

There is much research on the extended family system of caring for children in sub-Saharan Africa, particularly in the context of HIV and AIDS (Adepoju & Mbugua, 1997; Ankrah, 1993; Foster, 2000; Foster & Williamson, 2000; Mann, 2002; Oleke et al.,

2005), as well as a plethora of evidence on the diminished psychosocial well-being of both caregivers and OVC within this system (Kipp et al., 2006; Kipp et al., 2007). However this study focuses on aspects of extended family living situations that have not been the forefront of past research in this area – the factors that influence caregivers’ psychosocial well-being and caregivers’ attitudes towards OVC in their care, and the roles of perceived stigma and poverty - and highlights the importance of continued food support, a reduction in gossip among community members in improving caregivers’ psychosocial well-being, as well as the need for the introduction of income-generating activities in poorer households to supplement household incomes.

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APPENDIX A: DEFINITION OF PRIMARY TERMS

Orphans and vulnerable child/ren (OVC): These are children who fit into any one of the following categories:

- i. Children who, regardless of their own HIV status, have one or both parent(s)/guardian(s) who is either HIV-positive or ill with AIDS
- ii. Children who have lost either one or both parent(s)/guardian(s) to AIDS. This definition includes children who are classified in the literature as orphans, and the term “orphan” may sometimes be used in this review when referring to children who have lost either one or both parents to HIV and AIDS.
- iii. Children who are not included in the two categories described above, but are vulnerable due to lack of adequate adult support, AIDS-related stigma and discrimination or other reasons identified by the community or by the non-governmental organizations from whom the study sampling frames were obtained.

Burden of care: This is a combination of the household child dependency ratio and the presence of chronically ill persons in the household. WHO defines the dependency ratio as the ratio of persons in the “dependent” ages (under 15 years plus 65 years or older) to those in the “economically productive” ages (15-64 years). This ratio is usually referred to as the total dependency ratio, while the first component of the numerator (children under age 15) is called child or young dependency ratio, and the second component (those aged 65 and over), old-age or old dependency ratio. An ill person in the household can be either a child (that is, any individual aged less than 18 years) or an adult (any individual aged 18 years or older). For children, it also includes those who are physically disabled, for example, children in wheel chairs or who cannot walk without assistance, children who are either deaf or dumb, etc.

Caregiver: This is the primary guardian of a child and can be either a biological parent, a blood-related adult (aged 18 years or older) or an unrelated adult. Care includes meal preparation and other activities associated with the child rearing process. The term

guardian is also sometimes used in this study to mean the same thing. This study is focused on caregivers who are not biological parents of the child/ren in their care.

Fostering: Child fostering is defined as when the primary guardian of a child is not his/her biological parent, regardless of whether or not the biological parent is also living in the same household as the child. This is so as to account for households where the child's biological parent is ill and although the biological parent and child live in the same household, the parent is unable to contribute to the child rearing process, and this burden falls on another individual in the household such as a grandparent.

Household: A household in this study consists of, at the time of interview, related or unrelated people who slept in that house at least two of the past seven nights, with the exclusion of special events such as weddings, funerals and other festivals that would call for overnight visitors and other house guests to be present in the home. A household also consists of the wives of polygamous men and their children who live in separate houses in the same compound and who share in the daily chores of managing the household. However wives of the same man who live in different houses in different compounds are not considered as part of the same household.

Household socio-economic status: This refers to the amount of resources available to a household in comparison with other households in the community. It is constructed using principal component analysis similar to that done for wealth index by the Demographic and Health Survey and reflects factors such as ownership of material items/possessions such as radios, televisions, cars, motorcycles, the primary material that the household's dwelling is made of i.e. earth/sand/dung vs. cement/ceramic, etc.

Support network: Support for caregivers is defined in this study as both material and emotional support. Material support includes direct or indirect financial support such as donation of food, clothes, payment of children's school fees, etc from friends, relatives, or neighbors, as well as non-governmental organizations in the area. Emotional support includes a good network of friends, family and/or loved ones that the caregiver feels

he/she can rely on. It also includes psychosocial support from volunteers from NGOs, etc. A good support network is one that provides adequate material and emotional support as defined by the specific caregiver.

