HIV/AIDS CARE and SUPPORT PROGRAMMES
- And ORPHAN CARE

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1   BACKGROUND

1.1   AIDS today continues to kill about 2 million people a year in Africa. Women are the most affected with an ever-increasing rate of infection. There is a change in family demographics and social set-up of family units. The terminology of care and prevention, once miles apart are seemingly so intertwined as the links between HIV/AIDS and poverty follow a similar pattern. In the midst of all this there is hope. There always is hope. The paper looks at a historical approach in this journey to hope. The role of the Church cannot be underestimated. It is imperative and this is the premise of the entire presentation.

1.2   **The AIDS problem in Africa, the case of Uganda**:

Uganda, in the late 80's & early 90's was for long synonymous with HIV. Just when it had been known for the dictators before, it came to light that there was a silent Holocaust that was consuming the people, AIDS - or *slim* as it was called - because of the loss of weight it caused in its 'victims'. The country, as many others have done since, went into denial for fear of being ostracised by the international community. It was not uncommon for one to hear that the problem of AIDS was being played by the 'West' to undermine Uganda.

1.3   **Initial responses**

It took the head of Government to understand the devastating effects of HIV/AIDS and the required courage to set Uganda on a path of action. The interventions that followed after the denial period can be divided into three phases:

(i) Government action,
(ii) community action and
(iii) joint Government and civil society action.

Initial church response was slow, hampered by the prevalent doctrine and thinking that it was judgement from God. This we see as the example of a church in denial.

2   CARE PROGRAMMES: HISTORY OF CARE PROGRAMMES IN HIV/AIDS

2.1   The natural entry point for most HIV in many parts of Africa is care - the nursing of patients. This seems to be a traditional response before it becomes a spiritual issue and prime mover of sustained care programmes. Initially, many people looked after their sick not knowing what the cause of the illness was. With time, when the cause because known, there was a backlash, as those who had been caring now started judging their 'patients'. They blamed them for sexual promiscuity. They felt that the disease was exposing what people had been doing in secret. Those that were infected, then also started to keep quiet about their situation until the "worst came to the worst" and they had no alternative but to share their plight. Many societies blamed the woman for bringing in the disease, a trend which we see repeating itself in so many other parts of the world. These patterns set in motion issues that are still the cause of great stigma to date.

2.2 Church and Faith Based Care Programmes

The initial involvement of the church was in response to a Governments call. The Church was asked to be one of the key members of the advisory committees to the AIDS Commission on Ethics. To this day, the Chairmanship of the AIDS Commission is by a Church leader.

On a practical, grassroots level, the parable of the Good Samaritan has been a key tool in getting the local independent churches to respond to the HIV pandemic. Evangelical Christians have used this model their engagement in the suffering of the afflicted. To fight the issues surrounding stigma, the story of Jesus and the Samaritan Woman at the well have been very pivotal (John 4)

2.3 Medical Programmes/responses

The huge numbers of patients put the hospitals at the forefront. This was compounded by the perception that illness, care, and disease are for the medical people. Christian institutions were quick to seize the opportunities. Many incorporated, or developed a PHC (Primary health care) component, focussing on HIV/AIDS, that went to the communities to create awareness and spend time in training the communities in how to look after the sick. The aim was to ensure that people only bring to the hospital cases that they can no longer/beyond their ability to handle.

i)   Mobile outreaches: Hospitals increased their outreach through the provision of certain specialist services. Mobile care teams, comprising medical people and local church and community volunteers, would go to the communities on specific days of the week to offer testing, nursing and other medical attention.

ii)   AIDS Clinics – Special Days: Mission hospitals started special clinic days where they would spend time to focus specifically on HIV/AIDS and offer diagnosis, treatment and counselling services. Many of the hospitals had Clergy as counsellors and a few trained Volunteers. These were some of the first models of community, churches and medical institutions working together.

iii)   Networks of Home based cared programmes: Networks were developed to avoid "double treatment" - people getting supplies from more than one hospital and then selling off the free drugs. These were designed to co-ordinate their efforts and work. Nurse and home care teams would meet regularly to share concerns and they actually divided up the city to ensure better coverage rather and limits of reach for each hospital home care team.

