

“Minor field study: AIDS – how it affects the elders and the social system in Zambian Society.”

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Introduction

In the last two decades HIV/AIDS has spread all over the world and it is today one of the deadliest diseases of the modern age and a major threat to global health as the epidemic affects the welfare of households, communities and societies.¹ Especially in the third world, where poverty, poor nutrition and lack of good health service are common, the HIV-virus has good terms of spreading. It is a fact that 70 percent of all people living with HIV/AIDS live in Sub-Saharan Africa. Most often, the disease affects adults in the fertile and sexually active age 15-50 with devastating consequences for the household and community, both socially and economically.²

When people in their prime age as adult members and workers of the family pass away and children and elders are left behind³, older adults such as grandparents become surrogate parents for orphans often under stressful and painful circumstances. In the absence of clinical treatment the HIV-patients are left with the care of the family, and the grandparents take on a new role of raising the children and running the family instead of being taken care of. It is these grandparent caregivers, which are the focus of this study. What happens when the parent generation disappears? How does family and community life change when the grandparent generation assumes parental responsibility in raising their grandchildren?

Zambia is suffering under the massive spread of HIV/AIDS and it is the most challenging development problem in most of Africa. On the surface Zambia seems as a country with every potential of becoming a wealthy and powerful nation – the country is rich on nature resources and has a big copper industry. There is the Copperbelt in the north, which is a huge area that produces massive amounts of copper and gives work to thousands of people. Zambia is also rich on a unique nature life and every year many foreign tourists visit the big game- and national parks. But behind all this the country is dealing with severe issues that have a devastating impact on the country and the population. There is a widespread poverty that is growing stronger mainly due to increasing unemployment, corruption and crops failure. Another major problem is the AIDS epidemic that is on the rise and is shattering the social life and organisation of all Zambians and strongly weakening the possibilities for this country ever to be able to grow independently. Families' dissolve, children are left without parents and grandparents without family support. The social impact from AIDS is growing and ruining the social security system, which is based on the family. Thus if we want to

¹ Barnett & Whiteside 2002:5

² Barnett & Whiteside.2002:46

³ Egerö, Hammar skjöld & Munck. 2000:2

understand the impact of AIDS in Zambia it is necessary to put more focus on the social affects caused by the disease not just on the individual but on the whole family and kin network. HIV-infected individuals affect the equilibrium of the collective units such as households, families, local communities and whole nations that have difficulties coping with the loss of many individuals who make up the social system. The stability and reliability of the social system is in jeopardy.

The demographic structure in many African countries is changing fast due to AIDS and the group of healthy older people grow relatively larger.

One of the reasons why there hasn't been much focus on the elders before is that it only became a real issue when a lot of the people that got infected in the beginning of the epidemic in the 1980's started to die leaving children behind. So far the main focus has been on the children who are orphaned by AIDS and they have been seen as the most vulnerable and the most adversely affected by the epidemic. Losing a parent puts the children under an immediate pressure and psychological distress. They are dependent on support with food, education, health-care, housing and clothing from the local community and NGO's.

Traditionally the elders in Zambia could look forward to a nice and relaxed retirement being looked after by their younger relatives. Unfortunately this is no longer the reality for a big part of the senior citizen in Zambia. However only recently the governments and organisations have realised the major effect of HIV/AIDS on the elder generation who now ends up with the responsibility of taking care of their children and grandchildren who are affected by the pandemic. This is a problem that will only grow over the next decades and even if the rate of infection were to decline, deaths rates from AIDS will remain high and the numbers of orphans will continue to be high for many years. Somebody has to look after these children because the government doesn't have the capacity to do that, which leaves the burden on the elder generation.

In this paper I will demonstrate that besides causing health effects on the individual, AIDS is also threatening to kinship and family life.

I will implicate that to diminish the negative consequences of HIV/AIDS, we need to set in on AIDS from the social side by creating a social support network for both the grandparents and other family members who end up as caregivers for the children and sick. But also for the family system in whole, which is disappearing under the heavy pressure from the effects caused by AIDS on the social system. Both the social health of individuals and communities is being affected by the spread of AIDS and there is a need to draw focus to both these areas and supporting solutions to be made to

sustain kinship and family life. I will describe what is already happening on the social arena in Zambian local community. How people react to the epidemic and starting to organise themselves, together with modes of coping for responsible individuals and their families and what is done to put up with the changes that will follow the AIDS impact.

The deep-rooted kinship systems that exist in Zambia and the in rest of Africa, as well as the extended-family networks - is an age old social security net for vulnerable children like orphans and for other family members to help and support each other. But because of the heavy pressure from HIV/AIDS this system is on the verge of a breakdown as all families are affected by the disease and don't have the extra capacity to look after any more children or patients, when they themselves already have enough.

Many governments in Southern Africa are beginning to see what impact AIDS has on the extended families and the economic status of the households. The elders have to provide food, medical care, psychological support and daily physical care for their sick family members and young grandchildren, and many don't have the capacity to do that.

Elders failing strength and energy because of ageing have difficulties earning enough money to support the family they end up as main caregivers for, when the head of the households dies. The loss of financial and other forms of support that the elders would have received from their children disappears and leaves them with a tremendous burden and this causes changes in the family network and social support.

At the same time many elders fear for the loss of culture and traditions as the proportion of older people to younger is changing. The young generations is starting to live more different than former generations and most importantly have a different view on sex and relationships. All this is magnified by HIV/AIDS. The question is how much longer the families can care for the increasing numbers of orphans and the general transformation of the society that follows in the footsteps of AIDS.

“The elderly are dependent; dependence requires support; support is found in social life; social life requires energy and inputs if it is to be maintained and reproduced – the elderly lack the energy to make these investments, that is why children are important and why, when they die and their work, remittances and other support cease, the circumstances of an older person can decline dramatically. What then happens when the grandchildren comes to live with them?”⁴

⁴ Barnett.2002:218

The elders lack the energy to contribute with input to social life and the adults who were supposed to contribute are dying of AIDS. Automatically there is a decline in social life and support as the ones who were responsible for it have died and the living conditions of elders decline and is pushed further when the grandchildren come to live with them.

Purpose

From the above described aspects and facts on the AIDS situation in today's southern Africa and Zambia, this paper will focus on how the older people of the population in Zambia are affected by the illness and death of their adult child. Focus will be on changes in the whole kinship-system and Zambian social system in general.

Specifically I will address the following key questions:

- *In what way is the traditional social kinship system altered by the change in care taking and social roles?*
- *How do the elders adjust to their new caregiving responsibilities?*
- *What impact does AIDS and the new caregiving burdens have on the elder's vision of a family?*
- *In what way do the elders cope with all the changes and the stigma that surrounds the issues of HIV/AIDS? What role does gender play in all of this?*

Method

In the following chapter I will present my field study and method.

This is a qualitative study that provides an analysis of empirical material. As method I have been doing ethnographic fieldwork, which has included participant observation and interviews in Ng'ombe, an area on the outskirts of Lusaka, Zambia. The area includes the local suburbs Roma, Olympia, Olympia Extension, and the townships Old Ng'ombe and New Ng'ombe, where I conducted most of my fieldwork. I spent two months in the capital Lusaka, where I lived in a hostel and daily took the local bus to Ng'ombe where I did my interviews and general fieldwork. Of course this made it more difficult to get integrated in the local area as I wasn't present 24 hours a day and didn't spend the nights there but lived in a hostel with a lot of tourists and in general a western setting. It was a forced choice as it was not safe enough to live in the townships. This made it more complicated to fully get into the "native" way of thinking. Being from a western country myself of course has made me see the world and especially the third world and their way of living in a different way than they do themselves.

Sometimes it took a lot of effort to stay focused on my fieldwork because of the regular shifts every day between western and local settings. Also when you do fieldwork you have to be aware of the "lenses" through which you see the world and that it affects your way of interpreting the world surrounding you.

Coming from a western country and in that way being so different from the people I interviewed also made it difficult to get them to understand what exactly I was doing and sometimes they couldn't understand the purpose and the relevance of some questions as the answers seemed obvious to them. But my status as a curious foreigner also allowed me to ask stupid questions without offending anyone and they didn't blame me for trespassing borders into the private sphere.

Through my contact from the university of Zambia, Gertrude Mwape I got in touch with the non-governmental organisation *Care Zambia* who introduced me to Angela Malik who became my main contact and source of information.

Mrs Malik is one of the founders of the Home Based Care Group in Ng'ombe, Lusaka and besides that she runs a day-care, Kondwa centre for orphaned children and children affected by AIDS in the township Old Ng'ombe. Through her work she helped me get in contact with grandparents and other family members whom I interviewed.

I made nine taped interviews and several other conversations, which I afterwards noted down on paper. I have chosen to take a qualitative approach to my fieldwork with the purpose to get a higher understanding of the issues concerning this paper. Especially due to the cultural differences between Zambia and Scandinavia it is very important to be able to ask in depth questions and thus a quantitative approach would not be adequate.

My interviews were semi-structured as that gives a more relaxed atmosphere and thus gives the interviewed an opportunity to add whatever they may find relevant or interesting. Of course the person being interviewed would see me as a person coming from the outside and I think there is a risk this sometimes affected the answers they gave, as they were not completely comfortable with the situation and their answers would reflect that. People would be more careful about what they said. Of course their view on strangers from the west was influenced by the fact that as they are normally only in contact with foreigners through helping organisations, it was sometimes difficult for them to understand that I was not there to save them or make their lives better.

I generally had a sample of the same questions I would ask everyone. Depending on how talkative the person was I would ask more questions or let them talk if they had something they found important to tell or if they were not afraid to talk about sensitive subjects such as stigmatisation. I used the volunteer women from Home Based Care (HBC) as my translators as most of the elders didn't speak English.

These women came from all the different areas in Ng'ombe and therefore it was often easier for them to identify the people that would be interesting for me to talk to.

Normally it would be ideal to make the contact yourself, but as I only had limited time in the field and as I didn't live in the local area where the local population could get use to me in time, it was better to let the volunteer women arrange the interviews with people they knew from their local area who felt confident and comfortable with them.

As I moved around in different local areas I had many different translators, since it was best as well as safest to have one that knew the area and the person getting interviewed.

This way I worked with a lot of different translators and it was difficult to get familiar with them, thus I tried as much as it was possible to use the same ones at least more than once. Of course the validation of information is altered when it goes through a third person like a translator and you cannot be sure that all that is said is correctly translated.

Moving around in the different local areas of Ng'ombe both rich and poor gave a good idea of the different ways of seeing the AIDS pandemic and how the locals handle it depending on the

resources they have available and the area they come from. I will get into more about that in later chapters.

To also get a wider perspective on the issue on AIDS impact in local community and grandparent caregivers I sought out other members of the local community such as the female volunteers in questions concerning stigmatisation, believes surrounding HIV/AIDS and how it affects the community's social organisation. Through conversations with my key informants Mrs Malik and Mrs Mwape I got a better understanding of the social and cultural settings I was working in and it helped me to better understand how the elders live and why they would say and do certain things and take some things for granted, for example how they divide house chores between the sexes or expect a certain person to do certain work.

I have also made use of social network analysis as I in my interviews have been concentrating mainly on peoples social and family network to get an impression of the possibilities for help they had within reach.⁵

During my stay I met with Angela Malik at her office at the day-care in the mornings and we planned my week ahead; -what people to interview and who to come with me as translator. I went to the elder's house and interviewed them in their familiar surroundings.

