

"... and one dares to hope and dare to remember".

Memory Work: Coping Strategies in the Face of AIDS

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The Memory Project in Uganda Experiences of the National Community of Women Living with HIV/AIDS (NACWOLA)

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The memory project is a set of activities that were designed to address the critical need for HIV positive parents to prepare their children to cope positively with their situation and to inculcate children with a spirit of care and support for their parents and to make secure plans for children in case parents die.

The National Community of women living with HIV/AIDS (NACWOLA) started the memory project in Uganda in 1998. The idea of this project was conceived during psychosocial support meetings that were held to promote the objective of sharing testimonies and experiences based on the stigma and discrimination faced by the NACWOLA mothers and their children. During this time Uganda was still battling to address issues of stigma and discrimination and NACWOLA women played a role model by going public about their HIV status. However when the children received the news about the HIV status of their parents, they were traumatized more especially by the community members who confronted NACWOLA children with statements such as:

- Your mother is going to die of AIDS
- Your mother has AIDS the sickness of prostitutes

Subsequently this created guilt and self-stigma to the HIV positive mothers; therefore they decided to start the project memory project to support their children to cope with the impact of HIV.

Situation of orphans and vulnerable children in Uganda

Since the pandemic started, the country has lost about one million people and this has contributed significantly to an estimated 2.3 Million orphans. Approximately 20% of children in Uganda between the ages of 6- 17 years are orphans.

Many children who are orphaned are forced to live on the streets or under exploitative conditions of labor, sexual abuse, prostitution and other forms of abuse. Many of these children live in the child headed households where they have to fend for themselves and support their younger siblings.

The impact of parental death on children is complex. The child's mental health is affected; consequently intellectual development is stunted, low esteems and lack of hope for the future.

The Memory project is one of the approaches that have registered tremendous results in providing psychosocial care and support for children affected and infected by HIV and AIDS.

Testimonies of children

Case 1

"My name is B. (16 years old), I am a total orphan, and my parents died of AIDS I was 10 years old by then. I became a destitute after the death of my parents because life had lost meaning, my 2 little brothers went to live with a distant relative.

My life changed when I met NACWOLA women sensitizing in the community, I had gone with a motive to still something for survival but I was touched by the message of NACWOLA women, I interacted with the women and shared with them my experience so they asked me to join the children's club for counseling, consequently I benefited from the training of the memory project .My life has changed so much I now live in our home I brought my little brothers back and now I am the head of the family .I have been trained in skills of carpentry so I make stools and tables to sell, I earn income from car washing .My little brothers are in school and they are happy, NACWOLA mothers often visit us."

Case 2:

"My name is T. M.. My father died of AIDS when I was young. I grew up with my mother who was a member of NACWOLA. I benefited from the memory project and I was empowered to head my family after the death of my mother. I grow crops for food on our piece of land, sometimes I sell some food to get income.

I was in senior two by the time my mother died. Now I am in senior six, and I will go to university next year. Friends of NACWOLA women are now paying

my school fees. My sister and I are happy and we have hope for a bright future."

Objectives of the memory project

- Encouraging dialogue between HIV positive parents and their children.
- Improving counseling for children.
- Challenging the culture of silence about HIV/AIDS sexuality.
- Relieving the mental stress of children affected by HIV/AIDS.
- Improving children's understanding of their situation.
- Strengthening family coping mechanisms

The NACWOLA memory project was developed based on 4 pillars namely:

- Improving communication between HIV positive parents and their children
- Disclosing HIV status and other important information
- Succession planning
- Writing important family history in a memory book

The objectives of the memory project are enhanced through activities as follows:

Parents/Guardians training

The critical issues in this training are:

- Enhancing communication skills to prepare parents and guardians to disclose their status to their children and later support them.
- Understanding the needs of children at different stages
- Helping parents and guardians to understand inheritance rights and make secure plans for children and involving children and respecting their decision during planning.
- Imparting skills of income generation, small loan schemes and savings.
- Supporting parents to write memory books for their children.

Children's training

The critical issues in training children are:

- Providing knowledge to help children get a deeper understanding of HIV prevention and care for the sick.
- Helping children to understand their rights and responsibilities.

- Helping bigger children to understand stages of child growth and needs of different stages to prepare them in case they have to look after their young siblings.
- Empowering children with communication skills to enable them open up to parents and care takers on difficult issues they experience.
- Life skills training

Counseling

This activity is carried out to support parents after they have disclosed their sero to their children. Even the children are taken through counseling sessions by other NACWOLA mothers. This is achieved through home visiting.

Children's club and children's exchange visits

The children's club promotes peer support for children through child-to-child counseling, sharing experiences and testimonies to build resilience.

