

"... and one dare to hope and dare to remember".
Memory Work: Coping Strategies in the Face of AIDS
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Memory Work – Preparation for death? Legacies for orphans?
Fighting for life?
Concepts and experiences in various settings

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In the popular imagination, memory work is associated with a preparation for death. There is little doubt that classical memory work, that is, memory work as legacy for orphans, and memory work as succession planning, fits best and is most poignant in the face of death and dying. In ARV contexts, however, forms of memory work have evolved to assist people living with HIV and AIDS to live positively, to hold on to life, and, as some have suggested, even to celebrate life. And it is of course recognised, that the greatest service one can render a child whose parent is living with HIV, is to keep the parent alive.

There is a question whether these contemporary forms that turn classical memory work on its head can and should still be called memory work. Has memory work lost its focus, has it outgrown a one-size-fits-all approach, or is the problem that it has never been properly defined? This paper offers some definitions. It also sketches out how M.A.P (Memory Action Projects), a collaboration between REPSSI and the Psychology Department at the University of Cape Town (UCT), is beginning to look at all the memory products on offer, and to tailor make a range of tools in response to a spectrum of needs and situations facing HIV-affected adults as well as children, all with different levels of access to treatment and services.

Memory work

NACWOLA (the National Association of Women Living with HIV and AIDS), the Ugandan pioneers in memory work, refer to memory books primarily as a communication tool between parents and children. In contexts where treatment has not been accessible, the key messages that are communicated to children by parents living with HIV, are ones around disclosure of HIV status, changing health status as the illness progresses, the possibility of the death of the caregiver, succession planning, and information about roots and family history seen to assist in the process of identity formation for the child who might grow up without parents. For the purposes of this article, this kind of memory work is referred to as classical memory work.

Before examining how memory work has evolved in the context of widespread antiretroviral use, a job at a broader-based definition, that can encompass both classical and contemporary memory work will be attempted.

Memory work might be defined as the deliberate setting up of a **safe space** in which to contain the telling of a life story. This **space** might be a **room**, the **shade under a tree**, a **drawing** or a **map**, or a **memory box**, **basket** or **book**. In therapeutic contexts, the scope of memory work is not necessarily restricted to the past, its purpose is often to deal with difficulties in the present, and its main orientation often tends towards planning and the **future**.

For purposes of illustration, what follows is a range of client needs, and a selection of memory tools currently being developed, monitored and evaluated by post-graduate students and staff within the Psychology Department at UCT. The range of client needs is by no means exhaustive and it should not be assumed that any particular client will not find the other memory tools also useful and relevant. Buried in the rationale, is also the premise that memory work needs to be a systemic and integrated intervention, at times working only with the vulnerable child, at times working with several members of the household together, and at times only with the parent or caregiver living with HIV or AIDS.

Scenario 1:

Client: An adult with advanced-stage HIV who has no access to ARVs.

Memory work: The anticipated needs of this client are best catered for by classical memory work such as the model offered by NACWOLA in Uganda, and the core manual developed within the Memory Box Project (MBP) in the AIDS and Society Research Unit, up to 2003. This manual has been further developed with a stronger psychological focus within M.A.P.

This client might wish to:

- 1) Find his or her own reason for engaging in memory work.
- 2) Review and re-story his or her life and come to terms with probable death.
- 3) Map out his or her lineage and support system so that surviving children will know their roots and to whom they can turn.
- 4) Open up communication with family members including children.

Scenario 2:

Client: An adult with early- or middle-stage HIV illness who has no access to ARVs.

Memory work: Her needs are well described in the languages of Narrative Therapy and Treatment Literacy. She will be encouraged to find her own power, knowledge, skills and agency in the face of this formidable challenge. Before HIV becomes

AIDS, she may be able to slow down or even reverse the course of the illness via self care, and by becoming knowledgeable about a range of treatment possibilities.

In a support group setting, this client might wish to:

Go on a guided journey in which she traces a life-sized **body map** of herself onto a sheet of paper. This is an opportunity to explore, record and review the ways in which she pictures her body and her life. Body maps can capture the marks life leave on our bodies (laughter lines, scars, infections, bruises, beauty marks), and they can also be extended to trace and plot the paths our bodies make across life (our ancestral lines, journeys and hopes). It is a chance to engage in life drawing and full-length projective instrument. As art works and communication tools, body maps can convey powerful messages. A body map might be used to express how an infection flared up, how a traditional remedy helped, or a feeling held in one's heart. In another body map you might find a story of disclosure which gets shared in the group. Due to the highly evocative nature of the process, body maps should be used with caution, to avoid the possible retraumatisation of clients who have experienced significant challenges. It cannot be assumed that body mapping is therapeutic in itself.

Scenario 3:

Client: This client has HIV, reached stage 4 of the illness, his CD 4 cell count went as low as 200, but he was able to access ARVs.