I did participant observation in the day-care centre, watching the children as they received schooling and when they played outside. It was a day-care with 85 children in the age 3-8 years and they were in one way or another affected by AIDS, either infected themselves, had HIV-positive parents or had lost one or both parents to AIDS.

At the day-care the children are provided with breakfast and lunch and between meals the semi-volunteer teachers divide them into three classes and teach them. The observation I did was generally to try and get more insight in how the society works, and to make the local people in the area used to having me around. I talked to the teachers and to the cook and kitchen help, both women who were affected by AIDS one or the other way and they were helpful with information about the local area.

I participated in a Friday meeting for the Home Based Care volunteers to familiarise myself with the way they work and I also went to a Support Group Meeting for people on Antiretroviral -ARV- medicine in New Ng'ombe.

⁵ Helman.2001:268

I did all this to get a fuller picture of the local setting and how people deal with the AIDS pandemic that affects all aspects of the society and family system.

I have as far as it was possible tried to incorporate all aspects of the situation surrounding elders and AIDS, which meant that I had to collect and analyse data in different ways. It was important to get into four levels of data: 1: “*What people **say** they believe, think or do.*” 2: *What people actually **do.***” 3: *What people **really** think or believe.*” 4: *The **context** of the above three points.*”⁶

To try and understand all four aspects of the above I had to use a combination of methods. Since I had limited time in the community the interviews was most of the time semi-structured and they were primarily with the elders in the community as they are in focus here. The interviews with the elders and other caregivers were to collect data for the first level: What people say they believe.

Participant observation was carried out to see what people actually do, level two, and a combination of conversation with Mrs Malik, Mrs Mwape and *Care Zambia* and the observation in the local area helped to get an understanding of what the population really think or believe, level three. And a combination of all the above helps me to see the context of all three points, level four.

I would have liked to do some fieldwork in a rural area as well to see the difference between urban and rural societies, but because of limited resources and logistic difficulties working in the rural areas, I decided to concentrate on one locality.

⁶ Helman.2001:265

Organisation of this thesis

The data will serve to show how family organisation and caregiving roles are affected by AIDS, and how social and family networks attempt to cope with the consequences of AIDS.

The Zambian government has recognised AIDS as a big problem to social health and that it also has a social impact. But they don't have efficient money and other resources to deal with the problems adequately. This leaves the Zambian population to come up with local and non-governmental supported strategies to cope and work together with the NGO's that work against the spread of HIV/AIDS in the third world.

What makes a pandemic like AIDS so serious is not just the disease itself, but its social impact. More than other diseases AIDS does not only kill people, it can cripple entire social systems causing new burdens for those who are not infected, both younger and elder generations.

In this paper I will first begin with some historic details on Zambia to provide some background information on the country, so we can understand the current situation in a bigger perspective. I have decided to leave out a general chapter on theory. Instead I make a presentation of the different theories used for this paper and explain why and how they are applied to the empirical work. I leave the more in-depth study of the theories for the main chapters concerning my fieldwork. In this way I am hoping to give a fuller picture of the situation concerning this paper and elucidate how the empirical work and the different theoretical angles are connected and can be used together. The theories will be on kinship and family system, gender/generational perspective and medical anthropology in general.

I will then move on to the main chapters, which are based on my empirical data from my fieldwork and here I will discuss how the kinship organisation and family network has altered in order to show the effect AIDS has on the local society and the family network.

To clarify this I will compare the traditional and present organisation between families and kinship and the elders' position.

Urbanisation also has had a big effect on the importance of family and kin, due to changes in lifestyles has lead to new forms of households, such as multigenerational, grandparent-headed and female-headed households among others. I will also discuss how it is mainly women, who ends up as caretakers of the HIV-infected and also that more and more women are becoming head of household. I will describe some of the different coping strategies that are put in motion to try and adapt to the heavy changes on a local community level.

Background history on Zambia

In the following chapter I will shortly describe some background history and information on Zambia. This enables me to set later theories and my empirical work in perspective and understand some of the background for what has happened in Zambia concerning HIV/AIDS and the effects of that on mainly the socio-economic area and social system.

Like other poor third world countries the biggest problem for Zambia in the struggle against AIDS is poverty. Compared to the western world Zambia and other African countries don't have the resources to educate and warn the population properly against HIV/AIDS. After thirty years with economy crisis and trying to make the tight economical reform programs work, Zambia is today one of the poorest countries in the world with the biggest debt to the industrial/developed countries and almost half of the state budget is aid money. Three out of four people live for under one dollar a day.⁷

Some of the reasons for this development are corruption in the government, lack of proper management of the resources such as copper on which they are very rich and that the world market price for copper has been very unstable.⁸

The government have no means of reaching out in the local communities and set up expensive campaigns in the fight against HIV/AIDS unless they get help from western governments and NGO's.

The government want to make schools free of charge but as the economy is in a bad state they have had to introduce school fees which means heavy burdens and more trouble for the families with many children and the economically challenged.⁹

The same goes with medical care that was suppose to be free but as it almost drained the Treasury in 1990 it was abolished, and today you have to pay for treatment in the hospitals.

Today in Zambia the population counts around 11,2 million and almost half of the population live in the urban regions along the "line-of-rail" area that surrounds the railway from Livingstone via Lusaka to the Copperbelt. All major cities are located in this area and after independence in 1964 from Britain the urbanisation came very quick. People were offered good money to get into the mining business and other industries and left their villages to move into these areas and get part in

⁷ p.14-15. www.landguiden.se/pubCountryText.asp?country_id=190&subject_id=0

⁸ Ibid:15

⁹ Ibid:4

the wealth. As Zambia is a land-locked country it is very dependent on its relationship with the surrounding countries and their transport-infrastructure, especially Zimbabwe as they are the link to the south. The war for independence in Zimbabwe therefore gave problems for the export of copper and is one of the reasons why the economic problems in Zambia grew bigger.¹⁰

Zambia is today a republic under the government of president Levy Mwanawasa.

Zambia also used to be sparsely populated but because of the mining chances and good working opportunities a lot of migrants came to the country after independence and together with the rest of the population they gathered in the new established towns and today Zambia is one of the most urbanised countries in Africa together with South Africa and Algeria¹¹

The urbanisation was followed by split up in families and growing slum districts in the urban areas¹² and it also caused a big part of the young population to move into the cities. Thus the villages lost the most important workforce.

As a result of people moving away from their family, the traditional social security net and structure is disappearing and a lot of people are left on their own.¹³

Also this fast growing urbanisation seems to have divided the country in two, the rural area with the villages and traditional way of living and the urban modern cities with the western influence and where people strive to obtain the western standards of living.

This could seem a big problem but in reality most people move without any problems between the two spheres and in that way they combine the traditional and modern culture and behaviour.¹⁴

The same goes for religion. Since 1996 Zambia is officially a Christian state but most people practice a combination of traditional African culture and religion with western influence so the Christianity is mixed with older African beliefs to make it fit into peoples way of living. In Zambia there is almost twice as many Catholics as Christians.¹⁵

The age structure in Zambia is estimated in 2005 to be:

¹⁰ Crehan.1997:80

¹¹ Touwen:63.1996, Schlyter.1996:129

¹² p.2: www.landguiden.se/pubCountryText.asp?country_id=190&subject_id=0

¹³ Ibid:22

¹⁴ Ibid:4

¹⁵ Ibid:3

0-14 years: 46.5% (male 2,626,911/female 2,609,857)

15-64 years: 51.1% (male 2,848,402/female 2,904,376)

65 years and over: 2.4% (male 118,043/female 154,206) (July 2005 est.)

But what must be taken into account here is the effects of excess mortality due to AIDS; this can result in lower life expectancy, higher infant mortality and death rates, lower population and growth rates, and therefore cause other developments in the distribution of population by age and sex than, has been expected as seen above.¹⁶ We already know that the age group 15-64 years is a lot lower than expected because this is the group that is sexually active and most likely to get infected with HIV, which leaves a relatively larger number of both the youngest and oldest. At the same time the life expectancy is down to 37,2 years in 2004 compared to 50,4 in 1990¹⁷. About one million of the Zambian population is infected with HIV/AIDS and maybe this number is even higher as a lot of people especially in the rural and very poor areas don't get tested.

The age structure and proportions is changing rapidly due to the effects of AIDS. The group of older people (50 years and above) live longer because of the last decades development in the health area that has given way to better access to treatment and nutritional food while a big percentage of the young are dead or dying from AIDS.

¹⁶ www.cia.gov

¹⁷ Politiken.d.17.okt.2005

Presentation of argument

First I will explain kinship and family system then move on to the gender and generational perspective and at last some medical anthropological aspects, including the different sectors in the medical system. The section on medical anthropology will only be an introduction to the field and is included in this paper to give some general guidelines that will help to bring a better understanding of the empirical chapters.

Kinship theory

“Kinship is the recognition of a relationship between persons based on descent or marriage”.¹⁸

A kinship system is the ways in which a society defines and uses relations of kinship.¹⁹ A lot of cultures and countries social systems are built up around these relations of descent.

If one reckons descent from the same ancestors, you are blood relatives, *consanguineal*, and if the relationship is established through marriage the relation is *affinal*. Of course the roles and importance of kinship varies across societies but in general the kinship relations entail the idea of rights and commitments. Some of these obligations are written in the law such as legal rules of inheritance and property rights if someone dies.²⁰

The fact that links of kinship define rights and obligations between people gives kinship a central role and it is normally seen as a set of rules that allocate status and define rights and duties.

Kinship can be seen as having four coexisting levels:

1: at *categorical level* that comprises forms of nomenclature and classification that provides a framework for how people experience and understand their world and environment including relationship terminology. These categories are taken for granted and learned through cultural socialisation.

2: *The jural level* includes rules and laws, which affect people's kinship behaviour. From criminal laws to what in general are considered good manners.

The jural rules are explicit and object to disagreement and to be broken. Rules do not direct behaviour, rather they are used to interpret, explain or justify ones behaviour and actions.

¹⁸ Linda Stone.1997:5

¹⁹ Ibid:6

²⁰ Ibid:5

Under tribal and traditional conditions in many African societies it was the elders who had the jural authority and were in charge of the legal functions but today these responsibilities have been taken over by courts and other kinds of public jurisdiction in many places due to westernisation and development in general.

3: *The behavioural level* is what people actually do in relation to kinship. It can be subdivided into collective behaviour, such as marriage rates or as individual practice.

4. *The sentimental/emotional level* is how people feel about various kin, feelings and expressions of loyalty, alliance and dependence toward family and society.²¹

The above statements on kinship are significant for an understanding of the kinship system in Zambia. To understand what kind of role kinship plays when HIV/AIDS affects a family and how it is decided who should be responsible for taking care of the sick and the rest of the affected family members such as children who might end up becoming orphans.

Studying the kinship system helps us understand the status and roles of different members of a family and in the local society. What is expected from the different members and also what different members are allowed to do and say. A lot is about *obligation* and *commitment* between the members of the extended family network. Especially kinship and family status is important for this study as they define *rights, obligations, commitment* and *sentiment* inside the family network between family members and can be used to see how people explain their situation and their responsibility: How grandparents feel an obligation and commitment to look after their children and grandchildren that are kin and what care taking roles they take up to fulfil these commitments. Also how the families feel the right to leave the nursing and care to the grandparents. The sentiments and feelings kin members have toward each other.

To understand the function of the kinship system that operates in most local Zambian communities help us draw conclusions on how descent links and kinship relations can be very important for how families react and deal with tremendous burdens on the family balance such as HIV/AIDS and the new challenges and difficulties that arise in such situations.

