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SUPERVISOR: Sofie G Karlsson

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KEYWORDS: HIV/AIDS, orphans, grandparents, caregiving, stigma, Kenya

TITLE: GRANDPARENTS LEFT WITH AIDS-ORPHANS: Challenges and Strategies Handling Poverty and Stigma

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ABSTRACT

By 2010 it is estimated that one third of the African children will be orphans as an effect of HIV/AIDS. The crisis is already a fact and most orphans are absorbed by the extended family where the grandparents become the primary caretakers. This qualitative study was carried out in Kenya to explore the situation of these grandparents and to define their current resources and needs. Eight grandparents living in rural village or urban slum caring for their orphaned grandchildren were interviewed. The results showed that these families live under extremely poor conditions lacking food, other vital necessities and a basic social network. Local churches and support groups emerged as the grandparents main sources to enhance strength and support. Key factors causing the acute poverty is HIV-related stigma and lack of access to land.

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INTRODUCTION

Background

By 2010 it is estimated that one third of the African children will be orphans as an effect of HIV/AIDS and Kenya is one of many countries that has been hit hard by HIV/AIDS. An estimated 1,3 million people, that is 6% of the country population, are living with the virus and hundreds of thousands have already died as a consequence of the pandemic. Most of the deceased are in reproductive age of which their children are left as orphans (UNAIDS, 2007). In most cases it is the elderly generation who end up with the caring responsibility for these children, grandparents who’s situation is already strained due to age, workload and lack of own children who normally provide for the parents old age. In times like today with the massive impact of AIDS this elder population has become the pillars of a country where the public social safety net is insufficient (Miller, 2006). There are many organisations working for the poor in Kenya but the problem is that there are endless needs and limited resources. In Kenya the social safety net consists of the family and in order to find effective and long-term solutions organisations should start from this and concentrate the work on ways to support
and complement this original system (Foster, 2006). This requires a basic understanding for this target group as a criterion for successful cooperation.

**Aim of the Study**

With the child’s best in mind the own family is considered the best solution for orphans (Matshalaga, 2002). This is why it is of greatest value to give attention to and support the extended family’s conditions and capacity. The aim of this study is to create a greater understanding of the reality of the grandparent-headed household and to investigate the grandparents current resources and challenges in upbringing their grandchildren and what kind of change they could wish for. The results will be further considered as a source to create ideas of how to improve the state of the grandparents and orphans in terms of increasing the existing resources and to complement or bridge where there are obstacles.

**Former Research and Theoretical Framework**

In relation to the extent of grandparent-orphan households developed by the impact of AIDS little research has been conducted to describe the situation from the grandparents point of view in order to discover ways to assist this overloaded elder generation. Still a sample of relevant studies were found and used as orientation of the explored subject and context.