2.4 Community Initiatives (Home based Care as an entry point)

With increased awareness and establishing of a theological basis for intervention, Local churches, mainly, took the challenge to care for those in the communities.

i)   Home visiting: The entry point to many homes was caring for patients. The model of the Good Samaritan was pivotal in changing attitudes. Noteworthy is the fact that it was not always easy. There was a lot of suspicion at times, and in some case people hid the patients. However, as rapport was struck, the programmes were fruitful. They helped provide a needed service and support to the families.

ii)   'Relief' Packages: The most common response by organisations was the development of proposals to seek support to look after those that were sick. Coming from a culture where you never visit a patient empty handed, many of the programmes therefore focussed on assistance to those that were ill. They very

often needed help so the 'relief' packages meant looking for and providing material assistance to the patients and people living with AIDS. Provision of Food items, support to cover medical bills, pay rent and keep children in school was therefore common.

iii)   Counselling and Support: Counselling programmes were offered to both those infected and affected by HIV/AIDS. These included a wide range of options:

a)   Post-test clubs: These were established as a follow through. These were places where those tested could go for support. The members of these cubs did not necessarily have to be HIV+. IT was people that felt they needed the group support. The range of activities within this also differed. These ranged form Music, dance and drama, sharing a meal together, group counselling and discussions, prayer and spiritual support.

b)   Support Action Groups: These in many instances were volunteers associated to a local church that carry out visitation in the community regularly and also conduct awareness and prayer for the sick. The support would be in regular visiting and praying with the sick. These have since moved from looking after AIDS patients, because of the associated stigma to caring for the Sick and elderly in the community. Many are now being used as instruments to bring development in the local villages!

c)   Spiritual Days: Some NGOs developed fellowship days where patients would come, if and when they felt they wanted. These picked up in many places and even the secular programmes realised the need to look after the spiritual needs of the patients. These were opportunities for reflection, forward planning and encouragement.

d)   Care for the caregivers: Burn out cropped in and later gave birth to this approach. It became obvious that people could not care for the sick non-stop. Programmes and strategies to support the counsellors were developed. The link between the local church volunteers and the prayer groups was found to be very crucial. Issues that caused discouragements were talked about and together spiritual solutions sought and in other cases prayer and intercession for the counsellor sufficed.

2.5   **Integrated Programmes**

A couple of years down the line, it became apparent that instead of having specialised organisations in HIV/AIDS care, that there was a need to see the streamlining of some of these activities within other development activities:

i)   School support Programmes: The effects of AIDS were felt in many quarters, to benefit the orphans, it was observed that it may be better to improve the whole school as opposed to an individual, so that the benefit is ore sustainable. Some programmes therefore provided one (1) warm meal a day. Others constructed school blocks while others supported the provision of textbooks and or payment of teachers' salaries.

ii)   Micro enterprise/ Occupational Therapy: The provision of handouts became unsustainable. Other options were explored to help those in need. As the levels of stigma decreased, the demographics of the PHA ("Person having AIDS") client loads changed. The people started coming for assistance soon after knowing their HIV status, and not when. These programmes took on various forms. In some communities it took on revolving material loans, where some would get pigs, goats etc and pass on to the next in need once their animals reproduced. Others joined community – PHA income generation projects, or group support

and accountability. Others got small loans/ seed money to get them back to work life after they had been away or lost jobs because of illness.

iii) Community-wide development Assistance: A few new models were developed and piloted as it was seen that the HIV problem affected everybody in the society. To ensure that a child stayed in school instead of spending time nursing the patient, it was observed that things like water sources had to be brought nearer to the households. In other areas it was seen that the local communities had to take it on themselves to ensure that the children were in school and studying, hence the establishment of Parish / Child Development committees.

3   PREVENTION / SUPPORT PROGRAMMES

3.1   Prevention is largely seen as the stopping the further spreads of HIV. For long, their communities and local organisations felt that this was the domain of the government, i.e. ensuring of safe transfusion services and blood products, establishment of blood banks, the development of policies and laws to protect PHAs. Governments may or may not take it on, but sooner or later it is realised that there are intricate issues surrounding prevention that a government cannot influence. It needs the contribution of other actors. The churches to influence attitudes and values, the schools to give face-to-face education/awareness to children and the NGOs/CBOs who had the technical skills and the single focus to pursue certain activities, themes and outcomes to greater detail than government could.