Maybe kinship patterns help us clarify why some individuals and families do certain things and why a lot of actions and incidents are taken for granted without questions being asked or objections being made.

²¹ Barnard & Spencer. 1996:311-313

Reciprocal relationship between kin is one of the keywords in this paper and will be looked more into together with *commitment*, *obligation* and *rights* in later chapters as well as the levels mentioned above, especially the sentimental and emotional level. Reciprocity is a mutual exchange and obligation at the same time as a relation between people in an economic system. It is the obligation they have towards each other or the practices they engage in, in relation to one another.

With kinship theory we can include *family system theory*, which views the family as a system that strives for equilibrium all the time. The definition of family can be very broad as it can include the whole extended family network or maybe just the nuclear family with parents and their children. The aim of family system theory is to examine specific aspects of the family culture and its relevance to health, illness and lifestyle²² and doing so to better understand the choice the family make and under which circumstances these are made.

So what kind of position and role do the kinship relations and family network play in a Zambian community when dealing with a pandemic like AIDS? Is it possible for such a disease to affect and alter the traditional kinship patterns in Zambia? Is it possible for AIDS to change the whole local society?

Kinship roles determine some expectations for how cultures and societies act and adapt itself when a pandemic like HIV/AIDS affects the social structures. Together with gender, kinship creates views about expectations for how the individual expects to react and how the traditional division of tasks is divided.

²² Helman.2001:268

Gender and generational perspective

Gender study is about the understanding of female and male and how considerations about these terms are interwoven with other dimensions of social and cultural life such as social roles that both sexes play in a community and also the values that surrounds both male and female activities.²³

Differences between the sexes and how they are expected to behave is learned through observation and socialisation.

Both kinship and gender is surrounded by laws, norms and rules of how to behave and react in different situations and these expectations changes from culture to culture thus both kinship and gender are culturally constructed.

In many cultures and societies including the Zambian society the general view is that the public area is the males domain and the females are confined to the private sphere at home. This also strengthens the view that women should take care of the sick as this often takes place in the private sphere. Many societies see it as obvious that as it is the women who gets pregnant and gives birth, it is also them who should be the primary caregiver of these children and therefore be restricted to the home.²⁴

At the same time the domestic private sphere is less valued than the public sphere where the men are to be found most of the time. One of the reasons for this hierarchic thinking about private and public is the economic and political activities that happens in the public sphere and which makes it more important.²⁵ All this is also why women mostly end up as caregivers for the sick and the orphans.

A simple way of seeing the gender/sex discourse is to say that gender is the social differences between men and women and sex refers to the biological differences. That gender refers to the socially constructed relation between women and men and where the terms male and female, masculinity and femininity comes into work. Gender is socially constructed and therefore it is changeable and can be de- or re-constructed so it fits into the norms of a society. Gender perspective puts another light on the power relations and how work is divided in a society and how changes can redefine or change the power imbalance between male and female. These changes can be brought on by a disease like HIV/AIDS that calls for new ways of seeing the genders and their rights, options and ways of handling situations.

²³ Linda Stone.1996:1

²⁴ Ibid:2

²⁵ Ibid:3

The generational perspective is concentrated on the interaction between age groups and generations. What role do the different generations play in the local society and in the family? Some age groups have specific privileges and there is a general anticipation from their surroundings that the different generations take on special roles and fulfil certain responsibilities in the social and familiar hierarchy.

Both gender and generational contracts are negotiated between members of the family and kin that is directed by outcomes from national levels that provide a frame for what groups and individuals can do.²⁶

Using the gender perspective will help us to get a better perspective of how for instance the work in the public and private sphere is divided between the sexes and what is expected by the different individuals in the home concerning caregiving for the sick and the children.

Both from a gender and generational perspective it will be interesting to see how a disease like AIDS changes the power relations both between the sexes but also between generations and how the families and the society in whole cope with the pressure.

We can use the three perspectives; kinship gender and generation, to give us an understanding of what factors and social forces are in place in the *Zambian* society and how they affect the decisions being made on a local and communal level.

²⁶ Ann Schlyter. 1996:33

Medical Anthropology

Medical anthropology deals with the medical aspect of the cultures that are “examined” by anthropologists.

I have used perspectives from medical anthropology to better understand the health problem in the cultural and social settings in a local community in Zambia and to better understand the elders’ perception of HIV/AIDS and how they cope with the burden of being the main caretakers and what social effects this has.

Just to clarify I choose to define culture as *“that complex whole which includes knowledge, belief, art, morals, laws, customs and any other capabilities and habits acquired by man as a member of society”*.²⁷ It can be seen as a set of guidelines that is learned and this also goes for the medical part of a society such as perceptions of illness and health. Culture is never static it is always affected by outer influences from other cultures and is in a constant process of adaptation and change.

In most countries when people get sick there is a number of ways they can seek help – go to the doctor, emergency room, a witchdoctor, and so on depending on the health care system where you live. In Zambia a lot of the population doesn’t have easy access to the clinic when they get sick, maybe they live out in the rural area or in the townships and can’t afford the transport. Most people end up with the care and treatment that the family can provide.

In societies it is different whom you ask for advice concerning illness. In many places it is the elders but they don’t know much about AIDS because it is a new disease. Thus they don’t have many solutions and that can affect the way the society sees them: They are no longer necessarily the ones who know everything and you come to advice for. Their authority and status is questioned.

The health care system is pluralistic, which means there are a lot of different options to choose from concerning treatment. Both cultural and social aspects determine what kind of care that is available to the individual patient.²⁸

There are three sectors of health care: the popular, the folk and the professional sectors. Of course they overlap each other in some areas.

²⁷ Helman.2001:2

²⁸ Ibid:50

The *popular sector* is the non-professional, lay area of the society located in the private sphere of family and kin. It is here illness is first discovered and defined and where you decide who to go to for counselling or if you can take care of it yourselves with home-medication and self-treatment. Normally this takes place in the family and it is the women who most often are the providers of the health care. About 70-90 percent of health care takes place in this sector. The popular sector also includes a set of beliefs concerning health care, maintenance and treatment that is used as guidelines for correct behaviour preventing ill health and which are specific to each cultural group.²⁹

The *folk sector* is made up of individuals that are specialized in forms of healing; they are not part of the official medical system and are in a position between the two other sectors. It is located in the local community. It can be witchdoctors, spiritual healers, shamans, herbalists and many others. In many non-western societies people tend to consult this sector before the official as they are often closer to the traditional society life, and people trust them as they share the basic cultural beliefs and values that the community live by. This approach is holistic and includes not only the individual in question but also their whole social life and surroundings including the patients relationship with other people.³⁰ This will be seen in later chapters on Zambia and the populations' perception of HIV/AIDS.

Often in this sector a direct diagnosis is not provided but an explanation to what is wrong and why this has happened is given and often this assurance that something is wrong is enough for the patient and their family. Normally the family is present and the consultation takes place in the local community.

The *professional sector* includes the legally, organized healing professions such as the western biomedicine. This is the official medical system and includes doctors of various types and specialities and also nurses, midwives and so on. The surroundings for this sector are most often the hospital. The patient is admitted and taken away from their familiar settings and enters a whole new discourse as being "the patient". In the professional sector we have the well-known doctor – patient relationship, where the doctor gives a diagnosis without much help from the patient in person but more based on medical tests. The patient is not a part of the diagnosis compared to the popular and folk sector where they take active part in the analyses. Interactions between doctor and patient takes

²⁹ Helman.2001:50-51

³⁰ Ibid:53

place outside the patient's familiar sphere in a sterile isolated place with the presence of strangers such as nurses or medical students.³¹

One of the important differences between the folk and the professional sector is that the folk sector tend to involve the whole family in diagnosis and treatment.³² The professional sector can learn from this, as it will be shown with cases of HIV/AIDS in Zambia. Here it is crucial to include the family, as they are responsible for taking care of the patient and nurse them. The well being of the family is affected by the patient's sickness.

AIDS has become a global disease and it is different how human and social groups define it and their understanding of its origins, importance, modes of spread and what meanings they associate with disease differs. In every local context there is a unique understanding of AIDS and it is embedded in their beliefs, metaphors and cultural themes.

My point with the medical anthropological theoretical view is to elucidate the complex setting surrounding health care and what different sectors and beliefs the Zambian population has to take a stand on. Also for us to understand that individuals and cultures view ill health in very different ways.

When studying individuals and social groups in a particular society and how they perceive and react to ill health, it is important to know something about the cultural and social aspects of the society they live in and that is mainly what medical anthropology is concentrated around.

Anthropologists have pointed out that the beliefs and practices relating to illness are central features of a culture so by examining these you will better understand the concepts of a culture as a whole. In this specific area the concept of the extended family network and the vision of family compared with the reality where the roles changes.³³

Recently there has been a lot of critique towards the global model of AIDS prevention, which is designed by western experts. The critique points out that this model doesn't fit and is ineffective in the third world including Sub-Saharan-Africa. We have to realise and be aware that differences from country to country and different parts of the world in epidemiological patterns and cultural settings are real and take this into consideration when approaches to understanding and prevention are made.

³¹ Helman.2001:55

³² Ibid:54

³³ Helman.2001:.4-5 & Hastrup & Hervik.1994:7

Traditional way of living in Zambia

Kinship in Zambia

In Zambia the kinship relations are mainly build up around *matrilineal* descent which means that it is based on links through the females only, like patrilineal descent, that is based on male links it is based on only one side of the sex and so it is called *unilineal* descent.

In a matrilineal kinship system both female and male are members of their mother's matriline by birth but it is only the females that transmit this membership to their children and next generations.³⁴ Many cultures are built up around a matrilineal society like the one in Zambia but every society is different to how this is expressed and what rules surrounds it.

In Zambia it is normal that a male is head of the matrilineal kinship unit and normally if there is a male in a household he is automatically referred to as head of household even though he might not contribute to the household with money and the women do most of the work and actually are the main caretakers of the whole family. The male members of a family have most authority even though it is considered a matrilineal society. Since the Zambian society is built up around matrilineal descent but the men still have the majority of power the most important bond between family members used to be the bond between a sister and her brother. Power and property would pass from uncle to nephew, rather than from father to son, so you can say that a woman didn't get children for the sake of the husbands lineage but for her brother and her own descent story.³⁵

This relationship between a wife, her husband and her brother where the women is more attached to her brother than her husband, could be one explanation for instability in many Zambian marriages. The husband and father doesn't feel a close relation to his children or they feel that they don't belong to him. This way of seeing the family and mutual relationship has changed a lot today. One explanation for that is that families often live far away from each other and it is difficult to maintain the same bond between siblings and therefore the father has a bigger and more important role in family life today.

Urbanisation affects the relationship between sister and brother as they are spread out all over the country; the brother is too far away to look after the sister and her children and the father's role towards the children is growing stronger. The emotional/sentimental level of kinship is altered and the father feels a right to his children and more commitment and obligation to care for them.

³⁴ Stone.1997:109

³⁵ Touwen.1996:82

Even so there are still a lot of stories being told about husbands “*running away*” leaving their wife and family for another woman and starting a new family which can mean that the wife has to move back to her parents or brother or in other ways ask for support in the extended family.

This has happened to quite a few women in Ng’ombe. The husband left the family to marry someone else and often the wife and children had to move out of the house and live in a smaller one. A consequence is that more and more households are being “ruled by women”. This also happens when the husband die early of AIDS or other diseases.

