

Annex II

Impact of HIV/AIDS on Generational roles and intergenerational relationships

Introduction

It is without dispute that the family is the most important institution that provides care, support, continuity and stability to individuals. The family is, however, an institution under siege. It is an institution that has, and continues to face the bombardment of forces that threatens its very existence. While historically, it has been able to face the challenges of providing for its members one way or the other, the recent wave of bombardment threatens to overwhelm its coping ability and to throw it into total disarray. The family has faced conflicts and disasters (natural and man made), has faced such crippling diseases as influenza, polio, chicken pox and others, but has survived them all.

Of recent, however, the family is seeing challenges from which survival is becoming a big challenge. Poverty is increasing in almost all the developing countries despite efforts by the international community to come up with measures aimed at reducing that poverty. Interestingly, studies have shown that the so-called Economic Structural Adjustment Programmes (ESAPs) introduced by the World Bank and IMF to reduce poverty actually increased it in every country in which they were introduced.

The onset of the HIV/AIDS pandemic and its devastating consequences has left the family crying out very loudly for assistance to help it cope, remain solid, useful and performing its crucial roles and responsibilities to its members. The problem with Aids is that on one hand it is disrupting the family structure in an irreversible way and shifting the weight and pattern of responsibilities to those of its members that are ill placed to perform them or thought that they had done their part. At a time in their lives when they might normally have expected to be recipients of care and support, many older people have no option but to become 'Africa's Newest Mothers'. Older people are caring for the sick, the dying and the children orphaned or made vulnerable by the HIV/AIDS pandemic. Older people, mainly older women but also including a good proportion of older men, are providing economic, social and psychological care and support for orphaned grandchildren. They are doing so with very few resources and no recognition or support. Whilst older people have become the primary carers for millions of orphaned children, it should also be recognised that in many cases there is some degree of reciprocity in the care and support relationship and that in some situations children have become the primary carers of their older relatives. And, in a few cases, Child headed households have also emerged.

It is now critical that policies that strive to bring all the components of the family together, harness their potentials and marshal their collective resources for the benefit of its members be developed. In other words, those policies that are likely to succeed are those that do not compartmentalise the individuals or families, but see them as one whole, with interlinking and mutually supportive parts.

This paper will give a short historical perspective of what African families looked like in respect of the roles and responsibilities of family members; examine the changes that have, and continue to take place, the impact of those changes, the experiences of older people and give some recommendations. I apologise in advance that a lot will be said about older people. However, this is as a result of the fact that a lot has already been done for the other segments of the family – children, orphans, people with disabilities and other vulnerable groups but very little for older people.

Historical Perspective

The issue about the existence of the “extended family system” in Africa has been well documented. The fact that it is dying has also been documented fairly extensively, although, without much research or supporting evidence. It is argued here that the family network in Africa has never been understood as being “extended”. The brother of one’s father was father and not uncle and his son was brother not cousin. Any person that shared the same totem with a family became a member of the family and became referred to as “father”, “brother”, “sister”, “uncle” or whatever was applicable. This fact is important because it had a direct impact on the roles and responsibilities of the family members.

The elders provided care to the children who in turn provided care to them in their old age. The more children one had, the more chances there were of receiving better care when one was no longer able to provide for himself/herself. There was a system that ensured that the needs of individuals were catered for within the family. Nobody would starve when other members of the family had plenty. No children would live alone even if all the direct (or biological) members of their family died. Even in situations where there was a reproductive problem, the family had a way of ensuring procreation without embarrassing the impotent!

Inheritance of human beings (men and women) and wealth had a big role in the African family setting. It ensured that the widow remained in the family so that she could be cared for together with her children. The inheritance practice was not a selfish way of getting a woman and then the wealth of the deceased, leaving the family to suffer.

In the traditional setting roles and relationships were very clear, well understood and passed on from one generation to the other. It was like a relay race, where the baton was passed on from one team member to the other until the race was won.

That unfortunately is no longer the case.