3.2   Recurrent Difficulties

Early stages of HIV/AIDS involvement in many African countries have focussed on the condom debates. This is primarily perceived as a moral issue in Africa - Uganda, just like the aspect of Needle exchange, and controlled drug programmes have caused a stir in countries in Asia. Early prevention programmes therefore involved education at family level as to how to avoid infection, while nursing and looking after a PHA. The cultural taboos surrounding discussion around the subject of sex meant that the education work was to the few that were bold enough or who felt they had the skills to handle the subject.

3.2   Examples of Nationwide Programmes that emerged

i)   Mass Awareness and Sensitisation: Government, with the resources available to it started some nationwide programmes. The most basic of these as the IEC (Information, Education and Communication) campaigns.

ii)   School Curriculum Review: The AIDS/Sex graph data was a precursor to the discussion of HIV/AIDS and sexuality to the younger generation. The data revealed that the onset of AIDS cases was as early as 13 years, which implied that young people were having sex, whether by choice or through coercion, hence they were at risk. Data boys and girls revealed that in the age group of 15-19, girls were six times at higher risk of getting AIDS than their male counterparts. This information catapulted people to action.

3.3   Examples of NGO and Community Initiatives that emerged

i)   Life skills Programmes: Faith Based Institutions (NGOs and Para-church groups) got involved in life skills programmes. These were primarily designed to help young people develop abilities to make safe health decisions. This was all done within the framework of sound biblical teachings and /or values. This created a structure aimed at creating a system of positive socialisation.

ii)   <u>Adolescent Mentoring and modelling</u>: Treated as an offshoot of life skills, giving young people skills to make sound lifestyle choices, FACT Mutare, have pioneered church programmes were young generation get 'counsellors' in the older generation. People with whom they felt free to share issues related to lifestyle and challenges of growing up.

iii)   <u>Training of Clergy</u>: The development of training curriculum to equip pastors was developed with a three-prong aim. Firstly, to ensure that there was moral support for HIV/AIDS programmes within the church congregations, and that there was correct (accurate) information trickling down in the church structures. Secondly, to equip the Pastor, and Church leaders, with relevant skills to handle the basic aspects of HIV/AIDS. This meant that the pastor did not have to feel overwhelmed by the pandemic. The third benefit was that those in training would be prepared to handle HIV/AIDS issues realistically on the ground, something that previous training and academic curricular had not taken account of.

iv)   <u>Peer support groups</u>: Youth-to-youth programmes have been developed and are sustaining positive behaviour choices. Club Joseph, in Madagascar challenges boys to sound biblical principles and lifestyle. It provides regular meetings where issues of sexuality and growing up can be discussed. Youth Alive in Uganda, Tanzania and South Africa, challenge youth to similar values and provide the support for people to live up to those values.

4   CHILDREN AND ORPHAN CARE & SUPPORT PROGRAMMES

The care of orphans has been the most challenging of the whole lot. There are a number of models that have been tried and these put together all seem to show that there is still much more that needs to be done.

4.1   Statistics and AIDS Orphans

It is estimated that Uganda to date has between 1.5 and 1.9 million orphans to due to HIV/AIDS. The accurate figures are not known but are based on an initial orphan census that was carried out in 1990. Attempts to orphans Care have included:

i)   <u>Orphan enumeration</u>: An orphan enumeration was carried out in 1989, 1990. It was needed to ascertain the actual numbers of orphans but also to help planners forecast the future patterns and trends related to orphans.

ii)   <u>Institutional care</u>: The first attempts were orphanages. These worked for a time but were later disbanded by government policy that wanted a more community based and sustainable approach to looking after orphans. Periodic instances of child rights abuse and/or child neglect only compounded the difficulties.

iii)   <u>Strengthening of the extended family</u> (micro credit/ adoption, UWESO Model): The emergence of programmes to support the extended family was the solution. A few models included training of guardians and provision of micro credit to increase household incomes.

4.2   Orphan Assistance
- School/Tuition fees/Costs (limited to age 18; does not consider repeating)
- Vocational skills and Apprenticeship

4.3 **Challenges**
- Selection criteria (selecting one out of an already poor family)
- Packages... Christmas gifts etc to orphans
- Determining that all go for vocational skills (How many artisans can a community/society take)
- Limitations of age 18 – may leave people with unemployable skills and/or social misfits
- Sustainability of school fees programmes (for how long can school fees be provided?)