As children lose both of their parents there are in general two alternative ways to take care of them (unless they become street children) that is in institutions/orphanages and by the extended family, in general synonymous to grandparents. In Mass orphanhood in the era of HIV/AIDS the advantage of the extended family in relation to institutional alternatives for orphans is emphasized. Children’s need of a spiritual connection to their family and clan is fundamental, especially in the African context, for their social development and helps them to find their place in society (Matshalaga, 2002). The traditional African life is characterized by a deep-rooted brotherhood where the sense of belonging to a big family or group is essential (Foster, 2000) The main disadvantage with children’s homes is that it undermines traditional models of care and alienates the children from their families and culture. The extended family is a superior alternative as it allows the child to grow up within their family, culture and traditions, why the extended family-model should be given priority and be supported (Matshalaga, 2002).
Since it’s the grandparents who usually end up with the care-responsibility and they are considered the best able to meet the orphans non-material needs Ansell & Young suggests that policy interventions should aim at facilitating sustainable arrangements by enabling suitable households to provide care (Ansell, 2004). As the experience of being the surviving extended family includes many aspects a number of inter-connected issues must be considered to be able to understand the complex situation. Considerable factors are; the nature of the disease, the HIV-status of the bereaved, multiple losses (Demmer, 2004) and the age of the orphans (where the children below five are the most demanding) (Nyesigomwe, 2006). It is in general the poor who are hit worst by the effects of HIV/AIDS and neither the public sector or communities provide adequate safety nets (Miller, 2006). Inadequate social, financial and emotional support due to the social stigma associated with AIDS makes the elder generation unable to provide for the basic needs (Demmer, 2004; Miller, 2006). A study made in Botswana where the HIV-prevalence is extremely high shows that the grandparents feel overwhelmed and exhausted (Lindsey, 2003). Feelings like pessimism, rage, disillusionment, despair and powerlessness are common and the researches made indicate on high rates of depression (Demmer, 2004). Poor health conditions, malnutrition and lack of income (partly because of insufficient land for growing food and raising animals) and health services is yet another aspect that makes grandparents unable to provide quality care for their grandchildren (Lindsay, 2003; Nyesigomwe, 2006). Two qualitative studies explains the correlation between financial poverty and care. *HIV/AIDS, income loss and economic survival in Botswana* shows that the consequence of the heavy burden of caregiving for many children and the time and effort it requires is that the overloaded breadwinner loses his/her job (Rajaraman, 2006). In *Africas Orphan Crisis* a further aspect is examined where the consistent struggle searching for money or food gives no time to care or spend time with the children. Added to this the lost income from the diseased results in an extreme economic stress (Kidman, 2007). Many studies raises stress as one of the main problems faced by the caregivers. The stress experienced is related to the grandmothers experience of high physical and emotional demands, child behavioural difficulties and the limited support due to stigma and isolation (Joslin, 2002; Oburu, 2005). The author of *Barriers to Permanency Planning for Older HIV-Affected Caregivers* points out the grandparents lack of knowledge about legal processes and legal authority as the main obstacles (Boyer, 2005). According to a study made by the Human Sciences Research Council in South Africa the willingness to care for vulnerable extended family members is high but people will need considerable help to realize this potential (Freeman, 2006).
Suggested approaches for improving the living standard of the grandparents and orphans are many including for example training grandparents in meeting the emotional needs of the children (Nyesigomwe, 2006), social and legal services for the caregivers in terms of advocacy and networking to share resources and lessons learnt (Demmer, 2004), encouraging formal adoption and helping grandmothers to manage disclosures and HIV-stigma (Boyer, 2005).

Social Systems and Human Interaction

In order to enter into and create a greater understanding of the collected material concerning difficulties and management within the examined circumstances I have chosen to use System Theory which can be implemented at both macro and micro levels. According to this theory the world consists of different social systems of human interaction and resources, the systems are to be mutual and the actors have to consider the others (Moe, 1996). Payne mentions three systems that can help individuals in line with this theory; 1.) Informal and natural systems such as family, friends and colleagues, 2.) Formal systems, for example local government and labour unions, 3.) Social and public systems which can be schools or hospitals. This perspective is useful to clarify the systems present and available for the grandparent-orphan households and its functions. Social work in terms of the system perspective implies; helping people to use and improve their own ability, creating new connections and relations between individuals and different resource-systems and to develop or facilitate the interaction within and between these systems (Payne, 2002).

Self-Help for Improvement

The second perspective used to enlighten the outcome of this study and it’s potential to develop new ideas of ways to improve the explored situation is empowerment. Empowerment refers broadly to the expansion of freedom of choices and actions to shape ones life (Empowerment and Poverty Reduction, 2002), it is a self-help approach where the aim is to help individuals to obtain and maximize their control and power to influence actions and decisions concerning their own life (Adams, 1996). This is made through encouragement, strengthening individual capacities and increasing the possibilities to use this power (Payne, 2002). Due to the strained conditions within the explored context empowerment is one approach to make the best use of the grandparents inherent capabilities.
MATERIAL AND METHODS

Planning and Design

In order to explore the current situation in the new family settings caused by the massive spread of AIDS and to examine coping strategies developed by the elder generation the study was made from an inductive onset whereby no previous theories were directing the study (Halvorsen, 1992). With the aim to get an overall impression and to capture grass-root-strategies qualitative interviews was chosen as the most appropriate method to go about the topic. From the aim of the study and to cover most possible relevant information in a structured way an interview-guide was brought out including two parts. The first part consists background information concerning their own children, grandchildren, husband/wife, relatives and occupation. Part two brings about their challenges and strategies due to; main difficulties, other challenges, reactions, support, changes, lessons learnt, strength, advice and future. For the informants as well as the interpreters to know what kind of study they are to partake in an information letter was made explaining who I am, the aim of this study, their part of it, the role of the interpreter and ensuring confidentiality for them to make an informed decision to participate or not.