The Changes

Over the years, the family has been put under a lot of pressure first of all through the disruption of its pattern of survival. Because of the introduction of the money economy, family members started drifting into urban centres, living women, children and older people making a living in the rural areas. There was a time when individuals remitted money to their family members from

urban centres and supported them adequately. Indeed in a research by Wilson, Adamchak and Nyanguru in the Goromonzi area of Zimbabwe, it was found that the majority of rural people in the research sample were getting remittances from family members. All that changed as poverty began to bite when ESAPs were introduced. A piece of research carried out by Mupedziswa in 1999 demonstrated that ESAPs had brought untold suffering to the poor in Zimbabwe. Apart from this, families also had to deal with various conflicts and disasters.

While families were still grappling with these changes, the deadly HIV/AIDS arrived on the scene. It is a known fact that AIDS is culling off the productive age groups and living behind children and older people. According to the United Nations Food Recovery Unit (2003), food production in rural areas of Zimbabwe has declined due to the death of the core agricultural labour force. Consequently, the availability of income has also declined. The problem of HIV/AIDS is that its effects are permanent. The disruption that it causes to the family systems and survival strategies cannot be reversed, but also take a long time to adjust to. Apart from the loss of loved ones, AIDS is taking away those that originally provided support to older people and living a large number of orphans, the majority of whom are being cared for by older people. According to UNAIDS/UNICEF 2002, 12 % of all children in Africa are orphans.

It is important to reflect a bit here about the issues surrounding the care of those affected by AIDS and the orphans left behind. A lot has been written about these issues but without actually answering the question, “Who is actually providing the care?”

Statistics have been produced on various issues concerning the HIV/AIDS pandemic and are commonly quoted and used to inform the HIV/AIDS work of governments, international agencies, non-governmental organisations and the media. However, despite the mass of information collected and the resources directed towards understanding the pandemic, the enormous impact of HIV/AIDS on older people and the roles they play in caring for the sick and orphaned children are almost always unrecognised.

Many adults who are sick with AIDS related illnesses return to their parents’ homes when they are no longer able to manage by themselves. In a study carried out in six districts in Uganda, parents were most commonly cited as the principal caregivers of AIDS patients (Ntozi, 2001). In many cases, older people shoulder the responsibility of caring for their children when they become ill providing physical, economic and social support. The greater the care needs, the less the time available for older people to participate in income generating opportunities. At the same time, “older people, because of their ignorance about the disease, will run from one traditional healer to another trying to find a cure. They will sell all their wealth, possessions and strip themselves economically naked. At the end of all this, their reward is the burden they face in caring for the orphans - fending for them, providing food, clothing and school fees” (Nhongo, 2002).

A number of studies have found that in sub-Saharan Africa the majority of orphans, whether orphaned as a result of HIV/AIDS or for other reasons, are cared for by older persons, particularly older women.

In South Africa and Uganda 40% of orphaned children are living with their grandparents and in Zimbabwe, up to 60%. In Zambia, Uganda and Tanzania, grandparents made up the single largest category of carers of orphans after the surviving parent with 38, 32 and 43% respectively.

- HelpAge International (2000) found that older people have to shoulder the burden of caring for as large a number of orphans ranging from 12 to 17.

In 1992, a survey conducted in Zimbabwe (Jazdowska, 1992) found that 90% of those caring for orphans were older people and most of them were women.

In a study carried out in the same country in 1996 it was found that 143 out of 292 people caring for orphans were those aged 50 years and above. In fact, 125 of them were those aged 60 years and above

A study involving 20,000 households in rural Tanzania (Urassa et al, 1997) found that virtually all orphans and foster children (children with one or more parents alive but who are not living with the parents) were cared for by members of the “extended family”, often the maternal grandparents.

Research in Uganda (Williams and Tumwekwase, 1999) found that it was impossible to focus only on HIV/AIDS. In the village, 30 older people were looking after 58 grandchildren, of whom two-thirds were orphaned for reasons other than AIDS.

A WHO survey in Zimbabwe (2001) found that 71.8% of those providing care to the sick and to orphans were over the age of 60 years.

In study in Tanzania (2002), Dayton and Ainsworth found patterns similar to those presented by the WHO from Zimbabwe.