Memory work: _On one level, the needs of this client perhaps centre most strongly around adherence. ARV regimens demand that patients take the drugs several times a day (usually three), every day for the rest of their lives, for the drugs to be effective and to avoid building resistance. This client might need to keep tracking his wellness/illness, keeping current with his own emotions around this, and keeping communication channels open with significant others, including health care professionals.

The reasons why patients struggle to adhere/comply to drug regimens has more to do with social and psychological factors than purely medical ones. For instance, the client/patient might not have disclosed his status to other household members, which makes it difficult to store the ARVs in the home, and to take them at mealtimes. Or a patient might become depressed and forgetful. Or he might not have enough money to get to the clinic in time to collect his monthly supply of ARVs. These are all issues the doctor, nurse and social worker, and other support group members need to know about in order to offer help.

It is against this backdrop that the *Tracing Book as patient-held file* was developed. Tracing books are a form of memory work in the context of ARVs in that they help patients to remember and not to forget, amongst other things, to take their medication. One scaled-down version of the life-sized body map and a sheaf of blank pages made of transparent tracing paper, make up the handbound patient-

held file, in which the patient is able to track and communicate ongoing physical and emotional changes in his or her body and mind.

After one week, on the first sheet of tracing paper, an infection might be recorded and marked on the left thigh. By week two, it might have gotten smaller or bigger. A TB-related cough might find expression on the chest. With the patient's consent, the doctor might sketch out a lung or write down a CD 4 cell count onto a page. A change in environmental status, for instance, being forced to live outside on the street as a result of disclosure of HIV status, might be recorded as a note outside the body. In these and other contexts, communication between doctor and patient, and between patient and household members, and between support group members might be enhanced.

Some of the limitations of life-sized body maps are that they are one dimensional, unwieldy and not very private. By making a tracing book, which is both a communication tool, a patient-held file, and a reflective journal, with each new page, you begin to animate the flatness and fixed temporal limitations of the body map forwards in time and space.

This is what Eve Subotzky, a doctor at Masiphumelele Clinic who has been central to the development and piloting of tracing books, reports:

"The tracing books help me to see the whole person, not just their bodies and organs, but their thoughts and worries, even if I am not able to address these directly, it is important to me that I am able to acknowledge them. With one patient in the pilot, I was struck by how her record allowed space in the consultation for communicating wellness and not only illness. Another patient's beautifully graphic picture conveyed all the complexities and paradox around being at the same time, happy, anxious, unwell and better. Her tracing also illustrated a significant new symptom, peripheral neuropathy, which I may well otherwise have missed. A third patient's tracing book not only tracked all the dramatic emotional and physical changes he had ridden out in the last few months, but how he used this book primarily to communicate to me his overriding concerns about his son who was very ill but is slowly improving on ARVs."

Noxolo Mahobo was the first person to publicly disclose her status in Masiphumelele. She is presently an adherence monitor for CIPRA, and is also part of the MAP memory working group. About her own tracing books she reports:

"One week I showed it to my daughter and explained why I was not feeling well and couldn't help her with her homework. She understood me well. In it on another week, she also sees me with my hands up and feeling strong."

Scenario 4:

Client: HIV-affected child whose mother is HIV positive with or without access to treatment.

Memory work: Living with the knowledge or second guessing that your only caregiver, maybe your mother or father, has HIV is not easy. It is important that your caregiver/parent communicates with you and allows you to express your anxieties, to have these issues out in the open, rather than as repressed fears and/or as taboo topics. The kind of interventions to offer this child might take the form of play therapy, therapeutic interviewing, projective assessment, or child-focused narrative therapy.

In response to the extraordinary range of challenges facing so many children made vulnerable by HIV and AIDS, **Hero Books**, a particular kind of memory book which combines elements of several types of child-focused interventions, have been developed.

A Hero Book is a document, and a process, in which a child is invited to be the author, illustrator, main character and editor of a book that is designed to give them power over a specific challenge in their life. The Hero Book process can be described as one in which groups of children are led through a series of drawing exercises and autobiographical story telling, designed to help them with mastery over specific problems or challenges in their lives. At the end of the process, the child will have a handbound storybook of their own making, that heralds and reinforces their hero-survival-resilient qualities.

Hero books draw heavily on the theory of Narrative Therapy and “externalizing discourses” developed by Michael White and David Epston. There are also strong elements of expressional art and of projective drawing in the Hero Book process. The challenges a child might want to take on using a Hero Book, include behavioural, emotional and social problems. Behavioural problems might include bedwetting, poor concentration, aggression and bullying. Emotional problems might include depression, sadness, grieving and anxiety. And social problems might include having to look after the cattle and not be allowed to attend school, or being subjected to abuse in the home.

The basic formula or map of the territory to be explored in these externalising conversations is:

1. A particular problem is identified and named.
2. It is then located as something outside of the person and not bound up as part of their identity, personality disorder, or within their field of self-blame.
3. A ‘shining moment’ or ‘unique outcome’ is identified in which the person experienced, however fleetingly, some power over, or hope in the face of the problem
4. There is an unpacking of some of the things (tricks, tactics) the person can do, or has begun to do, to achieve a measure of control over the problem.