Kinship ties have always been of great importance to Zambians social life and relationships and support systems were built on the community of kin. But partly through urbanization kinship ties lose some of their traditional importance as a factor for social structure and kinship relations get de-structured because relatives don’t have the capacity to maintain the close relation over great distances. Urbanisation can be seen as starting factor for fracturing the kinship system but on the other hand it is highly reinforced by increasing poverty and spread in diseases.

Before independence and the following urbanisation social relations with family and kin included visiting relatives often; mainly young people would go and visit older people as it was easier for them to walk the distance if you lived in the same village. But today many families live far away from each other and don’t have the money to travel long distances and many are split up between the urban and the rural areas as many young people move to the cities and the elders stay in the village.

The kinship system is closely connected with how the extended family network in Zambia works. It is kinship, who you descent from and are related to, that defines the rights and obligation people have between each other. The kinship system has traditionally set up rules for who was entitled to certain status and rights in the family both due to age and gender and what duties towards others you had as a member of that kin. The children of a kinship network has learned the rules, rights, commitments, family terminology and the importance of all that through socialisation and enculturation.

In Zambia the senior citizen has had a very high status among kin and maybe in the rest of the village where they lived. E.g. Parents sent their children out to live with the grandparents so they could learn about their culture and the elders raised them while the parents worked to be able to send money to support both the children and grandparents. In the past the grandparents had a special

role in the social setting. They normally had a high status among family members being the eldest and especially the maternal grandmother was very respected. It was custom that when a child reached the age of 3-4 years he or she would be sent off to live with the grandparents, normally the maternal grandmother, and be brought up under her charge and watchful eyes. As the children grew older the grandparents taught them how to behave in life, and in this way they became the instructors concerning moral, behaviour, and gender roles but also on sexual matters as this is taboo to talk about between parent and child.³⁶ The different levels of kinship; categorical, jural, behavioural and sentimental was taught to the children by the elder grandparents.

But urbanization and the changed lifestyle that followed have over the years changed the grandparents' role and status. Living far away from elder relatives that often still live in the rural areas make it difficult for relatives in the urban areas to keep the close relation. They start living differently from the more rural traditional way and so the elders and other family members back in the village lose some of their authority and status and the respect that was expected to exist between kin dissolves. The HIV/AIDS pandemic of today has altered this tendency. New social roles have to be acquired by both grandparents and other family members and old ones have to be adjusted or completely abandoned.

Reciprocal relationship

An unwritten law in the traditional kinship system was that elders were to be looked after by their relatives when they grew too old to take care of themselves.

There exists a reciprocal obligation between relatives through which kinship statuses and bonds are bound together in a general net of mutual commitment. It is not based on a set of juridical rights but rather on a set of unspoken and accepted rules for kinship behaviour.

Reciprocal relations between kin where you exchange favours or objects to keep the relationship in balance is present at the jural level as one more unwritten law you live by. Reciprocal relationship is used between siblings who take care of their parents. Maybe one of the adult children is looking after the elder parents and the other siblings will send money and other support to ease the work of that adult child. Before the elders got support from children living elsewhere and the support was reciprocal, as the elderly would help looking after the grandchildren and orphans.³⁷

³⁶ Epstein.1981:201

³⁷Schlyter.1996:28

In Zambia the elders get no pension unless they have worked in the formal job-sector, as there is no general state pension. Retirement benefits are tied to formal employment.³⁸ Most elders have only worked in the informal working sector, which is not founded by either the government or private companies. Many have had pieces of land with crops to sell or food stands as well as selling manufactories at the market and these informal ways of working don't give any form of pension. Before the huge changes in the Zambian community caused by poverty, AIDS and urbanization and the lack of pension for many senior citizens was not a huge problem because their children and family was there to look after them. Since the extended family network was so big, elders could always find someone who would care for them in their old age and they would move in with relatives. Sometimes the elders would move around between their children who would take turns in having the parents living with them or one child would take the parents in and the other children would send money or in other ways give support. Traditionally in family life, sons and daughters were organized in such a way that the elders would move around and live in the different households of their children, so they shared responsibilities for the parents and the job looking after them.³⁹

But as families are so spread out over the country today and the children move to urban areas to find work, the elders stay in their village out in the rural areas. They are not interested in moving away from what they know and the children don't come home very often and lose their connection to their hometown and family. Some adults still send money to the elders in the villages but don't visit and the children go to school instead of being taught by their grandparents. Also children losing their parents would be sent off to relatives who jointly would take care of them. So due to development and urbanisation the elders today are much more dependent on a state pension to replace the economically help of the family network that is disappearing.

Both the categorical and the jural level of kinship, where classification and rules are made, affect what people in a kinship and society actually do. They give guidelines to how kin and families organise themselves with each other, as seen above with elders being looked after by adult children so that stability is maintained among kin and relatives and everybody know what is custom and accepted to do or not.

³⁸ Ibid:4

³⁹ Ibid:28

Concerning ill health and diseases every family in Zambia earlier had a system of how to take care of the patient, also when it concerned looking after the children of the parent. A kinship group had the obligation to look after their own kin and normally you would live close to each other. That made it easier to get help. If a male adult got sick the wife would nurse him and get help from the relatives living close by and if the wife fell ill she could be sent to her mothers to be looked after. This organisation has been fractured by urbanisation and HIV/AIDS has worsened the pressure even more. Often the wife doesn't have any relatives near by to help out with nursing. She has to look for help from other people such as neighbours and people in the local community.

Elders' position in traditional Zambian communities and changes

Among kin and in the family network elders would earn a lot of respect from the other generations because they were the ones having much of the information on kin relations, the traditional way of living and how to behave in the local community and towards other people.

Older people had a high position in the society and there were specific expectations from the rest of the society in roles and responsibility according to their age. Elders would teach the younger generations about values and what role they ought to play in society and senior citizens would be the ones people would go to for guidance in most matters including illness and medical questions.

An unwritten contract between generations also existed: a contract on how family members relate to each other. This intergenerational bargain is based on parents and adults in general taking care of the children that then again will look after and care for their parents and the elders when they get old.⁴⁰ Due to this interdependence of mutual support between children and adults it is important for the parents and elders that the children go to school and get educated so they can get a job later on and look after their family and elder family members.

This reciprocal relationship between the generations is still present in Zambia today but slightly changed. Before AIDS impact, adults would look after their parents when they got too old to work and support themselves. Now a big part of the reciprocal relation among family members is between grandparents and grandchildren as AIDS is on its way to destroy a whole working generation. Many adult parents are missing due to HIV/AIDS and other diseases and so the grandparents look after the

⁴⁰ Barnett.2001:196 & Schlyter.1996:10

children. Grandparents make sure the young ones grow up, get food and hopefully finish school so they can take care of the grandparents when they themselves get jobs, income and become self-sufficient. The biggest concern for the elders I interviewed was that the children were able to go to school and graduate so they could go out and get a well-paid job and to be able to support themselves and the rest of the family including the grandparents. The elders hope that the children growing up will be able to give them security both concerning living circumstances and financially.⁴¹

So today the reciprocal relationship between grandchildren and grandparents is important for the stability of the family and necessary to maintain the family unit and keep the relation between the younger and elder generation in balance. A woman in one of the suburbs said (translated, so said in third person): *“She is saying she would be very very happy if they could get educated because then she know there won’t be any problem even for her, she will be looked after in case she grows old, they will look after her, even for them they won’t have any problems in the future”* (Interview.d.10.May.2005).

Another woman said: *“..it is better for the children to go to school and starve”* (Interview. d.16.May.2005). They hope that if the children are able to finish school they can start earning money for the household and in that way get out of the vicious circle with lack of food and money. But to make the children functional in both school and at home they need to be fed so both food and school have to be prioritised equally as they are inextricably bound up with each other. Often the choice is between letting the children attend school so they are better off in the future or have them work now and earn money for the household.

Concerning status between the young and old generations there is a difference between a household of a younger generation that takes in elders to live with them and households of elderly that younger people come to join or re-join. In the latter situation the elders stand stronger as the relatives move in under the elders roof and their rules and so they keep the highest status of being the head of the house. Depending on whether the elders move to others or have someone moving in, they will be seen as head of household or dependant of the head of a household, which is normally run by either son or son-in-law.⁴² Elderly people’s position in the society and among kin is therefore affected by their residence and under whose roof they live. So even if the elder is the main caretaker of the

⁴¹ Barnett.2001:219

⁴² Schlyter.1996:24

family and responsible for looking after the young ones and nursing the sick she is still not necessarily seen as head of household if it is not her house.

The extended family network

Family life and kinship relations are closely connected with the extended family network. Barnett describes in his work on the consequences of the AIDS epidemic in Africa, that this extended family network:

“is a variable, it is dynamic and can become more or less extended depending on resource availability.

is ideological, it is something people want to believe because it validates their traditions

is ideological because belief in it relieves politicians of responsibility for thinking through implications of the epidemic

reaches a point where it can no longer cope”.⁴³

If the extended family is stable with good resources to draw from such as adequate food availability and members with good health it is possible to take in sick or old family members and orphaned children and care for them without putting too much pressure on the network. It is important both psychically and psychologically for family members to help each other with keeping traditions in place and legalizing them so they don't run the risk of being forgotten with urbanisation and diseases. Now with the impact of AIDS the extended network also take some of the pressure from the government and politicians that can leave a lot of the care taking of the sick, old and young to this family network. The major problem though is that the extended family can only extend so much as the resources allow. That limit has been crossed and the extended family network is on a retreat and shrinking because too many people are getting sick at the same time and poverty is enhancing.

A lot of the people being interviewed pointed out that the family network used to be a lot different and stretching much further. One woman said: *“In the past it was okay, people used to look after the other people of the family, there was no problem and that because food, there wasn't a problem with food and the relations in the family was so close, like your daughter...you never knew who the*

⁴³ Barnett.2001:187

aunties were, all the women were all your mothers...my mother my mother, my father my father. Everybody would be mom and dad. But today it is difficult” (Interview.d.10.May.2005).

This woman also points out that one of the biggest problems today is the lack of food to support the sick and that under more traditional circumstances the extended family would have such close relationship that everybody would look after the children together and titles weren't important for the children to relate to the adults. Everybody in the community would join in raising the children and food would be shared.