Considering time and estimated capacity the number of interviews was made to be eight. To cover a broad spectra of the grandparent-experience and to bring diversity to the results I choose to make interviews with both grandmothers and grandfathers, four of them living in urban slum and four in rural areas, four of them knowing and confessing their positive HIV-status. In order to reach this group of people due to time limits of the study and the fact that I am a foreigner the selection of informants was made through two domestic community based NGOs that were familiar to me before this study. These organizations are working in the two regions in Kenya with the countries highest HIV-prevalence (NACC, 2007), that is KICOSHEP (Kibera Community Self Help Programme) in Kibera slum, Nairobi and Good Samaritan Help to Self Help Programme based in Nyanza district. In Nairobi the informants were reached as clients of the organisation and in Nyanza one of the staff selected the required number of grandparents through contact with village elder, chief and church leaders. To get information of value for the aim of the study the criteria’s for the informants was to be (1) the only caregiver, (2) for three or more AIDS-orphans, (3) since three years back or more. The chosen informants were contacted and informed some days in advance by the organization staff, who also volunteered to act as interpreter for the interviews.
Carrying through the Interviews

With the ambition to make the informant to feel comfortable and to bring the sense that this session is made according to his/her own premises and conditions the most appropriate venue for these interviews were in the grandparents own home. This also as a way to get an increased insight and overall impression of their situation which favours my understanding of what they share in the interview. I was brought to the home by the local interpreter and the session was started with presentation, information, the informant giving their informed consent and an opportunity for him/her to raise questions. The interview was carried out according to the interview-guide, still open to stories and further questions. Everything being said within the session was translated from English to the local language (Kiswahili or Kijaluo) and vice versa. The interviews lasted from 30 to 50 minutes, the whole conversation was recorded on tape and I was taking notes throughout. After the session, as an expression of my gratitude towards their participation, the grandparent was given two packets of flour and sugar of which they were not knowing of beforehand.

Analysis

First of all the information collected through these eight interviews was transferred from audio version to text through manual transcription to make the material suitable for further analysis. Thereafter the results was structured through content analysis and categorized from the following topics; life situation and difficulties, sources of strength and support, advice and wishes. The issues mentioned within each topic was arranged into simple tables to view the width of the results showing similarities and differences in the collected data. After survey and initial orientation of the results, as a second step of the analysis, I turned to get deeper into how the grandparents talks about these issues to approach a greater understanding of the values and meanings of the issues raised. A number of representative quotations were selected to exemplify the findings and analysis made.

Ethic issues

HIV/AIDS

As most HIV infections are contracted through sexual intercourse with an infected person HIV and AIDS is commonly associated with unfaithfulness and immorality. This condition makes all studies related to HIV and AIDS to be delicate especially when it includes individuals who are directly affected and/or infected by the disease. This requires knowledge, respect and tactfulness in order to not offend or harm the persons included by the study. When
designing this study I formed the questions used in the interview-guide to be neutral and non-judging. When introducing the interview-session I expressed my greatest respect and reverence for the informant and his/her family.

**Children’s Death**

Secondly this interview is based on seriously damaged family-patterns. The men and women participating in this study were identified by the criteria’s of the death/absence of their partner, their deceased children and responsibility for needy children. This is a truly unfortunate situation and the information required in the interviews forces the informants to think of and talk about very heavy subjects due to sorrow, needs and unfortunate circumstances. In spite of the mentioned issue this interview is also an opportunity for these people to express their thoughts and feelings which can be relieving. The fact that somebody is concerned about their situation, willing to listen and valuing their knowledge and experiences might bring a sense of hope. Still there is a risk that my visit creates high expectations of a change in the near future.

**White Researcher**

The fact that I am a white person entering a home in the slum or a rural village might cause curiosity and reactions from neighbours in terms of financial support or assumed HIV-infection. This is hopefully not of great importance since the informant was contacted and voluntarily accepting the conditions for this interview some days before my physical appearance.

**Obstacles and Limits of the Study**

**Foreign Context**

Making a study in a foreign country where the culture, language and life conditions are in many ways different from the one of the researcher implies some issues to consider throughout the study. The choice of focus for this study is based on my previous experiences in Kenya within the areas of the study, that is urban slums and rural villages, where I have come in contact with many grandparents living under these specific conditions. The current context is therefore known to me and the interviews has been carried through in consultation with local actors.
Interpreter

One of the limits in the collection of information is the need of an interpreter for the interviews. Although English is the official language in Kenya most of the grandparents used for the interviews are not able or comfortable using English but prefer using Kiswahili or other local languages. This means that all material presented in the results are not direct quotations from the informant but the translation made by the local staff. The interpreter was given clear restrictions beforehand to not intervene or change anything of what is to be said throughout the interview. Still this arrangement could influence the communication between me and the informant within the interview session as well as the following analysis.