APPENDIX B: OVERVIEW OF TSA, SHIPO & ALLAMANO

Overview of TSA in Mbeya, Tanzania

The Mama Mkubwa and Kids Club program was developed by The Salvation Army to sensitize communities to the plight of orphans and vulnerable children and to help mobilize them and build their capacity to meet the needs of these children and their households. Services include the provision of psychosocial support to needy children through the implementation of kids clubs, providing emotional, spiritual, educational and material (for example, soap, food, clothing and school materials) support to OVC households through home visiting via community volunteers and sensitization of community members through community meetings.

Overview of SHIPO in Njombe, Tanzania²¹

SHIPO (Southern Highlands Participatory Organizations) is an NGO based in Njombe, Tanzania. It's primary objective is to work with village and community leaders, community-based organizations and other NGOs to develop small-scale self-help projects such as boreholes for communities with no reliable source of water and to provide material support such as food and clothing, as well as emotional support in the form of counseling provided by community volunteers to orphans and vulnerable children, as well as their households. At the time of data collection, SHIPO had just received funding to implement a program aimed at improving the living situations of orphans and vulnerable children.

Overview of Allamano in Iringa, Tanzania

Allamano's main objectives are:

1. To provide care and treatment for people living with HIV and AIDS (PLHA) in the form of free medical services and the provision of ARV therapy
2. To provide voluntary counseling and testing (VCT) services to people in the Iringa area

²¹ <http://www.shipo-tz.org/>

3. To provide psychological and legal support for OVC, PLHA and their families through counseling and kids' club activities for children

Allamano provides the following services for OVC as well as people living with HIV and AIDS (PLHA):

OVC Counseling/Psychological Support: OVC focal persons, who, although they are not professional counselors, have some training in counseling children, are responsible for providing counseling and psychological support at the Allamano Center. Children are free to see the OVC focal persons at any time and no appointment is required. Sessions are private and confidentiality is ensured, except in cases of abuse/mistreatment or property grabbing. Any child is welcome to speak with the OVC focal persons.

However, since Allamano Center is known in the area for providing HIV and AIDS counseling and treatment, those children who come to speak with the OVC focal persons are usually children impacted in some way by the disease. All children who are seen by the OVC focal persons at the Allamano Center are immediately registered and encouraged to attend a kids' club meeting in their area. Allamano also has one professional counselor on staff and OVC focal persons may refer a child to this counselor if he/she has a problem that is above the expertise of the OVC focal persons.

Counseling service is also provided during home visits conducted by Allamano volunteers who have been trained to provide HIV and AIDS counseling. When visiting a patient for the first time, volunteers provide HIV and AIDS counseling and encourage other occupants in the home to go to the Allamano center for voluntary counseling and testing (VCT) if they have not already done so. After the first visit, volunteers have also been trained to provide psychological, moral and spiritual support to their patients. The number of times a volunteer visits a patient depends on the health of the patient (for example, they are more likely to visit a bed-ridden patient every day and more likely to visit an otherwise healthy patient once every two weeks), however, on average, volunteers visit patients about once a week.

OVC Legal Support: During counseling sessions with an OVC focal person, a child may report abuse or mistreatment. In such instances, the OVC focal person will alert a volunteer who will then go to the child's home and ask the child's parent/guardian to visit the OVC focal person at the Allamano center. This is done without revealing what the child has reported to the OVC focal person. At the Allamano Center, the OVC focal person will speak with the parent/guardian privately to obtain their side of the story. She then compares the story obtained from the child and that obtained from the parent/guardian and then arranges a meeting to resolve the issue at the Allamano center with the child, his/her parent/guardian, and a trained counselor from Allamano, who acts as a mediator. After the meeting, the home situation is monitored and if the abuse continues, it is the duty of the OVC focal person to contact Allamano's liaison in the government who is specialized in dealing with legal issues. In some cases, if a volunteer is able to identify another relative who is willing to take the child in, assuming all concerned parties agree to it, Allamano may recommend that the child moves to that relative's house. In instances of property grabbing, the government liaison is contacted immediately.