In earlier days the extended family network was of great importance for keeping the society in balance and to have a security net for the individuals that could ask for help among kin, but today more and more families decide to concentrate more on the nuclear family with parents and their children and leave out the rest of the family. The most important reason for this development is the pressure that HIV/AIDS have put on the extended family. As the families' capacity to take care of other members of their family decrease, a way of trying to cope with the situation and development is to cut loose of the extended family network and concentrate on the closest family. Families try to concentrate their resources on fewer members. Another reason for this development toward nuclear families and the removal of the extended family is the western influence and values that finds its way through globalisation and affects the younger generation that strives to establish a nuclear family with greater privacy.⁴⁴

Sectors of treatment and care in rural and urban areas

In the rural areas in Zambia the population still pretty much live the traditional way in small villages and not all the information about AIDS reach them the same way as it reaches people in the urban districts. Lack of information is a problem when a lot of HIV-infected adults go back to their parents in the village to let the mothers look after and care for them until they die. Traditionally it is normal for girls to move back with the parents if they get sick so they can be taken care of by their mothers. Generally it is not expected of the husband to care for his wife if she becomes sick, rather he will sent her to her parents or let a female relative move in and look after the wife until she is well again. The husband will not provide any nursing but as head of household he will normally make sure that the needs of the patient can be fulfilled, for example providing money for food and

⁴⁴ Schlyter.1996:17

medicine. This way of dividing the care taking role is done from the traditional view that elders and mainly women know best how to treat illnesses. But because of lack of knowledge the parents and elders in the rural areas don't know how to take care of an HIV-infected patient properly and how to avoid getting infected themselves. In the urban areas it is easier to seek a doctor and maybe get information on how to deal with the disease. Because Zambia is very short on doctors it is difficult to reach all the way out in the rural areas. Here a lot of the population choose to treat the infected with traditional medicine and keep it in the popular and folk sector. There is about one doctor per 100.000 inhabitants in Zambia, which are about 700 doctors in total.⁴⁵ In Zambia most cases of AIDS get treated in the popular zone in the private sphere of the family though it should rather be taken care of in the professional sector where adequate medicine like ARV-antiretroviral is available. In Zambia many people in the rural area tend to seek help in the folk sector because that is their only option. Many elders would have a high position in both the popular and folk sector, as they were considered wise and knowledgeable because of their age and they would share the same cultural and local beliefs as the community. This would give them certain status and people would come to them for medical advice. But as AIDS is a considerably new disease the elders don't know a lot about it, how to treat or prevent it, and this is followed by loss in status in the local surroundings as people tend to seek out other ways of help.

Consulting the folk sector for treatment normally means that it is not only the patient that is getting an examination and treatment but also the whole family that the patient is a member of. A holistic view is used to come up with a solution by both looking at the physical, psychological and emotionally levels and interaction between the family members. It is important to include the whole family in the diagnose and ways of treatment as it is usually the family that will be responsible for the care and nursing. This is a traditional way of doing it in the rural areas with different kinds of illnesses and this could usefully be applied on consultations to HIV-infected patients and their family in the professional sector. Often in this sector it is only the patient that is present at the consultations and this leaves the family with a lack of knowledge of how to deal with the disease, how to nurse the patient and avoid getting infected themselves. The family should be included when a patient is using the professional sector so they get the same information and feel like they are together in it as a family, which can also prevent stigmatisation among family members.

⁴⁵ p.22. www.landguiden.se/pubCountryText.asp?country_id=190&subject_id=0

Another difference between the rural and urban areas is that out in the rural areas people live more closely together and if possible share everything. In the cities and urban areas you lose the closeness to your surroundings when you have a big fence or wall around your property. Some of the townships are more like the rural areas cause they can't afford to fence themselves in, but due to the growing poverty problems even the villages and townships don't have the capacity or food enough to help each other. There is a bigger tendency of helping each other in the townships cause most of the inhabitants here also need help with food so they are more dependent on each other than the ones in the richer areas, who have food but need medicine and doctor help and therefore only need to be in touch with the medical sector. The middle class and richer part of the Zambian population don't have to rely so much on their neighbours and local area for help concerning food and medicine as they have money to pay. Still they can have problems finding people to help with taking care. There is a tendency to more secrecy and silence surrounding HIV/AIDS in the more well off areas both due to fear of stigmatisation and because people don't need to socialise so much to accomplish help as they have what they need materially. However stigmatisation is a big problem both in the urban and rural districts, people are afraid of discrimination and judgements from their society if it is found out they are HIV-infected. So they hide it and don't ask for help. Being afraid of being judged or discriminated can keep HIV-infected people and their families from seeking help in their community and of neighbours.

One woman in a Lusaka township said:

“Life in the village was a bit easier for her when she was growing up, because in the village when you have nothing you go to the neighbour, that neighbour will take you to the farms or gardens where you can get some vegetables, some tomatoes, they help you, you go and prepare and you go and eat with your family. Whereby in the town whatever you want it should be bought it is not everybody who helps each other in town. In the villages it is much easier cause they understand and help each other. Maybe even in the villages now a days people might change because of the hunger striking” (Interview.d.16.May.2005).

There used to be a sharing mentality in the villages but the families in the rural districts are also getting affected by the AIDS pandemic. People in general but especially in rural areas don't know much about AIDS and there still is a lot of taboo surrounding the disease that makes people hide it. Also many don't know how to protect themselves against infection or choose not to believe what they are told by the authorities, which gives a rise in the numbers of HIV-infected people.

The younger and older generation

In the urban areas the way of living has changed a lot, and the young people today live differently from older generations and they adopt a different more liberated view on sex from western influences. Moving to the city takes young people away from their family and they lose an important connection, roles of guidance from relatives and are left on their own. With time this is followed by a change in lifestyles so it fits urban values where the individual comes before the collective group.

Liberal sexual behaviour among the younger generation in the urban areas is causing a spread in AIDS. Compared to their parents the new generations of young people have a different view on sex and partners. Normally you would not have sex until marriage and you stuck to one partner, but today many people choose to have more sexual partners before they decide to get married and even after marriage some still practice sex with others besides their spouses. Because of this change in viewing sex, more people are becoming infected by their spouses, and marriage is not an automatic safeguard against HIV anymore.

For women it is most likely to get infected by their husbands – they are often the only ones they ever have sex with but at the same time they are not in a position to negotiate safe sex or prevent their partners to have additional sexual contacts with other women such as prostitutes or girlfriends.⁴⁶

“In my time you couldn’t meet a boy until marriage and these values were installed in you where you come from they’ll tell you from the day you are matured they’ll tell you keep fire burns – fire is good – you can cook your food very tasty food but if you manhandle it, it could cut off your hand. So we feared, sex before marriage was very rare as children out of wedlock. So with that on mind we a still dying and with lesser fair attitude is not helping us” (Interview d.23.May 2005).

But all though this more liberated way of viewing marriage and sex has occurred, and having several sexual partners is common, it is still important for social status to make a good match in marriage in the end.⁴⁷ Even though more people especially in the towns choose their own partner, it is still common to ask for parental acceptance.

Traditionally when young people reached a certain age they would get married and move out from their parents house, maybe they would live under the parent’s roof for a while until they were ready to get their own place and still then it would be close to the wife’s family. Today many girls get

⁴⁶ Barnett.2002:185

⁴⁷ Touwen.1996:98

married very young because they lose their parents in a young age and need someone to support them as the rest of the family don't have capacity to take them in.

"...my father and mother died fast, so I stayed alone and kept my families. I was married when I was 15 years (in Dec. 1970) cause of problems so I have someone to keep my family, so I have seven brothers and sisters, all of them they are dead...dropped of school and got married, because I was confused to keep my young brothers and sisters" (Interview.d.17.May.2005).

When young girls lose their family in a young age they don't see any way out other than marrying an older man that can support them. Many girls also get married very young so they can get help with younger siblings whom they are responsible for. Many girls start having sex very young either to get approval from their surroundings or sometimes to earn more money for the family they prostitute themselves.

Many people of the older generation have difficulty accepting how younger generations change their lifestyles and move away from the traditional way of living and start viewing things like sex and relationship in another way. Some elders even blame the young generation for the spread in AIDS and the raising number of orphans: *"What is causing all this is our behaviour, because they are not steady, they get drunk, they have boyfriends, they have girlfriends, and as a result one gets sick and dies while he or she is still very young, that is why she (the interviewed) ends up looking after orphans"* (Interview d.16.may 2005).

Because of the change in sexual behaviour the elders end up with a growing responsibility for orphaned grandchildren. Above statement where the young part of the population is blamed for dying young and causing the raise in orphaned children can come from the lack of knowledge around HIV/AIDS and how this is transmitted.

In most cultures respect for the elderly and unspoken rules for how you interact between generations are very clear and it is common knowledge that the younger generation have to show respect for the elders and learn values through them. This unspoken relationship between young and old people is changing and the younger generations don't feel the same respect for the knowledge the elder generations can provide. A lot of the elders in Zambia feel they have experience and knowledge to pass on to the younger generation, but they sense the young ones don't listen,⁴⁸ and so community respect together with commitment and obligations between generations fade. Power relations are shifting and elders lose status and respect from the surrounding community.

⁴⁸ Schlyter.1996:4

Earlier senior citizens had status in the economic, social, religious and political areas,⁴⁹ and they were highly respected both by kin and community. You would ask the elders for advice in most matters both concerning the individual and the group. But modernisation and the independence of Zambia have altered this. Many elders in the villages and townships still get a lot of respect from their surroundings but not in the same way, for example they can't judge in legal matters, as there are public laws in force now and as the elders don't have a lot of knowledge concerning treatment of HIV/AIDS people tend to seek out other instances for information.

Elders would also teach about traditional religious beliefs and guidance, but they lose their religious authority as people turn to western religions as Christianity, Catholicism and priests as religious leaders for guidance.

The present attitudes towards ageing people are changing and reflected in the way the elders are treated. The elders come to play a different role as submissive to the younger generation that finds new ideals and values to chase and don't need the guidance of the elders anymore.

In several of the interviews made with grandparents and other elderly people who were responsible for orphans and heads of households, many claimed that there had been no discussion between family members to where the orphaned children should be sent: *"There was literally nobody to come and look after the kids so they decided the old lady should"* (Interview.d.9.May.2005).

Indicating that the elders didn't have anything to do anyway and might as well take on this extra burden.

Ageing can be seen as a process that involves ongoing changes of a person's status and identity. The process and outcome is negotiated in a web of power relations related to control of livelihoods, living space and property among other things.⁵⁰ But if the social capacity is failing to keep the web of power ongoing this gives imbalance that can cause new roles for elders. There are certain unwritten rules of how to behave and what rights you have according to age and through life you constantly have new commitments and rights that have to be fulfilled to keep the family and kinship system in balance. If one age group such as people in their working age that have certain obligations and responsibility for providing for the family by working and earning money disappear, the balance is broken and someone else has to fulfill this role to keep the family system in equilibrium. Among