In Kenya, 2002, K'Oyugi and Muita highlighted that older people were not only taking care of children orphaned by AIDS but orphans in general.

The work of HelpAge International in Tete, Mozambique found that 774 older people were caring for a total of 2,187 orphans. Of these, 95 were caring for children whose parents had died through war, domestic violence, road accidents and so on.

In the Cape Flats, South Africa, a study of older carers found 156 grandchildren below 19 years of age living with 43 older people. Of the children, 19 had AIDS. (Ferreira, 2002)

An analysis of Demographic and Health Survey Data from sub-Saharan Africa found that orphaned children are more likely than others to live in grandparent headed households (Bicego, forthcoming)

This scenario has significantly changed the family structure, the roles family members should play and the relationships in the families.

The Impact

Older people remain one of the poorest groups in every community of Africa. A study commissioned by the Ministry of Gender, Labour and Social Development to analyse the available data in relation to the poor and vulnerable groups, found that 64% of older persons (60 years and above) fell below the poverty datum line. When these older people have to take on the role of providing care to the sick and the orphans, then the burden is really huge.

In a study carried out in Zimbabwe (HAI, 2003) older people described the burden of care as the need to provide medication, cleaning materials, lifting, washing, feeding, cleaning the sick, fear of infection, fetching of water, and because they to worry about leaving the sick behind, older people miss the opportunity to work in their fields. Older people added that the sick people made comments when they saw the caregivers using gloves. In addition some of the sick were mentally affected and shouted at the caregivers.

Caring for orphans provided several challenges for the older people. While some issues were the same, caring for boys was different from caring for girls. This related to the different needs between the boys and girls and also issues of discipline and abuse by other family members. Whilst boys can be left half dressed, it will be considered a form of abuse if girls were to be found in that condition

The problems of older people caring for disabled orphans were found to be more difficult. Mercy Nyakaskwa is 52 years old and has 7 orphans from two children (3 daughters and a son). One of the orphans 12 years old is disabled and uses a wheel chair, which was donated by a local Samaritan. Living in a polygamous marriage, she is the 5th wife to a man who cannot support her and the orphans. She ploughs her land alone with the support of the orphans. She said, "my main problem is food and clothing for the children. They are growing fast and need clothes every now and then". The disabled child is not also mentally stable and any clothes he puts on he tears them". She added.

"I have to struggle looking after these children. We receive nothing from the government or NGOs. I have to work for their survival". An older woman caring for 17 orphans in Uganda, 2000.

"To be left with these children was a greater shock than the death of my son. I am struggling to feed, educate and clothe these children". Denis, 78 years, who takes care of four grandchildren in Kenya.

A report by WHO (2002) talks of older people having 'taken on new roles by providing care and financial support to orphaned children and playing child-rearing roles within their extended families', however the idea that the role is 'new' is debatable. In many communities, older people, particularly older women, traditionally played an important role in the care and upbringing of children. Studies from Tanzania (Urassa et al, 1997) provide evidence of the many and varied care arrangements that existed within the community, with orphaned children cared for by various family members and 'foster-care' arrangements common when one or both parents moved away for work or other reasons.

What is not debatable however, is that in communities hard hit by the HIV/AIDS pandemic the magnitude of the task has changed and older people are no longer assured of support in their role as care providers. “In the past, grandparents would have cared for their grandchildren some of the time and, in many cases, would have received support from the parents of the child in return – either through remittances if s/he was living elsewhere or through the provision of food and care if the son/daughter was still living in the same community. With HIV/AIDS however, many older people are now the primary carers of many grandchildren with absolute responsibility for their welfare” (HAI, 2001). As Ntozi (1997) notes, in the long run, the relationship of mutual obligations and concerns is being changed by the disease. The family has been weakened by the epidemic and will probably not be the same in the post-epidemic era.

The trauma of the death of their child is followed by feelings of desperation as to how to adequately cope with the surviving orphans at a time when resources have dried up and other forms of support are not available (HAI, 2002 (a)). Whilst caring for the sick, many older people use all available resources and sell assets to meet the costs of medication and treatment, only to be left with the economic challenge of caring for orphans. The costs of feeding, clothing and paying the school fees for orphaned grandchildren have proven to be major concerns for older people across the continent. In research carried out in South Africa, older women caring for children affected by HIV/AIDS “referred to a scarcity of food and a day to day struggle to procure food to feed the family,” Ferreira (2002) comments, “they walk a tight rope between survival and starvation”.