Widows and other surviving members of an Allamano patient are also encouraged to make use of the legal support provided if they need it. Property grabbing is the most common problem reported by widows and other adult surviving members and as in the case of that reported by OVC, the Allamano government liaison is always contacted immediately to resolve the issue.

Kids' Club Activities: These are held once a month at local primary schools – Kihesa, Igeleke, Ilala, Mlangali, Ipogoro and Nduli primary schools - and are run by one OVC focal person and Allamano volunteers. Each kids' club has its own name - Hisia Ndogondogo Group, Tumaini Njemanspaa Group, Umoja Group, Ushirikiano Group, Huruma Group and Tupendane Group. They are held at different times during the month so that the OVC focal person can attend and supervise them all. Activities in the clubs are organized according to three age categories: children aged 3 to 5 years, children aged 6 to 12 years and children aged 13 to 18 years. Children in the two youngest categories are engaged in the following activities: games, stories, singing, traditional dance,

personal hygiene, and learning good behavior for school and home. Children aged 6 to 12 years are also taught life skills (for example, cooking, how to wash clothes, how to take care of a home, etc). Activities for children aged over 12 years also include HIV and AIDS education, safe sex, and health and nutrition information. All children are also encouraged to visit the Allamano Center to speak with the OVC focal persons if they need to talk about personal problems at home or at school. No counseling is provided during kids' club activities due to the lack of privacy.

Care and Treatment: Through its Care and Treatment Center (CTC), Allamano provides free medical services and free anti-retroviral (ARV) therapy to all HIV positive patients. A physician is on staff daily to see patients. In some instances, a physician may visit a patient at home if he/she is too ill to travel or is bedridden. Patients co-infected with tuberculosis (TB) are also provided with free TB medication. Allamano also provides heavily subsidized (an entrance fee of 500 Tanzanian Shillings is charged, which is less than US 50 cents) medical services for children of PLHA, such as medical visits, laboratory tests, drugs for diseases that have been diagnosed by the Allamano physician and if necessary, referrals to local hospitals for any treatment that cannot be provided at the center. Allamano Center also provides these children with food through their food distribution activities, cleaning supplies and boiled water for use in the home. Allamano also provides similar services to a limited number of OVC (about 150) who are selected because they have been identified as needing extra help.

Allamano also provides HIV prevention services to both children and adults in terms of spiritual, social and psychological counseling. The Allamano Center, as a Catholic-based organization, does not advocate condom use.

Allamano's Clinic Activities

Allamano has two OVC focal persons whose primary duties include running the kids' clubs, providing counseling and psychological support for OVC, supplying school materials such as uniforms, textbooks, pens, pencils and school fees when deemed

necessary, and distributing food to needy children and families. Food distribution, which generally occurs once a month at the center, is given to five groups of people:

1. Patients with nutritional disorders or with low BMI (body mass index)
2. Children with HIV and AIDS, especially those with older caregivers such as grandparents or relatives with little income
3. Patients living in very poor conditions
4. Infants with HIV positive mothers
5. Patients in tuberculosis (TB) therapy who are also HIV positive

For those in groups 1, 2 and 3, the following is usually provided: 6kg of corn flour, 4kg of beans, 1kg of sugar, 1kg of nutritional flour (consisting of a mix of dried legumes, rice and peanuts), 0.5kg of salt, 400g of peanut butter, 0.5kg of sunflower oil and soap. Those in group 4 receive a daily supply of 0.5litres of fresh milk. For those in group 5, a daily supply of 0.5litres of fresh milk is provided.