Existing Programmes

The time frame of this study imply some limitations which affects the extent of research in terms of existing governmental and non-governmental strategies and programmes in helping grandparents in this specific situation. This fact might however favour the inductive approach of the study with its aim to discover new ways of support and management of the grandparent-orphan situation.

RESULT

From the information collected I have chosen to present the results according to the themes and issues that appeared through the analysis. To begin with the grandparents describe how they experience the situation of being the only caregiver for their orphaned grandchildren and what challenges they face. The most significant concerns raised was the children wishing to be like “normal” children, the devastating poverty, the powerful impact of stigma, the effect on the children in terms of schooling and exposure to prostitution and hopelessness due to alienation and the extent of the problem in the surrounding community. The second theme, as the informants were asked about their ways of handling the difficulties, especially the church and the support group were mentioned as sources where they get encouragement, company, distraction from their daily worries and occasionally some financial support. Finally the grandparents shared their advices to others facing the same challenge where the importance of showing genuine love to the children and to learn how to tackle stress was emphasized. Coming to their hopes and wishes for the future they all pleaded for the children to get education and stressed the meaning and value of getting their own land to stay and cultivate.
To maintain anonymity pseudonyms are used instead of the informants actual names. Beatrice, Pauline, Ester and Doreen lives in Kibera slum, Nairobi. For income they offer services as fetching water, washing clothes or massage, except Doreen who is only begging. John, Edward, Lillian and Theresa stays in the rural areas of Migori, Nyanza district. Theresa is selling roasted groundnuts while the others live on farming.

**Life Situation and Difficulties**

The overall condition of the families affected by AIDS-related deaths is marked by hardship. Loosing a son or a daughter is a great trauma itself and added to this these grandparents face great demands of their capacity in compensating for the loss. The extent of the grandchildren’s needs related to the existing physical, financial and social resources leaves these elders to a daily combat against poverty and depression.

**Orphans Wanting to be Like Other Children**

The grandparent-orphan family set-up is what no one wishes, neither grandparent or child, it is an alternative used in the absence of others. Wishing and trying to look and function as an ordinary family in spite of the circumstances and the limited capacity is the essence of their everyday struggle. What emerges through the grandparents tellings is the expression of an impossible task where the resources never are sufficient to sustain the children’s different needs. A suppressed frustration is perceived over the kind of life they ended up with in their old days.

_They might need to look as other children that have parents … because to me I wanted to make them to the living standard so that they can be like other children, but the condition does not favour us … even though it is a great burden, I have to carry that load. So the thing that is at this age of ours as now it has come to us, we the old people has now become the youngest people to feed these children, it becomes a very heavy burden_ (John).

**Poverty**

The main condition which they have to face every day is the reality of severe poverty. AIDS is a costly disease that first eliminates the ability to generate an income and secondly drains the family savings on drugs required for the different opportunistic infections. When the parents finally die they leave nothing but needs and debts behind. As the only caregiver for a
number of children in a community where the majority are living below the poverty level, income and the daily bread becomes a true challenge.

_They were working, the parents of the children, but when they started illing their job was stopped. So whatever they had during that time when they were sick they sold it, everything … …sometimes we sleep without eating_ (Beatrice).

Soon they end up depending on loans and leftovers from neighbours, a process that affects the relationships with the surroundings as well as within the household. Neighbours dismisses a parasite, the orphans loose respect for the insufficient family provider and a general despise grows towards the grandparent.

_Because there is no food they (the children) go to the neighbours to look for food and then the neighbours will come and tell me that the children are just disturbing us here …and you see it is like I have a debt. I borrow and then whatever I get as a profit I eat that profit and then return the money to where I got it …_ (Pauline).

**Idle children**

One of the grandparents main worries is the outcome of the children being idle. As an effect of the absent parents, lack of money for school fees, and loosing hope for the situation to change the children estrange from the school and the household and expose themselves to risky behaviours. The desperation of not having school or a “real” home to go to drives the children into dangerous sexual relationships. They risk being exploited for money or food which implicates a great risk to contract HIV. The grandparents are aware of the situation but incapable to intervene because of their lack of money.

