

Inspiring futures: the Memory Project

Towards a more holistic thinking in helping patients and families come to terms with HIV

Memory work in sub-Saharan Africa has, to date, been operating on a relatively small scale but there is hope that it will spread more widely. The approach has opened up channels of communication about HIV between children and parents with profound effects. It has led to increased testing and treatment for people living with HIV, reduced stigma in the home and community, and allowed adults and children to feel more secure about their future. In Uganda, memory work has even been integrated into the national strategic plan to combat HIV and AIDS.

What is Memory work?

Memory work was first developed by the children's charity Barnardo's in the 1990s, as a response to help African families living in the UK who were affected by HIV and AIDS. Memory work is rooted in oral history approaches that value the transmission of knowledge between generations as a way of building cultural identity.

In 1997, Barnardo's worked with the National Community of Women living with HIV (NACWOLA) in Uganda to adapt the approach to use with women living with HIV in Africa. Since then, memory work has expanded to countries in sub-Saharan Africa where it is increasingly employed as a response to help women, children, and young people who are disproportionately affected by the HIV and AIDS epidemic.

Since 2004, Healthlink Worldwide worked to support the delivery of the International Memory Project (IMP) partnering with community organisations in five African countries: Ethiopia, Kenya, Tanzania, Uganda, and Zimbabwe.¹ Comic Relief funded the 6-year initiative.

IMP focuses on the use of memory work as a way to encourage families to communicate about HIV.

Memory work is centred on four main pillars:

- Improving communication between parents and other family members living with HIV and their children.
- Supporting parents to disclose their HIV status if that is their choice and other important health information.
- Succession planning, including writing a will and choosing guardians for children.
- Documenting important family history and information in a memory book.

Over the years, the IMP partners have developed a range of activities which support these pillars. Through these activities, parents and guardians receive training and support in: child development; improving communication with children; and making plans for the future.

Support groups enable parents, guardians, and children to explore issues in a supportive environment and receive support from other people who are experiencing

similar situations. Children are also involved in activities which aim to: increase their knowledge of HIV and AIDS; develop and strengthen life skills; and develop peer support groups. Activities with children use child-centred approaches, which ensure that they are appropriate for the child's stage of development.

Since 2004, country partners have systematically integrated memory work into their HIV programmes. Each partner adapted the approach and applied it in different ways depending on their own organisational structure and local context. Through this we have learnt that memory work needs to be rooted in existing HIV programmes and services, and is generally only effective when it works alongside other services which offer treatment, support to generate income and other healthcare provisions.

What is the impact of memory work?

Evidence shows that the impact of the work has been profound for families and communities. In 2008, advocacy by the National Community of Women living with HIV and AIDS (NACWOLA) at national level with the Uganda AIDS Commission and Ministry of Health was successful in getting memory work included in the national HIV and AIDS strategic plan.

The main impact on children has been to increase their participation and communication within the family. Their knowledge of HIV has increased and children are learning not to stigmatise their parents and others who



Memory work helps families talk about family matters

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Positive parenting helps meet the needs of children

are living with HIV. One father in Ethiopia said, 'I first took the training and then my children did the training. Their knowledge of HIV has increased and they can protect themselves. We have also been able to have discussions on family matters – it's like an ice-breaker for the family and issues beyond HIV are discussed.'

The biggest impact of memory work to date is seen in the lives of parents and guardians living with HIV. The training and ongoing support group activities have consistently increased the quality of life for parents. Very often, the training empowers the parent to disclose their HIV status within the family. This leads to more open communication, initially within the immediate family but then also with the wider community. The 'self stigma' of many parents also decreases as a result of their involvement in memory work. Parents also value the increased knowledge and strengthened links with the wider family, emerging from memory work activities such as drawing of the family tree and planning for the future. Parents reported feeling more secure about the future and anticipating their children would be cared for in the future.

Communication about HIV at family and community level increases greatly and opens up opportunities to increase uptake and adherence to HIV treatment, stimulating a more effective response to the HIV and AIDS epidemic. The disclosure of the parent's HIV status has enabled children to become involved in the care of their parents and closely linked to this is the role that children are taking in supporting their parent's adherence to antiretroviral drugs and other medication. Children remind their parents to take medication at set times, collect more medication for them when necessary and help prepare food for the parents and for the family. 'Now my child helps me to take medicines, and when I am not feeling well, the child understands and protects me,' said one parent in Tanzania.

Lessons for practitioners

Memory work is a powerful way to support community-responses to HIV and AIDS. Embarking on memory work needs careful consideration and planning to fulfill its potential. Incomplete memory work without sufficient support structures in place may do more harm than good.

- Develop good linkages with other organisations to support components of memory work and to ensure the existence of strong referral systems. Partnerships with legal organisations are proving crucial.
- Increase activities and support for children participating in memory work. Giving children opportunities to be involved in leading and developing activities will make memory work stronger.
- Consider extending memory work to the whole community, not just families affected by HIV and AIDS.
- Learn from other areas where psychosocial support is practiced such as in situations of conflict.
- Ensure memory work participants can also access ways of having their basic needs met.

Recommendations to policymakers

- Memory work needs long-term involvement with parents, children and communities to ensure that the initial positive impacts of memory work can be maintained until children reach adulthood. This will demand either long-term funding formats, which allow support over a 10-year period or longer, or a very low-cost approach which can be supported by communities themselves.
- Further research and evaluation needs to be carried out with existing memory work programmes over a minimum 10-year time period, to increase knowledge and understanding about the long-term impact.
- Children need to be placed at the centre of memory work, with a genuine commitment to facilitating their involvement and leadership of the work. Strengthening child-centred responses benefits the whole community.
- The experience of implementing memory work across five African countries shows that there is potential for social change but that the approach needs committed investment and support in a way that lays the foundations for the approach to flourish in future.
- Memory work does not work in isolation. Successful memory work is either integrated into other programmes such as home-based care, economic strengthening, orphan support or treatment provision, or works closely alongside programmes that offer this support.

Reference

1. Partners working with IMP include: National Community of Women living with HIV and AIDS (NACWOLA), Uganda; Family AIDS Caring Trust (FACT) in Mutare, Zimbabwe; Women against AIDS in Kilimanjaro in Moshi, Tanzania (Kiwakkuki); The Kenya AIDS NGOs Consortium (KANCO) in Nairobi, Kenya; Hiwot HIV/AIDS Prevention, Care and Support Organisation (HAPCSO) in Addis Ababa, Ethiopia; Tilla association of women living with HIV in Awassa, (Tilla) Ethiopia.

This article draws heavily on a learning publication: **Inspiring futures: learning from memory work in Africa**. It is available online at http://healthlink.org.uk/PDFs/IMP-learning-paper_Inspiring-futures.pdf. If you would like a hard copy please email: info@healthlink.org.uk