Income generating activities

This activity facilitates the planning process, it entails training parents in skills IGA and loan scheme management. The children are direct beneficiaries of IGAS but their parents are just care takers. The children identify the IGAS based on their existing skills and capacity.

Vocational skills training

This basically benefits children who have dropped out of schools due to failure to raise school fees. Most children heading families are beneficiaries of this activity.

Writing the memory books

Parents/guardians write the book, the information is stored for children to use in future. The book contains information such as;

Information about the parents and the early life of each child, beliefs, traditions, hopes for the future etc

The focus is not death and disaster but on helping children understand who they are and giving them the right information to make the best of the future.

Coping with the impact of HIV/AIDS through memory project support

In situations where parents are dead, the children are prepared to cope with life without parents. But there are situations where HIV+ parents are still

living with their children; in this case the project creates a supportive environment between the parents and their children.

- The project enable HIV positive parents to disclose their status to their children, this in turn creates a supportive environment for the HIV positive parents as their children understand the ill health of their parents therefore they show them care and love.

Testimony by Christine O.

"Ever since I disclosed my HIV status to my bigger children, at first they were shocked but I counseled them. Now they are my very good friends. They remind me about time to take my medication, and my big daughter ever reminds me to cover my chest when the weather is cold."

- HIV+ parents are relieved of stress after disclosing their sero status to their children.
- This project bridges the communication gaps between parents and children thus it enables parents to understand the problems and need of children to be able to support the children through counseling.

Case of statements made by NACWOLA mothers during follow up refresher training

"We see a big change in our children after they have been taken through the memory project training .The children are now very free with us, they share with us their challenges and seek our guidance, the girls have started consulting us on issues of their reproductive health."

- The project takes on a child-centered approach during planning for the future sustainability of the family, for instance HIV+ parents help their children to identify foster parents.
- Children are involved in activities that generate income for the family, so they become familiar with survival skills, therefore bigger children are empowered to look after their young siblings.
- The project helps parents and their children to prepare for bereavement with fewer traumas.
- Memory book writing encourages HIV+ parents to record their own and their children's past lives, celebrating the good, loving memories. This builds a coping mechanism of positive attributes in children because they are not just reminded about the traumatizing stories of sickness and death.

Testimony

"My name is M. J., I am 17 years old, I have got 2 brothers and 4 sisters and am the first born. My mother is living with HIV, and she falls sick from time to time. I try to help her with house work and I read my memory book when I am bored. My mother had never told me facts about my late father but when I read the book I discovered that my father was a medical doctor. I want to read and become doctor so that I find a cure for AIDS. I want to encourage my mother to write information about the origin of my sisters because our fathers were different."

- The memory project encourages parents to write down the family history, traditions, beliefs and some other relevant information, these help to ensure that children have a clear sense of identity and belonging.

Conclusion

The memory project has become very popular among people living with HIV/AIDS in Uganda. Building upon the successful experience of NACWOLA the module is being expanded and standardized to benefit other African countries. To date Healthlink worldwide UK is working in partnership with African countries namely Uganda, Kenya, Tanzania, Ethiopia, Nigeria and Zimbabwe to promote the best practices of the memory project.

To date Healthlink Worldwide UK have worked in partnership with NACWOLA to up date the international memory project, to take on an inclusive approach that bridges the gaps that were identified by NACWOLA during the implementation of the original model. Issues that have been considered are:

- The involvement of widowers and guardians of children affected by HIV and AIDS.
- Bringing on board children heading families who are looking after their younger siblings.
- Bringing on board children with disabilities.
- Strengthening linkages with other organizations so as to achieve comprehensive support for children living with HIV; for instance getting these children onto ART and treatment of opportunistic infections.
- To enhance child counseling skills to all trainers of the (IMP)
- Helping parents and their children to smoothly deal with new relations without traumatizing children.

The (IMP) manual is in the final stages and it will be translated into different African local languages.

Challenges

- The memory project has registered good practices that have been recognized by other African countries, however NACWOLA has not yet built the capacity to enable all the members to access the services of the project.
- A lot has been said and done about this famous project but very little has been documented.
- The project does not address the need of very young children.
- The project does not also holistically address need of children in special groups like children living with HIV and disabled children.
- Children heading families have got other needs besides the psychosocial needs, thus the project is not holistic in addressing the needs of children affected by HIV.
- The project entails dealing with very sensitive issues of disclosure of HIV status, death and bereavement, therefore it needs to be implemented by people who have got practical experience of the issues being addressed otherwise if not well handled it might become stressful to the beneficiaries.

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