“Grandmother gives all of us food, she ties her stomach with a kitenge and goes to sleep”.
Young girl, Freedom Compound, Zambia (Nhongo, 2001)

Large numbers of older people simply do not have the resources to cover the cost of bringing up several grandchildren and meeting their own needs. The economic burden is not only a cause of concern for older people, but is also a source of dissatisfaction for some of the children in their care. Research in Tanzania (HAI, 2001) highlights that some orphans feel they are not well supported and that their needs are not met by their grandparents. Older people echoed these sentiments, saying that as they care for the sick and later strive to generate sufficient income to meet food and other basic needs, they are unable to care for the grandchildren in the way they would like.

Quoting information from Zimbabwe, Beales (2002) states that although it is often recognised that older people are primary carers, there is little support for the grandparents. One result is that the grandchildren opt out of school in order to support themselves and their aged carers.

Even where resources are dedicated to supporting the care of orphans, older people often have difficulty accessing them. In South Africa for example, older people caring for orphaned children may be eligible for foster care or child support grants but take-up rates are very low. Not only are there stringent eligibility requirements, but older people face discrimination from social workers who deem many older people ‘too old’ to be the carers of the children despite the fact that they are already undertaking this role.

'We need nothing less than a dramatic reorientation of attitudes, ideas and policies towards ageing. Rigid and dismissive notions of 'age' and 'ageing' have no place in today's world.'
Kofi Annan, Secretary General of the United Nations, 2000

Accessing services provided by NGOs is often equally difficult. Misguided beliefs and ageist attitudes serve to exclude older people from development programmes that could help support them and the children they care for. For example, older people are routinely excluded from credit programmes on the basis of their age and the assumption that they will not be able to manage. Yet, evidence from income generation programmes supported by HelpAge International demonstrates that older people can implement development programmes effectively and that credit repayment levels are comparable to other age groups

"As older people, society considers us more knowledgeable about issues and people in general will listen to our words of wisdom. We want to be part of the prevention of HIV/AIDS", An older man in Zimbabwe, 2002.

Consultations with older people in many countries have found that although they are aware of AIDS many are misinformed about its causes. This is hardly surprising given that almost all HIV/AIDS prevention campaigns target the youth and middle age groups and exclude older people (HAI, 2003). As a result, older people do not receive information and education that would help promote behaviour change and so they remain at risk of HIV infection¹. With the lack of accurate information older people may perpetuate misconceptions about HIV/AIDS and contradict prevention messages targeted at the youth in their care. Furthermore, in most societies older people play an important role as advisors to their families and communities and so there is enormous potential for older people to play an important role in HIV/AIDS awareness and prevention campaigns. However, this potential remains under-utilised as most HIV/AIDS organisations exclude older people from their work.

A number of publications produced by several organisations to create awareness on HIV/AIDS were assessed over the project period. The assessment revealed that most of the HIV/AIDS communication tools are designed for the so-called sexually active age group with little consideration given to the older people. The materials are mostly written in English and pictures used only feature children, the young and middle-aged people. Even if these materials are written in local languages, very few older people can read due to low literacy levels.

During some of the consultations held, older people acknowledged that they have children who could read for them as they could only look at pictures and make assumptions. Some of the interpretations made about the pictures were not correct, implying that they were not suitable for older people. On the other hand, the pictures were not necessarily related to the wording, hence

¹ Older people are at risk of HIV infection and, like all other age groups, the most common cause is unprotected sex. However, available data does not often include how the pandemic affects this age group. In the USA, 10% of all AIDS cases occur in the 50+ age group. Yet, while 83% of all AIDS deaths in the world have occurred in sub-Saharan Africa, very little is known about the epidemiology of HIV/AIDS among older people in Africa (WHO web site, 2003).

by only making assumptions about what the pictures were saying, older people were not getting the intended messages.