5 **POLICY CONSIDERATIONS**

In Ezekiel 3 we see clearly the role of the watchman. In a network like this one, there could be nothing more true of our Christian duty that this. There are roles that we have to play at various levels. The approaches are two pronged, like the illustration of the double-edged sword. There is what we need to clean up in-house and that for which we are advocates. A few specific challenges that remain are highlighted.

5.1 **Church policies**

There is need to get churches to develop polices that encourage engagement. Many actors are still merely at the periphery. Church denomination policies should be outworked through to parish levels.

5.2 **Fighting/decreasing stigma**

Stigma is still a big hindrance today. There is rampant prejudice among the communities including the church. This in some places is primarily a result of basic teachings in the Church (Theological World View). With the role the church in Africa plays it is imperative that they lead the way in fighting stigma.

5.3 **Human Rights issues**

The poor are still the ones most affected. The plight of women needs to continually be addressed in ALL HIV Programs. Cultural worldviews and stereotypes need to be challenged – right from the pulpit. Cultural blind spots, which encourage the continuation of an oppressive worldview must be identified and challenged. Looking at Christ as the model – I look at the attribute of Meekness. This has been defined as

> *"being angry when you should be angry and*
> *not being angry when you not be angry when you should not be angry"*

We need to rise up to this challenge and get this balance in our lives.

Child rights and protection issues: Property, inheritance issues, family disintegration (separation of siblings) at death. These are issues that need thorough thought and alternatives in all our domains of work.

6 **CONCLUSIONS**

6.1 **Good Practices for Building capacity for Care and Support Programmes**
- Solicit Leadership commitment and interest if training is to have sustainable community action and results;

- Involve PWAs – as means of Advocacy, experience sharing and Role models – timing is crucial;
- Carry Out a Training Needs Analysis – community to define its needs and work around them – bottom up participation;
- Have Quality Assurance Bench Marks – regular simple but firm;
- Follow up your Trainees – support people/staff so that they do not feel caged in, help them grow from one level to another;
- Let Training Programmes Grow organically – in the same proportion with the needs around them;

6.2 Lessons Learned

- Meaningful **Church involvement** needs the involvement of its leader – Pastor. Where a church leader is not enthusiastic, it is counter productive to try and insist on an intervention there. IT could have undesirable results.
- Many of the sick people want **spiritual input.** It was not uncommon for patients to ask their visitors and carers to pray with them. It is important to plan or it in the programme and have wisdom in its application. It is a key pillar.
- **Unconditional Love** shown to people affected by HIV/AIDS is a language that is so powerful, and is most appreciated by the sick.
- **Home care and visiting** are simple activities that any church member can be trained to do. These are instrumental in changing attitudes and stigma towards people with HIV that is common in many societies.
- **Material support** is useful at the beginning of a programme to help those that are in serious need. However, societies need to be challenged to help care for the sick in the community and <u>not</u> look towards the projects.
- **Caring for people** in the community should not only be for HIV +ve people but should include the elderly and the sick. This helps to decrease the stigma towards people living with AIDS (PLWA). It also increases the churches witness.
- **Everybody** has a role to play in HIV prevention. Respect the different roles and specialise in the role you play best.
- **Young People** need to be targeted and educated about responsible living. It should not be assumed that all are waiting for marriage before engaging in sex. Many are sexually active. They should be helped to develop positive values and to live by them.
- Giving **Knowledge** does not mean that people will change behaviour. Programmes should be designed to give knowledge and skills that help the young people develop positive values.
- **A Life skills Education based** approach to behaviour change as a training tool renders more changes and opportunities for behaviour formation and behaviour change (Use Illustration).

6.3 Finale

- The church has a key role to play. Christ commands us to show love to those that need it, visit the sick and those is prison. The current problem of HIV is an opportunity for the church to share the love of God.
- The Church is a respected institution in many African countries. It is time for it to rise up to the challenge and give direction and solace.

- However small the intervention one has, it is a potential to touch lives and to shape the destiny of many people and to save a generation.