⁴⁹ Ibid:4

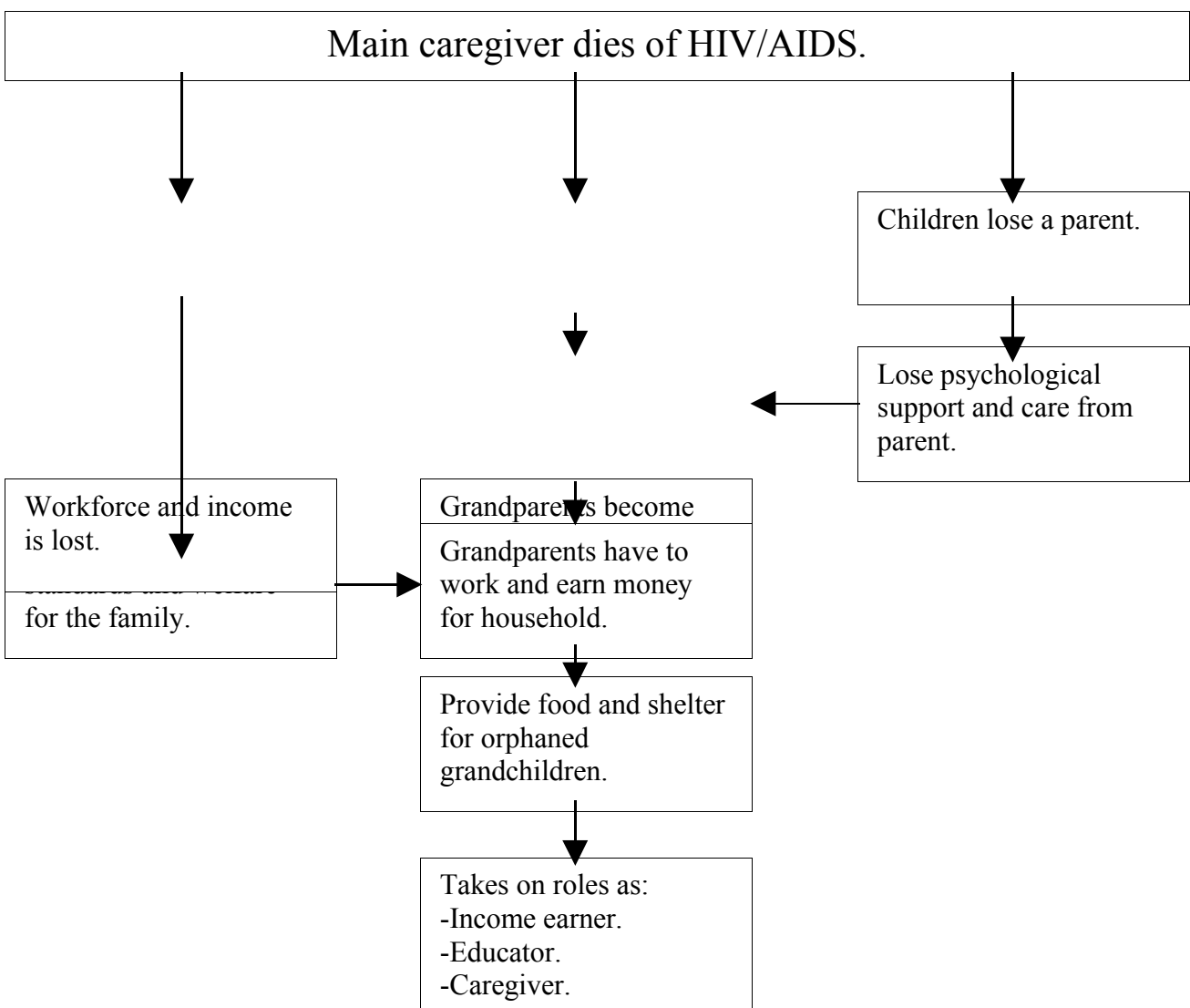
⁵⁰ Schlyter.1996:9

kin and generations, roles and responsibility is renegotiated. In the next chapter we will have a look at how AIDS has an impact on the family household and how elders role and responsibility in the family is changed.

AIDS impact on family, kin and households

In this chapter we examine how the death of an individual affects the whole household and family. The elder's of a household have to fulfil new care taking roles and the relationship and responsibility between family members change. We can envision this relationship in terms of the following model, which shows some of the effects the death of a main caregiver has on the rest of the household both children and adults and how the role of the elders change.

Model: AIDS impact on the household



A household can be defined as a unit of consumption, production, place of socialization and where children are educated; all these can be combined in different ways. A household is a collective

entity constructed by separate individuals and there are both conflictive and supportive relationships among members.⁵¹ The disease of an individual affects the economic and social relationships in the entire household.

The model above shows the effects of the death of a main caregiver on the children and elders'. For the children to lose a parent and also for the elders losing a child it can have major psychological effects, and both parties have to create a new emotional network between each other and try to fill out the emotional role of the deceased. The elders also become responsible for the children's schooling and education and make sure they attend school and fees are paid. They take on new roles in the family as income earner, educator and main caregiver. These functions are taken on, on behalf of being a cultural mentor for the grandchildren and instead they give priority to fulfill the psychical needs as shelter, food and cloths. Traditional cultural and kin values are neglected in favour of more basic needs and this development promotes changed lifestyle in the lives of the younger generation. They come to focus on new ways of living such as having more boyfriends and girlfriends before marriage and not living by old values.

The death of a main caregiver and breadwinner has heavy socio-economic consequences on a household. E.g. the elders have to get back into the labour market and earn an income to support the household that they have become main caretaker and breadwinner of. Generally there is a decline in welfare and living standards in households where working adults die and elders have to take over. The elders' capability to work is not the same⁵² as they don't have the same strength to do the same kind of work as the deceased and so the pay is not the same.

Still if family members that used to work and provide food have passed away, this is now the elders' job and in that way they get more visible in market activities as they have to replace the productivity of the deceased.

The inhabitants of Southern African countries including Zambia are not old compared to the global world but they still have a growing proportional number of elders because of AIDS, which kills the adults in their prime age.⁵³ With AIDS the middle generation aged 15 till 40 years who are in the

⁵¹ Crehan.1997:94

⁵² Barnett.2002:190

⁵³ Schlyter.1996:5

working age are diminishing and disappearing and leaving the elder and younger generation to grow bigger in the demographic distribution.

HIV/AIDS has a big effect on the kinship system. It affects the balance and changes who is head of household, and more women and elders end up as head of household as the men dies or run away. The men are at high risk of getting infected with HIV, as they are the ones who seek out prostitutes or have affairs with other women. Women tend to stay with one man and concentrate on the family. It is more or less accepted by the community that a man finds sexual pleasure elsewhere but frowned upon if the woman does the same. This has something to do with the fact that in a lot of African societies it is normal for the man to have more than one wife. There is also higher incidents of men infecting their wives and at the moment young women are in the highest risk-group of getting HIV-infected as one man can infect many women as their sexual experience is bigger than that of the women.

One way of trying to lighten the burden for the family and kinship is prolonging and improving the life of the HIV-infected patient with medication. Unfortunately antiretroviral medicine – ARV is not available for many Zambians. ARV can prolong and improve the life of many Zambians and give parents an opportunity to raise their children themselves and in that way lighten the burden on the grandparents who else end up with the responsibility for the grandchildren.

ARV-copy medicine came available in Zambia in 2004 but you have to go to Lusaka or one of the other bigger towns to get it. This makes it difficult and costly for many people in the rural areas. A lot of the Zambian population, around 15 %, lives under the poverty line, which makes it complicated when you can't take the medicine on empty stomach and can't afford proper food either. To make things worse and even more difficult the last years have been dominated by dryness and bad harvest to an extent that has made the Zambian president declare a state of emergency and has asked the industrial countries for help.

Grandparents as parents

When grandparents take on the role as parents for the grandchildren, they have to deal with a lot of compromises with the way they live, values to prioritise and general change in lifestyle.

During development and AIDS impact the grandparents have lost both the privilege of being teachers and mentors for the next generation as there is no time for that due to other chores and their expected and anticipated retirement.

The grandparents spend most of the time worrying how they are able to take care of the children and often most importantly how to provide food. Teaching the children about cultural values and norms is being undermined by these prior needs such as food and shelter, and the elders have a lack of energy and can't deal with both physical and psychological needs of the children. Culture is lost at the expense of basic material needs. It is not just psychically hard but also emotionally distressing for the elders to lose a child to AIDS and at the same time as dealing with own grief take care of the orphaned children that also are in need of emotional support and comfort.

“Nowadays it is really sad cause our children are supposed to be looking after us but now it is vice versa, we are the ones who are looking after our children, we don't know what to do now, it is very difficult” (Interview d.16 May. 2005).

In economic terms the elders are often seen as non-productive, but due to urbanization, increasing poverty and the impact of AIDS new roles are coming up for the elders and more responsibility is put on their shoulders thus changing the gender and generational support system.⁵⁴

For the majority of the elderly the main problem confronting those who are affected by AIDS is poverty and often they are the poorest people in the community, which makes it very difficult to take care of the affected family. The elders don't have the energy to both take care of the whole family and at the same time teach them about the culture and heritage. The most important thing is to get food. They have to abandon education on cultural and traditional life in favour of working to get food and psychical support.

Today many elders end up as caregivers in two different periods of their life, where they would normally only have one phase as main caretakers. Traditionally elders would take care of their own children in their own youth and with time it would turn around and the children would in turn take care of their parents growing old. But today many elders also end up with a main caregiving period in their pension years as well because they also end up with the responsibility of taking care of their grandchildren as the parents die. Very often the two-generational household consisting of grandmother and grandchildren are the most vulnerable of households as they are extremely poor⁵⁵

⁵⁴ Schlyter.1996:7

⁵⁵ Schlyter.1996:22

and it is more difficult for elders and in particular women to find work and earn adequate money. This will be looked more into in the next chapter.

Different kinds of households

Modernization generates the development of small nuclear families and changes in the extended family network. Because of AIDS impact new household types are evolving and survivors of the extended family compose them. The goal for individuals is to maintain a home and make a livelihood and provide a home and care for orphans, sick and elders,⁵⁶ and there is a constantly strive for equilibrium and equality.

Normally equilibrium for a family would be to have a main caregiver and breadwinner – the man who would provide money and food – the wife would take care of the household chores and look after the children and the elders. The older family members would in turn help with the children and give cultural learning and spiritual guidance. Different people and age groups would fill in the different roles and together create a reciprocal and functional livelihood.

The society today is affected in many ways by AIDS and households develop new ways of responding to the impact of AIDS, with for instance creating new forms of households and in that way new ways of coping.⁵⁷ Because of AIDS a three-generation type of household appears – with the middle generation missing,⁵⁸ and so it is also called the “skip-generation” household that is made up of grandchildren and grandparents. Only a decade ago you wouldn’t see many households like this. In the new household types there is a lot of confusion surrounding status since gender, age, breadwinning and ownership all points in different directions and makes it difficult to decide who should do and be responsible for what.

If there is a man in the household he will usually be presented as head of the household even if he is not the breadwinner or owner of the house.⁵⁹ At the same time in many of the households I visited the woman who was the oldest presented herself as head of household even though she had a grown up grandson who worked and earned money. Because he was her grandson, she would look at the status among them and she would require most respect from him than the other way around.

⁵⁶ Ibid:20

⁵⁷ Barnett.2002:188

⁵⁸ Schlyter.1996:24

⁵⁹ Ibid:24

But often there is more than one person who is head of the household and the different members share the income work and the house chores and care if they are old enough to do so and roles and status become blurred.

Also multigenerational households occur when you have three generations or more living under the same roof in the same household such as children, parents and grandparents living as a family unit.

Gender perspective

Ageing is also about gender. But most often older people are treated as gender neutral in statistics and research but in this paper it has a certain importance, as it is mainly older women who end up with the biggest burdens and troubles of caring for grandchildren and sick.⁶⁰

Views on gender roles and expectations towards these are altered both due to AIDS impact and change in lifestyle. Especially women have to adapt and get used to new positions and responsibility in the household and community when they become head of the family household. In Zambia most of the widowed people are women and it is many of these women who take on new roles as head of household and caregiver of children and sick as the men often die first or have left the family.

Normally female-headed-households are especially poor, because the way of living in many areas in Zambia is based on traditional guidelines that make it difficult for women to own anything such as land or house the same way as men.

Most often it is the women who end up as the ones looking after the patient and children including chores like cooking, washing, cleaning and fetching water, as there is old traditions for this to be the women's job.

There are differences between men and women in work relations. Most women do work in the informal sector such as petty trading, selling crafts, artefacts and cooking or brewing⁶¹ and the men work in the formal sector where the pay is better. In general women tend to have work that is an extension of their domestic roles and chores. Today the informal sector is important for the survival and extra income for many people in the developing countries⁶² and many families in the Zambian society is represented here. The men work in the public sphere outside the home. Thus it is more difficult for women alone to support and take care of a whole family without a man to earn money. That is why a lot of women are forced to marry in a young age or remarry if their husband dies or leaves the household.