_They are sent away from school to come and take school fees from me and now I cannot produce that. Now they are here_ (Ester).

_So she [one of the orphans] doesn’t even want to do anything because she has seen that there is nothing in this house, now she just walks_ (Pauline).

_So if at all she had something to do, something at least to make her busy, it could be easier for her to not mind about men_ (Beatrice).
I advice them [the children] to go for VCT (Voluntary Counselling and HIV-testing), to know their status. Maybe she might be cheated when she is hungry, and maybe the person is sick … they exchange sex for food or maybe money because they don’t have (Doreen).

Left Alone
Making bad things worse, when the providing children die, even the precious friends withdraw from the grandparents. The heavy workload the grandparents are left with, of feeding and raising children which requires all their time, and probably the limited financial ability to show generosity to others alienates these elderly people from the valuable neighbourhood. This is a serious aspect of the situation as it excludes the grandparents as well as the grandchildren from the spirit of community.

When my wife was alive and the children were alive I had free time even to go and visit friends but since I remained alone in the family with these orphans now I’m fully concentrated and cannot go out even to visit some people, I am totally in the home looking for everything (Edward).

When my husband died and I remained alone now nobody is coming to me, nobody is asking for anything (Lillian).

No Home to Go to Because of Stigma
Most of the people staying in the slum has a home of their origin in some rural part of the country, a precious place of identity where they can plan to go back to when things get better. But to be HIV-positive is commonly perceived as something very shameful. As a way to express dissociation, preserve the family honour and to clear oneself, anyone discovered to be infected with HIV is automatically rejected and excluded from the family homestead. The person hit by this hatred is left with shame, guilt and deserted from all means and the permission to go home.

When the boy died because of HIV that’s when they started hating me. They say I am the one who brought the HIV (Doreen).
When I feel that I want to go home – where do I go? The husband doesn’t want somebody who is HIV positive to go to the family (Ester).

I was chased away from home because I am HIV positive. They [the in-laws] demolished the house at home… they say they don’t want to see even the children or me at home. I have no future, no life (Pauline).

Wants to Die

When the needs are increasing yet the resources reducing and the traditional safety-nets disappear the hardship becomes too much and some of the grandparents starts loosing hope. The severity of the situation becomes evident when some of the grandparents in the slum give out an expression of the greatest desperation. They have reached a point where they see no salvation from the misery but wish to die. Still they are kept to continue their struggle because of their responsibility for the vulnerable orphans.

I wanted also to take medicine to die. Because he left very small children so there was nobody who was to help me (Ester).

I feel I could run and kill myself but there is no way I can do that when I think back that where would I leave the children because the moment I would die that is the moment the children will also suffer more (Pauline).

Too Many to Get Support

There are many churches and NGOs addressing the needy but because of the current extent of poverty and the constantly growing number of AIDS-orphans in these communities the chances to enhance any kind of external support are minimal. Looking for assistance requires time and energy and the competition is high among the poor and needy why many have even given up trying to access these sources.

Like now when you go to the church, because here in Kibera people are, they are poverty, and they are too many. So once you take the case, like me, if I take that case to the church, there is another one who is having a very big problem, than mine. So it becomes difficult for us to get that support from the church (Ester).
Almost every grandparent in this area/sub location is caring for orphans. So many and no support (John).

Instead of going to the NGOs or to the government, it is better I go to fetch for somebody water (Pauline).

Sources of Strength and Support

In relation to the range of challenges mentioned throughout the interviews the grandparents were asked where they find strength to move on and whether they have any alternative channels to get assistance. Most of them referred to the fact that they ended up in this despair just because of the non-existing support. Yet I insisted asking what keeps them on the track, practically as well as mentally. The answers show that there are still some sources that makes a difference in their life. The most significant sources emerging is the church and the support group who provide fellowship and solidarity.

Church

The number one religion in Kenya is Christianity and all informants referred to their Christian belief in one way or the other as a source to manage their daily life. In times when the own family network turn out to be deficient the church becomes an important haven for the bereaved to divert their mind from the problems, to get social as well as financial support and to get spiritual encouragement.

First of all I believe God is the one providing us strength to move on, because nothing else we can be proud of, because even the way they are learning, even how they are feeding, even the way they are getting clothes it is only God providing for us (John).

I went to the church and heard what they were preaching. So I got that courage from the spiritual (Pauline).