All those receiving food are either patients at the Allamano Clinic, or families of patients at the Allamano Clinic. In limited circumstances, a patient or family of a patient may receive food more than once a month if prescribed by the Allamano physician. Children who attend the clinic are either HIV positive or have AIDS and thus are receiving treatment or they are children/wards of adults who are HIV positive or have AIDS and are receiving treatment from the clinic.

The Allamano Clinic does not provide basic health services. All services offered are HIV-related. Voluntary counseling and testing (VCT) is also offered daily at the clinic and is open to the public. Both adults and children are encouraged to attend if they have not already done so.

Children who are HIV positive or have AIDS are referred by the OVC focal persons for treatment at the CTC, where they receive free medication and other free medical services. Some children, depending on their living conditions as reported by the OVC focal persons, also receive material support such as payment of school fees, school uniforms and books, etc. All children who receive school support are required to present report

cards from their respective schools for inspection at the Allamano Center. Counseling services are also provided by the OVC focal persons, during which children are encouraged to talk about their feelings, home and school situations. Children are also informed about kids' club activities in their area of residence and encouraged to join; however, participation in kids' club activities is not mandatory. When necessary, Allamano also provides legal support in collaboration with government authorities. The OVC focal persons also act as contacts for patients/OVC who require legal support.

Not all children who attend Allamano Center are HIV positive or have AIDS. Some are children/wards of adults who are HIV positive or have AIDS who are receiving treatment from Allamano's Care and Treatment Center. Children whose parents or guardians are HIV positive or have AIDS are immediately registered at the Allamano Center and referred to a counselor who encourages them to get tested for HIV. Consent is also sought from sick parents/guardians to have their wards tested. HIV positive children are referred to CTC for treatment. Those who are negative may or may not receive direct services as this depends on the health of their parent/guardian. For example, if a child's primary parent or guardian is very sick and is unable to work, Allamano provides material support for the whole family, in the form of food and school supplies. If a child's primary parent or guardian is able to work and support the family while receiving treatment, no direct services are provided to the child or family, although the child benefits from having a healthy parent. All children, regardless of HIV status, are encouraged to join a kids' club in their area.

Allamano's primary goal in keeping track of children with HIV positive parents/guardians is so that if a parent or guardian in their care passes away, they can easily step in to ensure that the surviving child receives proper care. From a legal perspective, Allamano strongly encourages all patients to prepare a last will and testament that will protect the rights of surviving children, widows and families in general. If a patient is willing to prepare this document, they provide assistance by contacting the appropriate people in the government who can help and following up to make sure that this has been done. Allamano also helps patients to designate guardians

for their children. However in rare instances where no guardian can be found, after the death of the parent, Allamano refers the child to specific homes run by other missionaries in the area specializing in the care of orphans.

Allamano's Home-Based Care Activities

Not all children on volunteers' list are HIV positive. Some are children of adults who have died of AIDS or children whose parents/guardians are receiving home-based care services from an Allamano volunteer. These children may receive spiritual, social and psychological counseling if the volunteer deems that this is necessary. They are also strongly encouraged to join an Allamano kids' club in their area. However, the target of the home visit is the HIV positive patient and his/her needs are the priority.

Generally, volunteers live in the same area as those patients to whom they have been assigned. A volunteer is required to visit at least once every two weeks, although he/she may go more often if the patient is seriously ill or bedridden. Volunteers receive a month's training and are paid a small stipend per month. They are qualified to turn bedridden patients, conduct physical therapy, dress sores and give bed baths. Volunteers also trained to provide spiritual, social and psychological counseling during home visits. Once every month, they are required to submit a report on the conditions of all their patients. These reports are combined into one report and shared with the District AIDS Coordinator (government liaison) and Tunajali staff (that is, staff from the follow-on projected implemented by Family Health International).

All needy HIV positive children/children with AIDS receive home-based care as long as their primary parent/guardian gives his/her consent. HIV negative children whose parents/guardians receive home-based care may also be asked to go to the center to receive school supplies, food and other forms of material support depending on their living conditions as reported by the volunteer. For example, children are more likely to receive school supplies if a volunteer reports that their parent/guardian is bedridden. If the parent/guardian is reasonably healthy and can perform daily activities, his/her children are encouraged to join a kids' club held in their area, but no other services are provided.

