

International Memory Project

Memory work:

Learning from the Ugandan experience and expanding in new directions

Authors: Nicola Ward, Programme Manager – Africa Team, Healthlink Worldwide, UK with input from Jacqueline Nabwire, board member and Jacinta Magero, member, the National Community of Women Living with HIV and AIDS in Uganda, (NACWOLA) and Dafrosa K Itemba, Executive Director, Women against AIDS in Kilimanjaro (Kiwakkuki).

This article will look at the pioneers of memory work in Africa, the National community of women living with HIV and AIDS in Uganda (NACWOLA), how they started the project and what lessons they have learnt from this experience. It will also look at new developments in memory work since the original project design to see what is being done differently. Memory work is being scaled up into different African countries, this is in part due to the International Memory Project which has enabled NACWOLA to scale up their approach into four other African countries through the support of Healthlink Worldwide funded by Comic Relief. An example will be taken from Tanzania to see how organisations are adapting memory work to their own contexts.

Memory work is becoming a more widespread community child centred approach for reducing stigma and discrimination and planning for children's future in communities principally in Africa. NACWOLA have been implementing the memory project since 1997 (see Nabwire, J, 2000-1, Sexual Health Exchange and p.30, Biryetega.A, 97/2005 MMS Bulletin). The initial training for parents and children took place in 1998. The project was targeted at women living with HIV and AIDS and their children.

“Memory work is a community approach to address fundamental issues around HIV communication in the family which focuses on: improving communication between guardians and parents living with HIV and their children, disclosing HIV status and other important information, succession planning and writing important family history in a memory book. A variety of activities take place around these four main pillars” (Starting to do memory work, HLWW 2005). Other family members are also involved who are likely to play a key role in succession planning within the family.

Learning from experience

NACWOLA's key to successful implementation of memory work relates to the way it is deeply rooted in the communities where NACWOLA are present and that the people who are implementing the project feel a sense of ownership of the programme. The trainer and follow up team have gone through the memory project training and memory book writing therefore they can easily implement in the community. The process is based on sharing experiences, the trainer and follow up team share their experiences with the communities they work in which encourages the community participants to share their own experiences. The trainers involved are also willing to work for a low level of pay or on a voluntary basis. This results in the implementation of a programme that is very low cost and reaches out to large numbers of individuals and families in the community. The project creates a strong

impact at the grassroots level creating interest among trained beneficiaries and a willingness to share with others. The project has expanded due to a ripple effect of those who have benefited from the project telling others about it and creating an every increasing demand for the project from the beneficiaries at the community level.

Through the process of learning from the years of experience in memory work NACWOLA has modified the programme and included some new components. For example fathers are now included in the programme which was previously focussed solely on women and their children. There was a need identified to bring fathers on board as they can have influence in family decisions and there were also some cases where there were single fathers bringing children up if the mother had passed away. Topics were included that specifically included the father eg. in the memory book there is now a section on the father's history as well as the mother's. Originally the memory book had been designed assuming that the women were all widows so very limited headings had been included. This was also because the surviving parents had limited information about their deceased spouse. NACWOLA eventually accepted to implement the memory project outside its membership due to the high demand and has now implemented in Lumero, TASO, UWESO and Reach the Child Uganda.

NACWOLA first started to involve men living with HIV and AIDS by working with two who worked with NACWOLA on a voluntary basis, these were then trained as trainers and started training together with other NACWOLA members. More men were then involved when the programme started with TASO to train their clients. Some of them chose to write a memory book and will and decided to train others in memory work. The present coordinator of the Positive Mens Union is one of these and he continues to support men to write memory books. He is interested in implementing the programme with members of Positive Mens Union. Other ways in which men are involved in memory work include those who have been identified as foster parents for the children within the NACWOLA memory project. Other men are involved if NACWOLA members then disclose to their spouses and involved them in important family decisions. In some cases men are the surviving parents who are now caring for their children, or may be grand parents or guardians for children and are involved in providing information for writing the children's memory books. In the Ugandan culture men are the heads of families, NACWOLA realised that they need to be involved in the project to give support eg. if a mother or child wants to go to a memory work club. It has also been beneficial to involve men in the community training as it brings up gender issues that can then be discussed eg. why a female child in some cases has to stop school to care for her mother when there is an older male present in the household who could do this.

Other changes in memory work implementation include a focus on planning for the children's future and involving children in home responsibilities for a smooth future take over. This led to the establishment of linkages with other organisations eg. Heifer International to help parents set up income generating activities. Children's clubs started to be set up and have now expanded into all memory project implementing districts in Uganda as they have the benefit of working as a peer support group for children. The same has happened with memory book clubs for parents who are completing memory books. The sharing of experiences assists parents to face the challenges and complete their memory book, parents are able to share their experiences and support each other. Refresher trainings are now carried out to enable beneficiaries and facilitators to share experiences and find a way of addressing challenges. It was recognised that due to the increase in numbers of orphans the guardians and carers needed to be involved in the project so that the

orphans are supported and could also benefit from the memory project. Community leaders are also involved and sensitised to enable them to support in the implementation of the memory project.