It is somebody like pastor I can go and say today I didn’t get any food. Then if God blesses him he can give … sometimes I go to one of the believers maybe a church member or a friend and ask for, if she gives me food then I will eat and get strength so that I will continue so I don’t feel stressed (Lillian).
Support Group

One of KICOSHEPs ways of addressing the needs of the HIV/AIDS infected and affected is through the Support Group. This is a forum where people are welcome to share experiences, discuss common issues and be taught on relevant topics such as HIV/AIDS awareness, Positive living, Psycho social support and income generating activities (IGA). The weekly gatherings are voluntary and among the slum dwellers an appreciated source of empowerment where they enhance hope and courage.

*You get hope from there because, someone might think that she is the only one but when you see that we are many you get hope from there…we interact together and then each and every person brings his or her own experiences. And through that I am empowered to live* (Doreen).

*When I come from the training, I feel I am very free to, I am very open to talk, in the church, in the public. Even the church knows [her HIV status] (Ester).*

When the stigma related to HIV destroys all social network, in times of troubles others living with the virus are the ones who remain or appear as true friends to lean on. As within the support group, one of the women in the slum explain that when she was evicted from the house by the landlord and the relatives rebuked her she was fortunate to have some HIV-positive friends who accepted her.

*So when I was looking for this job I was staying with people, those ones the friends who are having HIV/AIDS* (Beatrice).

**Words of Advice**

The vulnerability of an orphan, having lost both parents at an early age, is something important to consider for the one taking over the parental role. As the children’s world has fallen apart and their foundation is shaken by the loss of their parents the grandparent has to act carefully in order to create a new home and restore their confidence. The informants shared what they have learned through their years as caregiver for orphans, they are speaking of the importance of being humble and to do your best to create a good and positive family-atmosphere and to learn how to handle stress.
Showing Love

When the grandparents were asked what advice they would like to give to anyone entering their situation they all emphasized the value of receiving the children with a meek and loveful heart. An orphan needs you to talk and act wisely in order to restore some of their broken world.

First of all you have to humble yourself, then you will help these orphans … what I have learned through orphans. First – an orphan does not like to be an orphan, just accidentally finds that he has become an orphan. After the child has become an orphan and comes to you, so you have to give out parental love … the orphan needs a lot of comfort, the orphan needs to be given an atmosphere of advice so that their heart can be in a strong place so that they don’t think of the past that their parents have died (John).

Managing Stress

The often miserable living conditions and the uncertainty about tomorrow acquires guts and a strong mind. One of the things they have learned is that when stress and negative thoughts gets hold of your mind it affects your whole wellbeing in terms of your role as grandmother and the physical health. To learn how to be patient and keep a calm mind are some of their strategies for surviving. Some of the grandmothers shared how they have adjusted their mindset to cope with the tough situation.

I have changed my life because I don’t think so much. However I have the problem but I don’t take it so seriously. Because it is also one way of giving out stress … I would tell them not to be annoyed. If you become annoyed you will be sick (Ester).

Wishes for the Future

With the aim to help grandparents in this specific situation it is not only essential to clarify their challenges but of even greater value to consider their dreams and how they picture a good future. By the end of every interview the grandparent was requested to share their hopes and wishes. The children’s education and the issue of land is of the grandparents major concern.
Education

How to create a future for the grandchildren is what the grandparents are constantly reminded of. Unemployment is high in Kenya and anyone without a proper education will automatically be left behind, destined to a life in poverty. Since the children have no parents and their caretaker is growing old there is a great need for them to become independent and self-sustaining as young adults.

Because I am growing old and at the same time I am sick, so that is why I am crying for the children to get enough education to sustain themselves (Pauline).

Land

The geography and climate of Kenya makes it good for cultivating and the majority of the population live on farming. Land is usually inherited and of greatest importance as it functions as a grant for food, housing and a future for the children. The issue of land was raised within all of the eight interviews as the way to get back to a normal life and make themselves and the children self-sustaining. It would at the same time provide a safe place to gather the children as a family, something that is on the very top of every grandparents wishing list. The informants who are HIV positive have been deprived of their own land and are wishing for an opportunity to go and demand their legally owned land. Others would prefer to settle in a foreign district where they won’t suffer the discrimination from the relatives.

Another challenge is that how I could get money and go back to my husbands home and try to talk to the assistant chief even the D.O. such that they can give back that land and I can be able to build that land. Then I will go back and stay at home. It will also be cheaper than staying here (Pauline).