Women also have difficulty getting in on the work market and finding proper work with good pay, as they very often don't have the same educational background as the men. Boys have always been given higher priority to attend school and if girls went to school it was only when they had time

⁶⁰ Schlyter.1996:6

⁶¹ Schlyter.1996:4,29

⁶² Touwen.1996:69

from domestic chores and normally only for a few years. Lack of education and the general view that women should concentrate on the domestic sphere and house chores give difficulties in finding proper work and get adequate pay to support the family. Women in market trade have increased since the late colonial period, which doesn't mean they are getting better economy but just that market trading is one of the few opportunities women have to get an income themselves.⁶³ Even though there is a male main caregiver in the household it is normally the woman or one of the daughters that look after the sick.

The greatest burden is on the elders and in general elder women have to struggle more to get money to support the family as they probably never have been on the working market and at the same time are getting too old to work at all. Of course due to development and modernisation the view on women and their rights are changing and more and more women are getting in on the public market and get work the same places as men but the pay is hardly the same. Still there is a tendency in the rural and township areas that women stay in the private sphere and take care of the housekeeping and sticking to the more traditional way of living and dividing responsibility and chores.

For elder women ending up as single main caregivers, it is important to have a house of ones own. This provides security both psychically and economically and you need not worry that the husband's relatives will claim it and therefore you can use it to get an income by renting out rooms.

Normally it would be elder women who took up small scale work for extra income and they had more time as child care was no longer a critical issue for them, but this has changed with the AIDS epidemic⁶⁴ and elder women alone with running the household have difficulty in finding time to both care taking and income earning.

There is a lot of injustice in the practice of inheritance of matrimonial property and women hardly ever inherit.⁶⁵ Even though there is a public law saying that wives and children should inherit from their husband and father, very often the mans family go the traditional way and take everything both house and artifacts as soon as the man is dead and the wife and children are forced to move somewhere else. The inheritance system in Zambia is combined by three lines, the matrilineal, the patrilineal and the bilateral and in all three systems men comes first for inheritance. That is partly

⁶³ Schlyter.1996:133

⁶⁴ Ibid:134

⁶⁵ Ibid:5

why so few women have control over land.⁶⁶ Unfortunately the widows don't have a lot of house rights, and are often chased away by husband's relatives when the husband dies. If the husband wants the wife and children to keep the house he has to write a will.⁶⁷

So access to house and property is through the husband and there is a general view that women are dependent on men to accomplish good living conditions. Many in the Zambian population don't know about the laws that gives the female relatives their right to inherit and often the family will go the traditional way and simply take the house and everything even the contributions to the house the wife have made will be seen as the ownership of the deceased husbands family.⁶⁸

If an elder woman is left with her grandchildren after both the father and mother have died, it is very difficult to care for them if the family has left her with nothing for support.

Sometimes the patients also spend all their money on treatment before they die and leave the relatives with hardly anything. In one family in Olympia Extension the AIDS sick son spent most of his money on medication and private doctors, so the money the family should have had from his work when he died were all used on that. The grandmother has no means of caring for the four grandchildren she is left with. Fortunately they kept the house, which is big enough for them to rent out a room and in that way get an income. Many of the female-headed households make use of subletting out rooms for income.

⁶⁶ Touwen.1996:68

⁶⁷ Schlyter.1996:31

⁶⁸ Ibid:136

Coping strategies

The AIDS pandemic has a devastating impact on the family that breaks down under the massive pressure and the consequence is that families stop supporting each other because of lack of resources. This leads to new forms of support as neighbours get to play a new role in social support as well as Home Based Care Groups made up of volunteers who gives support to the local area. To support and help all the different groups affected by AIDS, patients, orphaned children and elders, new models for support and care taking has to come in place and we will look at some of the coping strategies that are being used as AIDS has impacted and fractured the social system in Zambia.

New models of helping each other sets in as the family is either to far away or not able to help and neighbours and the local society takes on a new role.

These new models of aid can be summarized as follows.

1. Neighbours
2. Home based care
3. Institutional childcare in day-care centres

Neighbours

Neighbours tend to play a supporting role between each other. There have always in Zambian village society been help to get from neighbours when you were short on food or needed help to get something done. Now a day this helping role is taking whole new proportions as the extended network is breaking up and new ways of getting help to cope is needed.

The neighbours takes some of the pressure of the caregivers of children and sick by helping with shopping, laundry and other house chores, as well as they give moral support. Of course stigmatisation and discrimination in some areas can give problems and help can be left out because people are afraid of the danger a sick person presents. Stigmatisation is seen when a family affected by AIDS is frozen out of the local community and nobody wants to visit them, help them or come near their house. Neighbours spread rumours about the AIDS-affected family and this leads to, that nobody wants to come near them. People see it, as the infected persons own fault that they have become sick maybe because they have lived a promiscuous life or have done something bad and AIDS is their punishment.

A lot of the elders points out that they seek help from the neighbours but that they not always get it. It also depends in which area you live. In the townships of Ng'ombe it seems easier to get help from the people living next door, maybe as they are both poor and know they can't expect anything from the other. That there is no fence between them also makes it easier to contact each other or maybe because there is no fence it makes it more difficult to refuse and hold the others out.

Maybe the elders' don't always ask for help because they are afraid of having to give something back in return. In almost all societies and cultures there is a state of reciprocity, which is all about stabilizing the society through gift giving and exchanging. If you receive something you are expected to give something back eventually. Maybe this form of traditional thinking is still present in many Zambian societies today and makes it difficult for some to reach out for help if they can't give anything back. Relationship with neighbours is grown out of shared problems where people help each other with food, moral and psychological support such as assistance at funerals.

There is a difference in where you live concerning stigmatisation, how people help each other, possibilities of getting help from family and surrounding society, and also differences in opportunities whether you have money to pay for help or receive it out of kindness from others. "Ng'ombe where the more deprived people live, more open because not just help with medicines but also with a bag of mealie-meal so they can feed their family. That's why they need to be open, cause they need help with different things as food and transport" (*Interview.d.23.May.2005*).

Home Based Care

Impact and changes due to HIV/AIDS occur on different levels and affects the household, community and nation all together. The three mentioned areas are all linked together – individuals make up households that make up communities, which makes up nations and the impact occurs on all levels. Many governments and researchers are seeing the community level as one of the only places where a solution to prevention of AIDS and impact issues can be found. One reason can be that it is normally easier to reach people on a local familiar level. In that way the government also disclaim the responsibility for prevention and impact solutions themselves.⁶⁹ The Zambian

⁶⁹ Barnett.2002:193-194.

government don't have money for AIDS campaigns and treatment due to bad economy and the welfare system is almost non existing, which makes it more important for NGO's and other organisations and churches to set up helping programs.

Home based care groups is a community solution that works in the local community that provides volunteers, who visits the sick and help the caregivers with nursing the sick and helping with food and medicine. Home based care try to open up about the silence and stigmatisation surrounding AIDS and the HIV-infected patients by openly show that they help and support the sick. They give help to the main caregiver of the family. It is mainly women who join the volunteer groups, as it is also mainly women that care for the patients in the home.

People with authority such as the home based care group have it easier to make people listen to them and do as they say – by being open about HIV/AIDS they prevent and work against discrimination.

I visited a Home-Based Care Group (HBC) located in the township Ng'ombe where I did my fieldwork. The Home based care group have their office at the Roma Parish Church and the church is another also very important means to get support. HBC in Ng'ombe came about in November 1997 by six people because of HIV/AIDS – to many people getting sick, lack of health centres and bad hospital conditions and people getting discharged when there was no hope for survival.

It was first started, as a project with no outside help and the main purpose was to visit the sick and support the primary caregivers that take care of the sick 24 hours a day. The help is concentrated on the local community where the volunteers themselves live. It is easier that way to get people to ask for help and to open up and talk about AIDS and other problems as extreme poverty, as they know the volunteers from their local surroundings and therefore feel more comfortable. The HBC volunteers also find it easier to approach people they already know.

The volunteers help as secondary caregivers to give the primary caregivers a break, and do things such as bathing the patient, cook food, wash and sweep – normal household chores and if the family have no food they try to provide it as well as clothes. The care is holistic and tries to fulfil both physical needs such as food, medication, transport etc and also psychosocial needs as memory works and memory books for the children, which also helps them open up about the disease.

In the beginning there was no funding but after two years when they had proved self-sufficient-ness, they started getting support from the nation office and now also different organisations gives

funding. They have gone from 6 to 45 secondary caregivers/volunteers and about 265 patients on the register – all affected by AIDS. The Care Group take the patients on their program as they come and if patients die and that person was the breadwinner of the family they help the family with food for at least three months till they start finding other ways.

Zambian society is social and cultural combined by old traditions and new western/ “modern” ways of seeing things. This can be difficult for people that are doctors and nurses or in some way in touch with the medical discourse as they learn to believe more in the western biomedicine instead of the traditional way with healing and witchcraft to cure diseases. The same goes for people in touch with the western world through Home Based Care as the volunteers that work closely together with western organisations and people. Through volunteer work they also work close with the clinics and hospitals and organisations being responsible for medicine as Anti-retroviral medicine and they try to pass this information on to the local districts.

People affected by the western view on diseases such as AIDS try to enlighten the population on what is the right thing to do concerning protection and treatment but often you see that the old or more traditional way of doing things is followed. Often the information about protection and treatment don't reach the homes where the caretakers that really need this info are located, as they are the ones looking after the sick. And caregivers including the elders don't have much time to get out or go to meetings where this information is shared, as they don't have time or the physics to walk long distances.

Also maybe the traditional way of seeing things is more trusted as this has been in their culture and social life for so long and the western way is so diffuse and hard to understand that many people choose not to get HIV-tested. Another reason for not getting HIV-tested is the fear of stigmatisation and expulsion from the community.

In Zambia, home care is the most that an AIDS patient can expect. The government's Health Service is in a virtual state of collapse after the massive cuts in government health expenditure under 'structural adjustment'. At the same time many families can't afford to go to hospital for treatment as hospital fees is completely beyond their means, so home care is the only alternative.

“In hospitals when somebody is very sick and there's no hope for survival they discharge them”.
(Interview.d.23.May.2005)

Kondwa Centre

Another way of supporting and trying to strengthen the community is a day-care centre for orphaned children who live with their relatives that have a hard time caring for them. The day-care centre “Kondwa Centre” in Old Ng’ombe, which started in September 2000, is such a place.

At the centre the main priority was to feed the children and later the pre-schooling came to life to fill in the time between breakfast and lunch.

The day care is mainly for orphaned children who have lost one or both their parents and live with other family-members that have difficulties providing food for them. The Kondwa Centre works together with HBC who as they work out in the local community are able to identify the children that are in the most need of help. Usually the children come from a family who already is on the HBC-help program. Right now there is about 85 children and the centre gets funding from private persons and NGO’s. This centre brings daily relieves for the adults who are looking after the orphans and they need not worry about providing food for the children during the day and it also gives them more time to work or nurse the patient without feeling they are neglecting the children.

All three coping strategies take place in the sphere of the local community and is mainly used by the poorest and most disadvantaged people of the society. Most families I meet in Ng’ombe made use of the neighbours for help when it was needed and see it as the easiest and closest way of getting support. Many of the households who were connected to the home based care and getting help from them were run by women who were the main caregiver and in charge of the care taking of the HIV-infected patient in the family. A reason for this tendency that it is mostly female-headed-households that get help from Home Based Care is that the women are more open to ask for help compared to the men. Men often hide their own or other family members HIV-positive status as they are afraid of being judged and blamed for getting the disease themselves or for having infected others.

