

International Memory Project

Scaling up Memory Work: the challenges. Examples taken from Uganda, Ethiopia and the Philippines, 2005

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The success of the enterprising NACWOLA Memory Project in Uganda has prompted a huge amount of interest from organisations across Africa. Through the International Memory Project memory work is now reaching into new districts in Uganda and Kenya. Plans are in place to expand the project into Ethiopia, Tanzania and Zimbabwe and to strengthen the existing partnerships in Kenya and Uganda. This paper will discuss some of the issues around scaling up Memory Work in new and challenging contexts looking at examples from Uganda, Ethiopia and the Philippines.

There are various definitions and interpretations of the process of scaling up (DeJong 2003, p.14). In the context of this paper it is referring to “increasing the scale of activity engaged in”, to “reaching more people” and to “increasing the intensity of impact within a given social group”. Memory Work presents its own set of challenges for scaling up some of which can be recognised by the HIV and AIDS field in general and some of which are more specific to the field of psychosocial support.

Jonathan Morgan defines Memory Work as the deliberate setting up of a safe space in which to contain the telling of a life story. The concept was originally developed by people affected by HIV and AIDS to combat stigma and to help parents to discuss changes in family circumstances with their children including death and to plan for the future. The National Community of Women Living with HIV and AIDS (NACWOLA) are the pioneers of Memory Work in Africa. They have developed a holistic community approach to Memory Work. Working with their approach in Uganda since 1998, the NACWOLA Memory Project is now recognised within Uganda as a good practice for psychosocial support.

Transfer it with care

One of the challenges for NACWOLA has been how to scale up this experience to reach out to many more families and children affected by HIV and AIDS within Uganda and Africa. Healthlink Worldwide are supporting NACWOLA to do this through implementing the *International Memory Project* which is developing Memory Work in Ethiopia, Zimbabwe, Tanzania and Kenya through local partner organisations, who have experience in working with HIV and AIDS and orphans and vulnerable children issues. Partner organisations include Hiwot HIV/AIDS Prevention, Care and Support Organisation (HAPSCO in Ethiopia), the TILLA association of women living with HIV in Ethiopia, Women Against AIDS in Kilimanjaro (Tanzania), Kenya AIDS NGOs Consortium and the Family AIDS Care Trust (Zimbabwe). It is a challenging process with each country context being very different to each other. The partner organisations, with the support from Healthlink

Worldwide, are in the process of finding new ways of working to adapt the Memory Work approach of NACWOLA to their own country context taking into consideration local customs, culture, the HIV and AIDS policy environment, levels of stigma at community level and civil society involvement. Memory Work presents key challenges for partner organisations as it addresses HIV and AIDS issues starting from the family and how parents living with HIV disclose to their children. It is addressing the key issue of discrimination and stigma around disclosure, a very sensitive issue in many contexts.

Scaling up of development programmes presents a range of challenges for any organisation. Some of the key challenges that the International Memory Project faces will be discussed. One of the challenges is to effectively reach more children whilst maintaining the same impact on the individual. Memory Work is a process rather than a single event or activity and the impact of Memory Work develops through time. Monitoring and evaluation tools are being developed to follow the level of impact at different stages and in the different contexts. Memory Work is a community owned process and this approach needs to be maintained when scaling up. Communities in different places may have varied expectations, this may direct the range of approaches used for Memory Work. However, It is necessary to ensure the same level of quality and standards of the activities.

Stigma and discrimination is a key challenge for successful Memory Work and is one of the important issues that the Memory Work programme addresses. It will vary greatly between countries and communities within the same country and it will be necessary to monitor the levels of stigma and discrimination to ensure that effective entry points are identified and appropriate strategies found to introduce Memory Work in the different settings.

Memory Work has worked well in the African setting and there has been interest shown and initial activities developed in the Asian setting. Care will need to be taken when transferring the African experience to Asia and new approaches developed that are culturally relevant for that context. There will be different key issues that are more relevant for the Asian setting. There is a need to experiment with different Memory Work approaches in new settings, monitor the impact and identify what approaches are most relevant.

One effective way of scaling up Memory Work is to integrate it into existing HIV and AIDS prevention, care and treatment programmes. In this way it becomes an integral component of HIV and AIDS activities. The need for Memory Work to be integrated with ART programmes has been recognised and partner organisations of the International Memory Project are active in developing ways to support ART programmes with Memory Work.

To successfully scale up Memory Work there is a need to strengthen the community structures and institutions including the local government. This is a challenge for any NGO working in any field of development. It is an aspect that the respective partner organisations can possibly address by working with the local health authorities especially the HIV/AIDS district coordination and national AIDS councils. It is important for the holistic community approach of Memory Work to create the necessary supportive environment for it to take place and be successfully scaled up without being “criticised for taking on tasks more appropriate to the state” (Dejong 2003).