APPENDIX C: OTHER RELEVANT TABLES/INFORMATION

Table C. 1: Assessment of interaction terms between study sites and primary variables of interest

Interaction Term	p-value
Study site*caregivers' feelings towards OVC in their care	0.605
Study site*caregivers' psychosocial well-being	0.342
Study site*OVC psychosocial well-being	0.055
Study site*isolation stigma measure	0.092
Study site*gossip stigma measure	0.398
Study site*OVC perception of stigma	0.266
Study site*household socio-economic status	0.322

Table C. 2: Correlation matrix between dependent and independent variables used in analyses

	y1	y2	x1	x2	x3	x4	x5	x6	x7	x8	x9	x10	x11	x12	x13
y1	1.0000														
y2	0.0593	1.0000													
x1	0.1747	0.0783	1.0000												
x2	0.0083	-0.1264	0.0441	1.0000											
x3	-0.0580	-0.0376	-0.0423	0.5202	1.0000										
x4	0.0393	0.0135	0.0090	-0.4477	-0.9039	1.0000									
x5	-0.0719	0.1688	-0.0353	-0.1937	-0.1208	0.1155	1.0000								
x6	-0.0135	0.1416	0.0506	-0.3037	-0.2555	0.2114	0.2217	1.0000							
x7	0.0095	0.0034	-0.0642	-0.5879	-0.3355	0.2991	-0.0099	-0.3783	1.0000						
x8	-0.1056	-0.1808	-0.1066	-0.1238	-0.0147	0.0412	-0.0148	-0.0575	0.1333	1.0000					
x9	-0.1125	-0.1888	-0.0416	-0.1251	-0.0479	0.0872	0.0020	-0.0139	0.1398	0.4332	1.0000				
x10	-0.0539	-0.0087	-0.1180	0.0314	0.0372	-0.0357	0.0047	-0.0387	-0.0474	0.0145	-0.0101	1.0000			
x11	-0.0650	0.0113	-0.0505	-0.0427	-0.0036	-0.0069	0.0619	0.0016	0.00427	0.0258	0.0161	-0.1754	1.0000		
x12	0.0115	-0.0016	-0.0065	-0.0816	-0.0617	0.0302	0.0351	0.0307	0.0901	-0.0028	0.0334	-0.0691	-0.0348	1.0000	
x13	0.0585	-0.0390	-0.0355	-0.0181	0.0099	-0.0303	-0.0329	0.0609	-0.0466	0.0903	0.0231	-0.0180	-0.0090	-0.0267	1.0000
x14	-0.0357	-0.1367	-0.0840	0.0667	0.1425	-0.0890	-0.2065	-0.1438	0.0106	0.0982	0.0188	0.0000	-0.0164	0.0025	0.0123
x15	0.0646	0.0062	-0.0413	-0.0000	0.0331	-0.0012	0.0241	-0.0603	0.0472	-0.0435	-0.0107	-0.0345	0.0400	-0.0198	0.0075
x16	-0.0447	-0.3160	-0.0553	0.1187	0.0805	-0.0089	-0.0830	-0.0982	-0.0347	0.1580	0.0607	0.0172	0.0139	-0.0213	0.0071
x17	0.0089	-0.1293	-0.0614	0.1471	0.1544	-0.1376	-0.0251	-0.0581	-0.0789	0.1098	0.0413	0.1083	0.0108	-0.0214	-0.0292
x18	-0.0018	0.0046	0.0592	-0.1511	-0.1556	0.1420	0.2802	0.2113	0.0635	0.0149	0.1129	-0.0556	0.0234	0.0330	0.0140
x19	0.0662	-0.1087	0.0038	0.0332	-0.0132	0.0025	-0.0965	0.0034	-0.0067	-0.0867	-0.0083	0.0173	-0.0272	0.0843	0.0462
x20	-0.1767	0.0712	-0.2159	-0.1515	0.1701	-0.1222	0.1352	-0.0447	0.1537	0.0286	-0.0425	0.0212	0.0817	0.0778	-0.0432