An important part of the Hero Book happens after the child has drawn and explained a whole series of drawings. The co-author or helper, then retells a hero story back to the child preferably in written form, which then becomes the introduction to the book. It stands beside the child’s own words which are explanations of the series of drawings.

In the box below is an example of a hero story, retold by Helen Meintjes and Jonathan Morgan to a child and his caregiver, both of whom participated in a Children's Bill Child Participatory Workshop facilitated by the Children's Institute, UCT.

Nelson and Pumla

This is a story about two heroes, Nelson and Pumla. Nelson used to live with his mother and father. He used to love his mother very much. They used to sing together. She was a very kind person. Unfortunately Nelson's mother became sick and she died. She would have been very proud to see what a hero Nelson has become. After his mother died things became very hard for Nelson at home. There was not enough food and not enough money to send him to school. Everyone was suffering and there were many times that Nelson was beaten. One day Nelson took a big big step. He ran away to his school principal Pumla, and told her that he was being abused, and that he could not carry on like that.

Pumla looked at her school, at the buildings that were only used in the day but not in the night, and at this little brave boy who needed a safe place to stay and a roof over his head. She said, "You can live in this school."

At this moment the hero in Nelson met and brought out the hero in Pumla. Pumla transformed her school into a community centre for supporting children. She and the other teachers started a seven- day feeding programme so that children who didn't get food at home on weekends could come to school to eat, even on a Saturday and Sunday. She bought chickens, and Nelson and some other boys looked after them, and enjoyed eating their eggs. They laid many!

Now Nelson lives at the school with six other children. They are his brothers and sisters now but he has also not forgotten his brother who died. To make his sadness smaller and his happiness bigger, Nelson plays soccer. He also wants to make other children feel better. Nelson has joined a children's group. They speak to children and teachers in schools educating them about abuse. Nelson is a hero because he has the courage to break the silence around abuse and stand up for his rights and for the rights of others.

A hero is a person who has experienced something bad and beaten it. An expert is someone who knows a lot about something because they have experienced it from the inside out. Nelson is a hero because he stopped the abuse in his life, is preventing others from being abused, and he is an expert on abuse. He can tell you the difference between verbal, physical and sexual abuse, and he can tell you what the Children's Bill says about abuse.

It says, "Parents and caregivers are allowed to hit children but not so hard that they leave bruises or marks" and that government must educate parents/ caregivers of other methods to discipline children ..."

He also knows that since 2000 the law has said that teachers are not allowed to hit children. No smacking in schools.

With all his hero qualities, and with the support of amazing people like Pumla, Nelson can look forward to a bright, bright future.

Remembering Books are a particular kind of Hero Book in which the child is helped to grieve and remember a lost loved one. Both a grandparent who is grieving for a child she has lost to AIDS, and her grandchild who is grieving the loss of his mother, might find a remembering book helpful and meaningful. It is something they can make together. MAP and the Ten Million Memories Project however recognises that the greatest service we can offer a child who has a parent living with HIV is to keep their parent alive.

Conclusion

The aim of this paper was not to suggest that classical memory work is *passé*, and that contemporary memory work is *the thing*. While we are waiting for and working towards the rollout of ARVs, there remain millions of children who have lost, are losing, and will lose loved ones. In these contexts there remains a need for memory work as succession planning and for grieving. The danger is that if memory work remains in this space and only addresses these contexts, there remains no opportunity for the work to be transformative and revolutionary. Confined to operating as if treatment is an unrealizable dream, it is in danger of being complicit with this unacceptable and inequitable distribution of resources.

It must also not be assumed that if memory work is for life, it is not for death. Many people who are on ARVs, die of other things, motor car accidents, heart attacks not related to their HIV status, murder, etc. Every one of us is both living and dying at the same time. Memory work is for everyone.

In all kinds of contexts it needs to be articulated into an art which holds central sharing, healing, documenting and containing. There are many inspiring examples to draw on. South Coast Hospice's lockable tin telephone. NACWOLA's prompts. Mad's Art Attack. Sinomlando's family therapy.

The time has passed for a one-size-fits-all approach to memory trainings. Hopefully this paper has made the point that client needs and their access to treatment have to be taken into account when designing memory interventions.

Lastly, if memory work is not necessarily just about death, but also about life, and if memory work is not necessarily about the past but about the future, should it still be called memory work?

Memory work is like a rear view mirror in a car that is going forwards. As a concept and as a field of study, **memory** is inclusive enough to embrace a diversity of thinking, feeling, art and science, all of which combine to make this work so rich. Quantum physics would also have us believe that all time - past, present and future, some would even say living and dying, life and death - are continuous. In a real tick-tock sense, the one follows and flows into the other. This is the space into which memory works.

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