Memory Work has been developed in an era with a need to constantly come up with new approaches to work with children to cope with the changing nature of the epidemic, and our collective knowledge about the successes and failures of programming work in this area.

The experience of Memory Work in Ethiopia

Ethiopia is a country with diverse culture, religion, language and ethnicity and in the rural areas the society is very conservative. Due to the high levels of discrimination and stigma experienced by people living with HIV and AIDS many people do not wish to go for voluntary counselling and testing or to disclose their HIV status even to their family members including their children and those that have, faced many challenges. There is a lack of discussion within the family context concerning HIV and AIDS due to cultural influences and taboos around sexuality and death and a lack of skills in communication within the family setting.

There is a need to consider the different socio-cultural context and language diversity both in the rural and urban setting together with the levels of stigma and discrimination in the communities. It may be easier to scale up Memory Work in urban areas rather than rural areas.

Participation of children in family affairs is very limited and given the level of child participation in Memory Work approaches, much will need to be done to convince parents that children have the right of access to information and meaningful participation in planning for their future.

Illiteracy levels among women in Ethiopia are very high (41.5% adult literacy ages 15 and above in 2002, UNDP Human Development Report 2004). This may affect the documentation of family history since in such a situation the involvement of a third party would be a necessity. This may not be easily acceptable by clients or even if they accept they may not find it easy to express or tell their private stories to a third party. New approaches may need to be found to address this issue including developing more techniques involving drawing.

The level of poverty in Ethiopia is very high (GDP per capita in 2002 was 780 PPP US\$, UNDP HD Report 2004 with a HDI value of 0.36). This may result in economically poor clients not making succession planning for their children a priority issue. Planning for the future of children is also normally only considered in material and financial terms. Skill transfer and emotional well-being for example are not generally considered. As a result children can be very worried about their future, how they will survive and who will be their guardians if their parents pass away. Parents often give their children to orphanages instead of giving him/her to a member of the community.

In most parts of Ethiopia, the responsibility of household management is given to mothers which may result in cultural challenges for involving men in the memory project. However, there is a great need to involve men as most mothers, especially in the rural setting are economically dependent on their husband. If men are not involved, they may not allow or support and assist mothers to disclose their status to children and participate in the Memory Work.

The above presents a series of challenges in order to reach many more women and children and successfully scale up Memory Work, ways will need to be identified to sensitise communities around these very sensitive issues in extremely low income community settings.

Despite the challenges, the policy environment in Ethiopia is supportive to this kind of work and presents some key opportunities for example the Ethiopian ministry of health has launched a free or low cost supply of antiretrovirals. This will create opportunities for more people to disclose their status. The government of Ethiopia has also provided positive assistance for organisations working on HIV and AIDS especially for those working with women. This has created a supportive policy

environment for Memory Work to be developed and scaled up within the Ethiopian context. This is assisted by the Director of TILLA being involved in HIV and AIDS advocacy work at a national level in Ethiopia.

HAPCSO and TILLA both have experience as organisations working in the field of HIV and AIDS and orphans and vulnerable children and have adopted appropriate and culturally accepted community approaches to HIV and AIDS work in the Ethiopian context. HAPCSO have developed a community programme that works with community leaders (idirs) in their home based care programme and have developed a system whereby the idirs contribute money to care for the orphans in the community. This has raised the profile of the issue of caring for orphans in the community. The idirs will form a key group as an entry point into the community to initiate the idea of Memory Work. HAPCSO also do a lot of community level work using the coffee ceremony as an entry point for education and sharing of information at the household level this can also facilitate introduction and discussions around Memory Work. HAPCSO are also part of a pilot project which gives access to some of their clients for antiretrovirals. They will therefore be able to develop ways of integrating the psychosocial support and antiretroviral treatment as part of the Memory Work approach.

TILLA, being a membership organisation for women living with HIV, has a key opportunity to sensitise many women in the community in relation to the different elements of the Memory Work and create the necessary supportive community environment. Members of TILLA are very committed individuals who have often faced much discrimination and stigma from their own communities. They are involved in carrying out HIV and AIDS prevention work and testimonies of their experiences in the communities where they live. Many participate in the TILLA home based care programme. They will act as key entry points to introduce the Memory Work into their own communities. As TILLA is one of the leading associations of people living with HIV and AIDS in Ethiopia, there are good opportunities of access to the media and to the public. The association can use these to inform the importance of the Memory Work and its benefits to mothers, fathers and children.