Institutional day-care as the Kondwa centre is connected to the HBC-programme and can only be used by the families already on the project but sometimes the volunteers of HBC also find very poor households not on the programme and the children are taken to the day-care to get food and in that way trying to lighten some of the troubles of that household. Both HBC and the day-care use some guidelines for who can come on their helping programmes to try and justify that they don’t have the resources to help everybody. Mainly people has to ask for help themselves to get it because then you

also know they are motivated to follow the programme and the advise they get and the day-care is an extension of the HBC work.

Modes of adapting to AIDS impact

Recently there has been a lot of talk in the media about how the African families and societies are able to handle the AIDS impact and it seems as most families manage to adapt the new burdens and changes in care taking roles and taking in the sick and orphaned. Some of the reasons why the family network is not working when it comes to HIV-infected persons and their children is that a lot of the Zambian population is still very scared of AIDS, they are afraid that if they take a sick person in, they too will become infected and sick. People are also afraid that the orphans after parents who died of AIDS is also infected with the disease, so to protect themselves they choose not to take the children into their household. Stigmatisation and lack of knowledge about AIDS among the Zambian population is a very important factor when dealing with the extended family support network. Some families do have the capacity to take in extra individuals but they are afraid of becoming infected. Family responses and ways of coping changes in how urban and rural communities and families are responding to the crisis. Some of the examples above both neighbour help and home-based care are trying to help households handling the impact.

There is also many visual proofs that families and households are not able to cope with AIDS impact and falls apart as it happens when we have split ups in families and orphans, widows and the elderly seek other households instead of staying together.

There are different modes of coping with AIDS impact for families and communities. On the one end of the spectre we see that the extended network breaks down and family and kin can't manage to support each other. Here you end up with child-headed households and grandparent-headed households that get no support from other family relatives. They are the poorest of the households that have trouble earning money and buy food cause they are either to young or old to work properly.

On the other end of the spectrum the extended network and kin/family relations manage to care for the sick and orphans and cope with the situation. Family members support each other both money wise and emotionally even though they might live far from each other. The old extended family network is maintained. In the middle of the two we have different ways of coping with different use of the extended family network support. Some of these strategies was observed during the fieldwork

and seemed as the most common ways for families to try and cope with the situations. Most often the orphaned grandchildren would come and live with their grandmother or aunt and other family members living elsewhere would send money for care. This was seen as the easiest way for a family to find care for the sick and orphaned as the elders didn't work and therefore had more time for care. Many elders pointed out that when the parents passed away there was no discussion about who should take the children in, it was just expected from the rest of the family that the elders should do it, maybe because it traditionally used to be the elders job to do so.

Many of the families with extra orphaned children can't afford to send the children to school, so they stay at home and help with house-chores or with making money on the market. In that way providing food and earning an income is done on behalf of schooling. Some households have to sacrifice education for the children that instead help with work and earning money for food. Another way for the household to cope is that the elder grandparents establish a small business for income or they sublet rooms in their house or maybe they have to move to a smaller and cheaper house and sacrifice the space for food.

Of course it's very different how families handle the situation whether they are poor or rich or male or female. Wealthy older men can take a young wife for example who can look after the orphaned grandchildren and in that way cope with the situation or the grandmother chose to go back to working and earn an income. Genders issues play a big role concerning the elders' possibilities of getting help and do something on their own.

Conclusion

We began by describing the traditional kinship in Zambia and the reciprocal relationship between generations together with the obligations and commitments between family members and kin. We saw that the extended family network is having difficulties maintaining itself as urbanization spreads out and AIDS impact. Changes in lifestyle give way for new values and priorities as the nuclear family is gaining support on behalf of the extended family. We described a model on how the AIDS death of a main caregiver affects the household. What new care taking roles elders' have to fulfill to support the orphaned children and maintain the household such as getting back into the labour market and take care of both the psychical and emotional needs of the children. It was argued that both elders and female-headed households have more difficulties in maintaining living standards as elders are getting to old to work and women have more trouble finding work as they are still seen as belonging to the informal work sector. This sector is an extension of the women's domestic chores and not paid well. It was shown that certain coping strategies are being put into work such as neighbour help, Home Based Care and institutional day-care to help the households and main caregivers to cope with AIDS impact. Families and households affected by AIDS cope in different ways to try and maintain their livelihood.

We can now see that AIDS has had significant effects on family life. These include:

The traditional social system is changed by the AIDS pandemic that forces the population to take on new social and care taking roles to help the family. The kinship system was built up around the extended family network, which was a flexible set of connections that adapted to needy situations and was a security net for the members.

This network is fractured by AIDS impact and families fall apart as they no longer have the capacity to help other members of the extended family as they themselves have enough burdens already.

AIDS affects most Zambian families, which is causing increasing number of orphans to be looked after and HIV-infected family members to be cared for. The elders end up with responsibility for both the orphans and the sick and become head of the household and the breadwinner who the others are dependent on for food and care.

The group of senior citizens are getting larger as a lot of them are no longer sexually active and not in such a big risk of getting infected. The elders have to earn money for the household, cook, clean and take care of the rest of the household members. They are not in a position to handle this burden

alone, but the family network is having difficulties handling the needs and often help has to be found elsewhere between neighbours and local resources. New relations among neighbours are starting to come forward as many of them are in the same position and we tend to see that this is creating a new form of helping network. Of course this is very different from area to area, and there is a tendency that people get more help from each other in the poor areas where you live close to each other. Maybe you get more help because it is difficult to turn people away here than if you live fenced in, in a big house, then it is easier to ignore.

New forms of local community help is coming forward such as home based care, where you get help with patient care and medicine and food for the patient that the rest of the family can live of as well.

The elders see their role in the family and local community change as they are given new responsibility for taking care of the sick and orphans. They lose their right to retire and become old cause they end up as main caregiver of the household. Many see the increase in the pandemic as brought on by change in lifestyle by the youth. In the urban areas the people don't live by traditional values anymore but take in western lifestyles with a more liberated view on sex and partners.

The AIDS impact on the family network changes the whole vision of the family as a close web of relations and interaction with relatives. Because of urbanisation families split up and move away from their home village and the family eventually lose importance because they are too far away to support each other. Death of family members and raising number of orphans and elders cause new forms of family households with only grandparents and grandchildren and the middle generation missing. The vision of a family is no longer made of the extended family network or the classical nuclear family but rather it is a mixture of generations and relatives with generational links missing and the remaining individuals are forced to stick together and make up a new form of family-bond to survive.

It is difficult to say how the elders cope with being the caretaker and breadwinner of a family, when I asked the elders I interviewed how they cope and handled the situation all of them said, "*I pray to God, I only live by the grace of God*".

They have difficulty coping and accepting the changes that AIDS causes and their biggest hope is that their grandchildren will grow up and be able to take care of them in return.

Gender issues has an interesting part as it is mainly women who ends up as the caregivers of an affected household, as the men has already died or moved out. It is also women who will give care to the sick as this is seen as the women's job as it takes place in the private sphere of the home, which is considered the woman's place to be. This view on gender roles also makes it difficult for women to get into the formal work-zone and find employment and earn money as many see them as restricted to the informal area where you most often sell food from small stands or other domestic like chores. Choice of work is limited for women and makes it more difficult to support the family.

It is both choice and circumstance that elders are becoming main caregivers of households with orphans and sick. They choose to look after their relatives because there is no one else to do so. So it is from the circumstances that they are the only ones that the choice is made- voluntary constraint.

Elder women and women in general have always been the ones to look after the sick and the children but they would get moral, psychological and financial support from the rest of the surrounding family. Now they are left on their own, as the family no longer has capacity to help out, as they themselves are caretakers of sick relatives. Even though most of the elders being interviewed proclaimed that they didn't get any money support at all it would normally turn out further in the interview that they got some money from their children living elsewhere who would sent them some now and again. But it wasn't enough. They don't see it as volunteer support but something they are entitled to from their children, that it is custom that the children send money home, something they have always done even before the AIDS pandemic hit.

The elders that end up as caregivers for their grandchildren and the sick will also die eventually and what will happen when the generation that are working adults now and who are suppose to become elders and grandparents already are dead. Who shall look after the children that are left behind then and also care for the sick? The generation that is growing up now will also to some extent get infected, some already are and some will and when they die and their parent are already dead also who will look after the children that are left without both parents and grandparents? One suggestion would be to take the stigma out of AIDS and to find ways to help families care for aids patients, since in the foreseeable future the state will not be able to do it.

Literature

Primary literature

Barnard, A & Spencer, J. "*Encyclopedia of social and cultural anthropology*". 1996. Routledge World Reference.

Barnett, T. & Whiteside, A. "*AIDS in the Twenty-First Century. Disease and Globalization*". 2002. Palgrave Macmillan

Crehan, Kate. "*The fractured Community*". 1997. University of California Press.

Egerö, B. Hammarskjöld, M. Munck, L. *AIDS: The Challenge of this Century*. 2000. SIDA

Epstein, A.L. "*Urbanization and Kinship. The Domestic Domain on the Copperbelt of Zambia 1950-1956*". 1981. Academic Press Inc

Hastrup, K. & Hervik, P. "*Social Experience and Anthropological Knowledge*"
1994 London: Routledge

Helman, C. "*Culture, Health and Illness*". 2001 Arnold

Schlyter, Ann.: "*A place to live. Gender research on housing in Africa*". 1996. Nordiska Afrikainstitutet, Uppsala

Stone, Linda. "*Kinship & Gender – An Introduction*". 1997. Westview Press

Touwen, Anne. "*Gender and Development in Zambia. Empowerment of Women through local Non-Governmental Organizations*". 1996. Rijksuniversiteit Groningen.

Secondary literature

Farmer, P. *Infections and Inequalities: The Modern Plagues*. University Of California Press. 1999
Berkeley, Los Angeles, London.

Joslin, Daphne. *"Invisible Caregivers: Older adults raising children in the wake of HIV/AIDS"*.
Columbia University Press.2002.

Kottak, C.P. *Anthropology- the Exploration of Human Diversity*. 2002 McGraw-Hill

Mckie, L. & Cunningham-Burley, S. *"Families in society: Boundaries and relationships"*. Policy
Press. University of Bristol. 2005.

Sachs, L. *"Sygdom som ubalance"*. Fremad. 1996.

Wright Mills, C. *"The Sociological Imagination"*. Penguin Books. 1973.

Internet links

<http://www.aegis.com/>

<http://www.aidsalliance.org/sw23839.asp>

<http://www.aidsalliance.org/sw1280.asp>

<http://www.bridge.ids.ac.uk/reports/R29%20Gender%20Prof%20Zambia%202c.doc>

<http://www.care.org/>

<http://www.cia.gov/cia/publications/factbook/geos/za.html>

<http://www.colorado.edu/ibs/pubs/pop/pop2005-0004.pdf>

<http://www.colorado.edu/ibs/pubs/pop/pop2005-0008.pdf>

<http://www.fozo.org/index.html>

<http://www.helpage.org/Home>

<http://www.humana.org/>

<http://www.icrw.org/docs/stigmareport093003.pdf>

<http://www.ilo.org/>

<http://www.medguide.org.zm/zhid/zhid0300.htm#gender>

<http://www.policyproject.com/pubs/SEImpact/zambia.pdf>

<http://www.popcouncil.org/pdfs/wp/160.pdf>

<http://www.redcross.dk/>

<http://www.sida.se/>

http://www.usaid.gov/pop_health/aids/caba.pdf

<http://www.who.int/ageing/en/>