The use of inappropriate languages and cultural insensitivity of the messages completely cuts out the older people leading them to feel irrelevant. They also find it difficult to associate with these messages.

The leaflets and fliers also proved irrelevant as most of them were in a narrative form in English and printed in fonts.

Billboards also complied with the same rule as the posters. Due to lack of interest, older people could not differentiate HIV/AIDS billboards from those of Coca Cola or other products. As far as they were concerned, all billboards advertised Coca Cola, since the pictures were of young people and the language used was English or slang. E.g. on an advert for VCTs, a local musical artist appears with the message: '*Chanuka, tembelea kituo cha VCT*'. (Take control of your life and visit a VCT).

In Kenya, articles on HIV/AIDS in the Daily Nation and the East African Standard newspapers were analysed over a period of four months. Whilst 27 articles, features and news items appeared in the papers, they only mentioned several other population groups such as the youth, the army, teachers, the blind and women. No mention was made of older people, either in as far they are affected by the pandemic or the caring role they are providing to PLWHAs and orphans.

In Zimbabwe, newspapers of over two months were reviewed for relevance and appropriateness of information contained to the needs of older people. The assessment mainly looked at how often HIV/AIDS gets coverage in papers, the extent to which the issues of older people are acknowledged and whether the messages written have any relevance to them. The results were the same. No mention was made about older people in the newspapers analysed between 25th July and 25th August 2003.

In addition, several HIV/AIDS awareness materials produced to educate the public about the impact of HIV/AIDS were assessed to understand their relevance to older people. The results are given below.

A poster produced by Kenya Prevention of Mother to Child programme has a catchy picture of a pregnant woman in a wondering posture the phrase on the poster is a question that asks 'WILL MY CHILD BE HIV FREE?' Below it, in smaller fonts, the message read, "go for voluntary counselling and testing at your maternal child health clinic".

A poster with a map of Kenya and in it are paintings of young girls of ages 15 to 25, each saying something to the effect of the need to avoid sex before marriage, schooling etc. The bigger message on the poster is '**SMART GIRLS SAY NO TO SEX BEFORE MARRIAGE**'. Below, in smaller fonts is a message that says "Girls get together and start practising how to say NO! (It could save your life)."

Another poster shows painting of a football match where a player of about 20 years of age has shot the ball towards a goal post defended by condoms and the ball is on its way out. The message at the top is *'To win a match, good defence is a must'*. Below is 'Family planning and protection against STDS/AIDS, use a condom.' Obviously this message is targeted towards younger people.

In a similar exercise in Zimbabwe, over eight posters and leaflets produced by Zimbabwe National Family Planning Council, the Ministry of Health and Child Welfare and Africare to educate the public about HIV/AIDS, its transmission, prevention and care were collected and the messages reviewed. Most of the posters were produced in English and their focus was mainly on the youth. The posters had some pictures to go with the messages but none focused on older people.

One poster had a picture of a young man and woman wearing western fashion. The main message was *'ENJOY YOUR YOUTH but have the courage & strength to say "NO" to sex'*. The message encourages the youth to resist peer pressure and avoid STDs, HIV/AIDS and teenage pregnancies. It also talks about the availability of guidance for the youth from health workers, "*Sahwiras*" (close friends), peer educators, parents and knowledgeable community members.

A second poster has a picture of a girl and a boy in school uniforms falling out of a flying helicopter. The main message written is *'SCHOOL DROPOUT! Where are you going to land.'* This message stresses that school dropouts are likely to end up suffering from HIV/AIDS, unemployment and unwanted pregnancies. This poster targets the school age children and is therefore not relevant for older people.

Another poster had the following words "one person one life" – One partner for life. This poster too had a picture of a young person.

A poster had the following message "If you must then use a condom" and had a young person's photo.

In the era of HIV/AIDS, older people have become 'Africa's Newest Mothers' entirely responsible for the economic, social and psychological welfare of many grandchildren. Whilst ensuring that the rights of the child to food, shelter, care and education are protected, older people often compromise their own rights. Equally, in some cases, the rights of children have been eroded as older people struggle to satisfy their own rights. The failure of governments, NGOs and society at large to recognise and support older carers serves to exacerbate the erosion of the rights of children and older people.