Now I am wishing maybe if I had somebody to assist me in getting my own plot, my own shamba (field for farming), to build and stay there, because if I go there at home I am stigmatized and they say that maybe I am going to spread the disease to the people, the HIV to other people, so they don’t want me to go there (Beatrice).

Most people [the neighbours] has grabbed the land and nobody is in a position to take it back, because there is no son now (Theresa).
DISCUSSION

Summary

The current condition these grandparents express in the interviews is a situation marked by severe poverty, loneliness and worries about tomorrow. The consistent lack of money exposes the children for many risks such as contracting HIV. HIV/AIDS-related stigma and the great burden providing for these orphans alienates the grandparents from relatives as well as friends which increases stress and depression. The high extent of poverty in their surrounding society reduces all chances to get assistance due to the great needs and limited resources.

The sources of strength and support that are mentioned are mainly from church, the faith in God as well as support from fellow members, and the Support Group where they meet people in the same situation and get encouragement as well as skills. What they have learned through the grandparent-orphan experience is the importance to be humble, showing parental love to the orphans, to control feelings of stress and anger and to interact with others living under similar conditions. When it comes to hopes for the future their answers are unanimous – the children to get job and education and to get their own land to stay and cultivate.

In Relation to Former Research

Compared to the previous studies presented above the results of this study confirmed and supported what was already known in many senses. The descriptions of the grandmothers situation and living conditions are much similar to what appeared in this study in terms of; lack of financial, emotional and social support, stigma, lack of adequate safety nets, child behavioural difficulties, stress, depression, poor health, and insufficient land. Some issues like lack of knowledge about legal process and lack of legal authority (Boyer, 2005, Demmer, 2004, Miller, 2006) were not pronounced as difficulties by the grandparents but appeared implicit within the interview speaking about the problems in accessing land. Although some of the grandparents expressed a need of emotional and social support still others referred to HIV positive friends, church and support group as sources of strength and encouragement which has not been mentioned in the former studies. I agree with the fact raised in *Aids and bereavement* that the HIV status of the bereaved is of great relevance in understanding the grandparent-experience (Demmer, 2004). The informants who were HIV positive expressed a greater despair and hopelessness which was not articulated by the HIV negative grandparents. To which extent this is related to the place of residence, urban slum or rural village, is not
evident in this study. The power and severe effect of stigma should not be underestimated though which appears clearly through the interviews made.

**New Security Systems**

The social security system in the African context consists mainly of the three parts *relatives*, *friends* and *neighbours* (Foster, 2000). This kind of informal insurance is usually a sufficient and well functioning safety-net for the individual living under normal family conditions (which could be one reason why the public welfare system is not much developed). The disastrous impact of HIV and AIDS in Kenya must be understood from its consequences for the traditional patterns. First of all the AIDS deaths damages the first category, the family, through wiping out one generation who’s responsibility is to raise the children and care for the ageing parents. Secondly the two remaining categories, friends and neighbours, are nearly eliminated by the HIV-related stigma and the fact that grandparents and orphans are not able to contribute to the “system” due to their lack of power and resources. Alternative systems appearing are *church* and *support group/HIV positive friends*. Although they are of great importance these substitutes are deficient compared to the former since they do not contain much financial resources, they are not very stable, they do not secure the future for the children and also the grandparents ability to interact is limited due to their heavy workload that acquire all their time. According to the help approach presented within the system theory first of all the grandparents own ability should be improved to increase independence, through for example boosting their income generating activities. New connections and relations between individuals and different resource-systems should be created, as through the church and support group and finally this interaction within and between these systems should be facilitated which could be done through advocacy and networking.

**Empowered Grannies**

The destiny of many grandparents that is described through this study shows that they are deprived from resources as well as energy. The Support Group mentioned by the most unprivileged in the slum is one way to enhance courage and confidence. The issues of depression and stigma are being addressed there as two of the grandmothers express it “*we interact together and then each and every person brings his or her own experiences. And through that I am empowered to live*” and “*when I come from the training... I am very open to talk, in the church, in the public. Even the church knows [her HIV- status]*. This forum also avails resources in terms of knowledge and skills relevant to their situation. As empowerment
aims at strengthening individual capacities and increasing the possibilities to use this power
the support group combined with advocacy and knowledge about legal rights, especially
according to the rights of land, could be further developed as a very cost-effective and useful
way to guide the vulnerable grandparents to a better life.