HAPCSO and TILLA are in the process of implementing a Memory Work pilot project in Ethiopia. The first national level Memory Work training of trainers has recently taken place and in the coming months experiences will be gained from the field in relation to the communities reactions to Memory Work. HAPCSO and TILLA will be basing their approach on the NACWOLA model but adapting it to their local context. Representatives from HAPCSO and TILLA and likewise the other partner organisations in the International Memory Project were trained earlier this year in Memory Work approaches as part of the scaling up of Memory Work taking place through the International Memory Project.

The possibilities for implementing Memory Work in the Philippines

In 2004 the Pinoy Plus Association (Pinoy+) and Remedios AIDS Foundation (RAF), with the support of Healthlink Worldwide, carried out a three day learning retreat for orphans and vulnerable children together with their mothers and guardians, in the Philippines. Pinoy Plus Association is the sole organisation of people living with HIV and AIDS in the Philippines. It is a support group dedicated to the welfare of people living with HIV and AIDS and affected families in the country. RAF is a pioneer non-governmental organisation that provides preventive and promotive sexual and reproductive health and direct medical services to vulnerable populations and communities at risks.

The three day retreat provided a safe space for mothers and children, helping them explore sensitive issues such as disclosure of HIV status, bereavement and planning for the future. The project emerged from an individual experience of a mother living with HIV disclosing her status to her 12 year old son in a positive way, which he then shared informally with his peers. Various participatory methodologies were used and good practice guidelines developed regarding understanding grief and bereavement.

The outcome of the learning retreat showed that many of the key issues relating to Memory Work implementation are similar for families affected by HIV and AIDS in the Philippines as in the African context, although culturally there will be many differences. For example the challenges of discrimination and stigma within a society structure based on the family unit and where “a family member’s shame purportedly disgraces the entire family (which can) lead to severance of family ties” (Counselling Persons with HIV/AIDS, 2001) resulting in people living with HIV and AIDS fearing disclosure to their family. Another factor is the need for support groups to assist their members in relation to education, meeting economic needs through income generation activities and medical care. And the support children need to plan for their future, understand their family situation and what support their parents may need if sick.

Healthlink Worldwide in partnership with RAF and Pinoy+ are planning to carry out an after action review of the activities that have taken place around the learning retreat, to take this work further. A good practice guide for working with children in the Philippine context will be developed. The work that has taken place so far forms a basis for scaling up Memory Work in Asia drawing from the experiences in Africa. The approaches developed in the Philippines will serve as a pilot project for creating a network of partner organisations using Memory Work in Asia.

Conclusion

This article has exemplified some of the key challenges of scaling up Memory Work. These include 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. In Ethiopia approaches are being developed to successfully implement Memory Work assisted through a supportive policy environment. The challenges are many including being in a low income setting with extreme poverty, high literacy levels, high levels of discrimination and stigma, taboos around sexuality and death, lack of communication in the family setting, little involvement of children in family plans and cultural challenges around involving men. Local organisations are showing that it is possible to work in this context. In the Philippines, a very different cultural context, similar key issues around psychosocial support have been identified even though culturally the setting is very different and different strategies may need to be developed that are culturally appropriate. What the examples have shown is that scaling up is a very sensitive and challenging issue, but one that is possible and very necessary with appropriate care taken to develop cultural appropriate strategies at a community level.

For further information

J. Dejong, Making an impact in HIV and AIDS: NGO Experiences of Scaling Up, 2003

AIDS Bulletin, Volume13, Number 2, July 2004

Counseling Persons with HIV/AIDS: a manual, published by Remedios AIDS Foundation, Philippines, 2001

N. Ortega, Palliative Care in Resource Constrained Settings: Lessons Learned, http://hab.hrsa.gov/publications/palliative/palliative_care_philippines.htm

Healthlink Worldwide, The International Memory Project, www.healthlink.org.uk

1. Participants and facilitators of the International Memory Work Master Training of Trainers that took place in March 2005, in Uganda. Participant organisations include: Hiwot HIV/AIDS Prevention, Care and Support Organisation (HAPSCO in Ethiopia), the TILLA association of women living with HIV in Ethiopia, Women Against AIDS in Kilimanjaro (Tanzania), Kenya AIDS NGOs Consortium and the Family AIDS Care Trust (Zimbabwe).
2. Participants at the International Memory Project planning workshop that took place in October of 2004 in Uganda, producing work plans.
3. Members of TILLA, AWLH, Ethiopia at the income generating activity centre in Awassa, Ethiopia.
4. Members of TILLA AWLH, showing one of their income generating activities – table cloths and various embroidery pieces – at the income generating activity centre in Awassa, Ethiopia.

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