In HelpAge International's work across Africa, older people seldom say they are not willing to care. They simply ask that their efforts be recognised and supported so they can protect the rights of the children in their care and, at the same time, enjoy their own rights.

Recommendations for Action

Recognise the Impact of HIV/AIDS on Older People.

Governments, NGOs and society at large must recognise the fact that older people are caring for increasing numbers of children and must incorporate older people into their HIV/AIDS strategies. Failure to invest in older people will not only adversely affect the older generation, but also those they care for.

Implement the African Union Policy Framework and Plan of Action on Ageing and the UN Madrid Plan of Action on Ageing

Governments are urged to use the AU Policy Framework and Plan of Action on Ageing² and the Madrid Plan of Action on Ageing to guide the development and implementation of national policies for older persons and to inform the revision of national HIV/AIDS policies. The AU Policy Framework and Plan of Action on Ageing, in particular, has a section on the family. This section has recommendations and actions that call for the development of policies that aim to reposition the family so that it can respond to the current problems it is facing. For example, it calls for the identification and support of those traditional support systems, norms and values to provide care to its members.

It is well known that the African setting had provisions for the discussion of sexual issues and preparing children for adulthood. That discussion has to continue, but taking in the new dimensions in view of the threat of HIV/AIDS.

The AU Policy Framework and Plan of Action on Ageing also has a section on HIV/AIDS and some of the actions are as follows.

Ensure that policies and programmes relating to HIV/AIDS and other epidemics recognise that older people are major providers of care for those who are sick and for orphaned grandchildren. Provide a budget allocation to support older people caring for those affected by AIDS and other epidemics.

Strengthen community based care mechanisms to ensure that older people who are carers of those affected by AIDS and other epidemics receive support.

Harmonise policies

There is need to harmonise those policies that address the different groups within the family so that they are complementary to each other and can provide for the whole family rather than only a few segments of the family.

Review and revise national HIV/AIDS and orphan care policies

² The African Union Policy Framework and Plan of Action, developed in conjunction with HelpAge International Africa Regional Development Centre, received its final seal of approval at the meeting of the AU Heads of State and Government in July 2002. Copies available from the AU or HAI.

Governments, UN agencies, donors and NGOs should come together to review national HIV/AIDS policies to ensure that the needs of all people affected by the pandemic are equitably addressed. Furthermore, orphan care policies should be reviewed to take into account the role of older people in the care of orphans and other vulnerable children.

Include older people in the fight against HIV/AIDS

There is a need for an integrated, intergenerational approach to prevention, treatment and support to mitigate the impact of HIV/AIDS on families, communities and societies as a whole. Governments, NGOs and local communities need to work together to meet the needs of the whole community. In doing so, they need to include older people in policy development and programme planning.

Support older people caring for PLWHA, orphans and other vulnerable children

Community based programmes should be implemented that provide older people with support to care for the sick and the orphaned. Older people should be provided with skills that will help them cope with the challenges of caring for children. Collaboration between child-focused and older-people focused organisations should be promoted as a means of sharing and developing best practices. The negative policies and attitudes of many donor organisations that currently preclude funding of work with older people need to be changed.

Target older people in HIV/AIDS awareness campaigns

Older people should be targeted in HIV/AIDS awareness campaigns so that they can:
reduce their own risk of infection
care more effectively for PLWHA
provide orphans and other vulnerable children with accurate information about HIV/AIDS

Avoid Institutionalisation where possible

The issue of the institutionalisation of both the children and older people should be handled carefully. Research over the years has shown that these are not ideal for either group. Paul-Breareley (1990), had this to say, *“We have to ask ourselves: our really content to have our ailing grandparents living in prison like circumstances? And do we want to face the prospect of ending up in this?”* The UN (1994) also asserted as follows: *“While these institutions are necessary and respond to very real need, particularly for physical care, many studies indicate that none of these institutions has proven to be an acceptable substitute for the family in providing emotional, psychological and social support.”*

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