Table C.2contd: Correlation matrix between dependent and independent variables used in analyses

	x14	x15	x16	x17	x18	x19	x20
x14	1.0000						
x15	-0.4171	1.0000					
x16	0.0366	0.0507	1.0000				
x17	0.0401	-0.0029	0.1886	1.0000			
x18	-0.2129	-0.0679	0.0163	0.0747	1.0000		
x19	-0.0710	0.0158	-0.0585	0.0555	0.1040	0.0011	1.0000
x20	0.1773	0.1049	-0.0585	0.0285	-0.1199	-0.0834	1.0000

Key

y1 = caregivers' feelings towards OVC in their care

y2 = caregivers' psychosocial well-being

x1 = OVC psychosocial well-being

x2 = caregiver's age

x3 = caregivers' education level (no education)

x4 = caregivers' education level (some primary education)

x5 = caregivers' marital status

x6 = biological relationship between caregiver and child (aunt/uncle)

x7 = biological relationship between caregiver and child (other caregivers)

x8 = caregivers' perception of stigma ("You feel isolated from others in the community")

x9 = caregivers' perception of stigma ("People speak badly about you or your family")

x10 = OVC perception of stigma (child sometimes plays alone because no one wants to play with him/her)

x11 = OVC perception of stigma (child frequently plays alone because no one wants to play with him/her)

x12 = OVC age

x13 = OVC sex

x14 = household socio-economic status (poor households)

x15 = household socio-economic status (middle income households)

x16 = household food security

x17 = presence of chronically ill household members

x18 = total household size

x19 = community support

x20 = location (rural vs. urban)

Table C.3: Distribution of instrument 1 for caregivers' psychosocial well-being ("In the past year, have you been sick for 3 months in a row or longer?")

In the past year, have you been sick for 3 months in a row or longer?	Distribution (%)	Weighted %	n
Yes	23.09	23.43	193
No	76.91	76.57	643
Total	100.00	100.00	836

Table C. 4: Distribution of instrument 2 for caregivers' psychosocial well-being ("Your relatives who do not live with you visit you to see how you are doing")

Your relatives who do not live with you visit you to see how you are doing	Distribution (%)	Weighted %	n
Strongly agree	22.13		185
Agree	39.71		332
Disagree	15.55		130
Strongly disagree	22.61		189
Total	100.00	100.00	836

This variable was re-coded into a binary variable based on the median cut-off point of its distribution (strongly agree and agree fell together and were combined into one category (agree), and disagree and strongly disagree fell together and were combined into another category (disagree). The distribution of this new variable is shown below in table 5.

Table C. 5: Distribution of instrument 2 re-defined as a binary variable

Your relatives who do not live with you visit you to see how you are doing	Distribution (%)	Weighted %	n
Agree	61.84	60.23	517
Disagree	38.16	39.77	319
Total	100.00	100.00	836

APPENDIX D: AUTHOR BIOGRAPHY

Nana Koram was born in Accra, Ghana and raised in both Ghana and Addis Ababa, Ethiopia. In August 1998 she came to the US where she attended Vanderbilt University, and earned a Bachelor of Science degree in an interdisciplinary major, Communication of Science, Engineering and Technology, with a minor in French. She then pursued a Master of Public Health degree in Epidemiology at the Rollins School of Public Health at Emory University. After graduation, she was awarded a highly competitive Oak Ridge Institute of Science and Education (ORISE) Fellowship to work as a Surveillance Epidemiologist at the Foodborne and Diarrheal Diseases Branch of the Centers for Disease Control and Prevention in Atlanta, GA. At the end of her fellowship, she began her doctoral studies in International Public Health at the Tulane University School of Public Health and Tropical Medicine, focusing on HIV and AIDS research in sub-Saharan Africa.