Scaling up of memory work

The International Memory Project has successfully scaled up the memory project into Ethiopia, Tanzania and Zimbabwe and expanded the memory work taking place in Uganda and Kenya, through six partner organisations notably: the National Community of women living with HIV and AIDS in Uganda, Family AIDS Caring Trust (FACT) in Zimbabwe, Hiwot HIV/AIDS prevention, care and support organisation (HAPCSO) and TILLA association of women living with HIV and AIDS (TILLA) in Ethiopia, Kilimanjaro Women's Group Against AIDS (Kiwakkuki) in Tanzania and Kenya AIDS NGOs Consortium (KANCO) in Kenya. Scaling up has involved many challenges due to the wide range of different contexts, different types of implementing organisations and different cultures. Some of the key challenges are discussed in the MMS Bulletin article 97/2005 with respect to "the cultural context, high levels of stigma and discrimination, integrating memory work into existing HIV and AIDS programmes, how to strengthen community structures and institutions including local government and implementing an African approach in an Asian setting"(Ward, N, p.39). Examples from Ethiopia and the Phillipines are looked at.

Here the example from Tanzania will be considered of how a partner organisation involved in scaling up memory work has developed a memory project based on the experience and learning from NACWOLA but relating to their specific cultural and organisational context. The organisation is Kiwakkuki, *Women against AIDS in Kilimanjaro*, a women's organisation fighting against HIV and AIDS in the Kilimanjaro region of Tanzania.

Kiwakkuki has a wide reaching prevention and care programme working in all six districts of Kilimanjaro. They have successfully integrated memory work into their organisational structure having a memory work officer to oversee the process who works closely with the VCT centre, the home based care, orphan support and prevention programme. Kiwakkuki works with a large number of orphans in their operating region and early on in the implementation of memory work they have started to form children's clubs in Moshi municipality where the pilot project is. There are plans for expansion in to other districts from 2006 onwards. The children's clubs have proved invaluable for children to share their experiences with one another, to start to look into ways they can write their own memory books guided by their guardians and carers. One outcome has been for the club to request for assistance to set up their own income generating activity and for vocational training. The children in the club are an inspiration for others in the community and are creating a demand for memory work by sensitising the community around them about the project. For some children this had been the only outlet they have had to share their sometimes very painful and personal experiences in a safe environment.

Children's clubs are a good forum for the child to child approach whereby children with similar experiences exchange information and console one another. It has been proved that young people are much more willing to accept emotional support from young people of the same age than from adults. Through the clubs the children can be encouraged to make friends, share with one another and give each other psychosocial support. Healthlink Worldwide has experience in using a child centred approach to HIV and AIDS in Uganda and Kenya.

Kiwakkuki also involve grandparents in memory work as very often it is the case that the children's first point of care is with the grand parent. Some grand parents also

participated in the memory work training with and parents, guardians and carers. Some grand parents require much sensitisation and basic educational work around the issues involved in HIV and AIDS. Kiwakkuki is hoping to continually learn from their experiences to adapt and develop their memory work further to suit their context.

Opportunities for HIV prevention?

Memory work can be viewed as an entry point for HIV and AIDS work as the key issue of family communication around HIV and AIDS issues, disclosure of HIV status to children and planning for the future are fundamental issues for the success of HIV and AIDS programmes. Memory work creates demand for a variety of different programmes from access to anti-retro viral treatment, access to voluntary testing and counselling facilities and access to information concerning HIV and AIDS prevention. In areas where memory work has taken place there is evidence to show that the demand increases for other HIV and AIDS programmes. In the case of HIV prevention work, as more families start to discuss important HIV and AIDS awareness issues at home the increase in awareness of these issues for example, increases the awareness of children to access prevention information. As more families become involved in memory work it becomes a community concern and neighbours, other relatives and friends also become more aware of the situation and the need to become involved in prevention programmes. For the actual families involved in memory work there are prevention programmes alongside eg. the training at a community level with parents, guardians and carers will include prevention information.

Conclusion

Memory work is expanding in Africa as the importance of HIV communication programmes becomes more widely recognised and the need for psycho-social care programmes for orphans and vulnerable children affected by AIDS increases. There is also much potential to start memory work outside of Africa. Memory work has a unique approach to tackling core issues in HIV and AIDS around disclosure and communication in the family, the key to reducing stigma and discrimination in the community and an approach that forms the basis for any programme tackling HIV and AIDS. If all families discussed HIV and AIDS issues and planned for the future of their children it would greatly change the community response to HIV and AIDS and the prevailing attitudes present in many communities.