**CONCLUSION**

Entering into the reality that so many grandparents who are left with AIDS-orphans live in
and listening to their real-life-narratives has been a privilege as well as a challenge. Analysing
their urgent despair it is easy to start loosing hope. My conclusion after working through the
collected data is though that the main problem emerging in different shapes is the absolute
poverty they live in. This poverty is primarily caused by two main factors, that is HIV-stigma
and the issue of land. Working for the orphans and the grandparents situation today and in
future stigma and access to land must be the major obstacles to target.

The meaning of land should not be underestimated. To have your own plot is first of all a
cheaper alternative than renting a house in the slum, it means to have a homestead, a place to
gather the children, it creates independence in stead of depending on others, it provides food
as it enables them to cultivate and it is something sustainable for the children to inherit. If aid-
organisations and agencies could get committed to helping these grandparents to access their
own land by sponsoring the legal process it would probably be a cost-effective, long-lasting
and appreciated contribution as the elder people urge for independence. At the same time it
would strengthen the family-identity and self-respect of the deprived. If it was not for stigma
many of the sufferers in the urban slum would be included by the family-network where the
burdens are shared to some extent. The matter of land is much an effect of stigmatization as
the infected are chased away from their place of origin. As the issues of stigma and land are
inter-connected I suggest that they should be dealt with simultaneously to make work
effective. The support group emerges as a useful way to handle stigma. It provides an
opportunity for the HIV positive to be open with their HIV status and despise the shame and
the reactions from others. When more people turn to confess their status and show strength
and confidence the discrimination will gradually reduce as people will realize that they do not
rebuke just one single person but a major part of the community. Such a development would
change the common mind in to fighting the disease instead of the people living with it.
REFERENCES


Appendix II

INTERVIEW-GUIDE

Background:
1.) Own children
   a.) How many?
   b.) How many have passed away?
   c.) When?
2.) Grandchildren
   a.) How many grandchildren are you caring for by now?
   b.) How old are they?
   c.) Since when?
3.) Husband/wife
   a.) When did he/she leave/pass away?
   b.) What changes did that bring to your life?
4.) Relatives
   a.) Do you have any relatives staying in the village?
   b.) Do you receive any kind of support from them?
   c.) If yes, of what kind?
5.) Occupation
   a.) How do you make a living?
   b.) Does it bring enough to sustain your household?
   c.) If not, what alternative ways are there to get money/food/clothes…?

Challenges and strategies:
1.) Main difficulties. What has been most difficult during your time as main caretaker for these orphaned grandchildren? How did you cope with that?
2.) Other challenges. What other things that have been challenging? (ex. provide for all needs, upbringing, grief) How have you handled that?
3.) Reactions. What are the reactions from your surroundings of you caring for the grandchildren?
4.) Support. Do you receive any kind of support from friends, church, society, NGOs, or the Kenyan government? If yes, in what way?
5.) Changes. What has changed, for good or bad, during these years?
6.) Lessons learnt. What have you learnt from your experiences?
7.) Strength. How/where do you find strength to move on?
8.) Advice. What advice would you like to give to a grandparent who enters this situation?
9.) Future. How do you look upon the future? What are your hopes and wishes?
Appendix I

INFORMATION TO INFORMANT

My name is Linda Svedberg and I am a student in International Social Work at Mid Sweden University. I have been in Kenya four times before for voluntary work or studies and I am interested in how to help people who are infected or affected with HIV/AIDS.

I have come here to make a study for my final paper. Since so many children in Kenya and other countries have been orphaned due to AIDS and left with their grandparents I will make this study to examine how these grandparents, like You, manage this situation. The purpose is to get to know different ways to deal with the different kind of difficulties you face, practically as well as mentally. The results can be useful to discover new ways to help and my wish is to support people in Your situation.

The information will be collected through interviews which will take less then one hour. I will use a taperecorder and take notes throughout the interview.

Peter/Julius will translate for us, if there is something or some question that you don’t understand please ask us to repeat or explain it. If there is a question that you don’t want to answer to you do not have to.

Everything you say will be confidential which means that personal information about you will not be given to other people and your name will not be used in the report.

This study has nothing to do with KICOSHEP/Good Samaritan and what you say will not be taken as criticism or expectations of the organisation.

In this interview there are no right or wrong answers, it is Your unique experiences and knowledge that is of value for this study.

To participate in this interview is voluntary, are you willing to do this interview? If you change your mind, it is ok, just let us know.

Linda Svedberg
Mid Sweden University