

TREATMENT COMBINED WITH MEMORY WORK:

CONTRADICTION IN TERMS

OR

WHY NOT?

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In HIV and AIDS contexts, and in an era where ARVs and life saving and life prolonging pharmaceutical treatment have not been available to all who need them, memory work has evolved, more than anything else, as a preparation for death. There is little doubt that classical memory work, that is, memory work as legacy and memory work as succession planning, fits best and is most poignant in the face of death and dying. What needs questioning however, is the often unspoken assumptions that memory work applies only where there is no treatment and where premature death is inevitable, and that if it is not classical memory work, it is not memory work.

In order to interrogate these assumptions and to explore the notion of – “treatment combined with memory work” - , both *memory work* and *treatment* need to be more rigorously defined. Having done this, the paper will look at how MAP (Memory Action Projects), a collaboration between REPSSI and the Psychology dept UCT, has begin to tailor make a range of psycho social tools, in response to a range of needs and situations facing HIV affected adults and children, all of whom have different levels of access to treatment and services. The conclusion that is reached via this reflection, is that memory work, already known to be a flexible approach, but best described as a psycho social intervention, is able to cross into the bio medical, and offer something to the doctor–patient / treatment relationship. Its greatest offering however, remains that of auxiliary psycho social support, integrated into a wide range of treatment and service contexts and scenarios, some of which are spelled out and explored below.

What is meant by memory work?

The classical notion of memory work contains as key elements, a preparation for death and a “working through” of dying, in the form of a document which is both a communication tool and perhaps a legacy for children, with various therapeutic and other practical outcomes associated with the process.

NACWOLA (National Association of Women Living with HIV and AIDS) the Ugandan pioneers in memory work, refer to memory books primarily as a communication tool. In contexts where treatment has not been accessible, the key

messages that get communicated 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.

However most practitioners wish to avoid making memory work overly prescriptive, and wish to avoid placing pressure on people living with HIV and AIDS to disclose their sero positive status. There may also be the wish to avoid memory work adding to stigma by making too explicit the association between memory work / memory objects (books, boxes, etc) and HIV and death. An example of this might be, “Oh you have made a memory book, you have AIDS.”

In various ways many practitioners try and allow the author/artist/client to direct the process and choose the content and purpose for themselves. In a sense this high degree of client participation and power sharing sets up a kind of dynamic which places memory work as almost anything the participant wants it to be.

At this point, when considering the question, what is memory work, one might ask, how memory work differs from psycho therapy in which the recollection of memory also plays a key role.

What might distinguish memory work from psycho therapy or counselling, may be the elements of:

- expressional art which makes it more like art or occupational therapy,
- the element of reorganizing lived experience and hopes and dreams into stories (which makes it more like a distinctive type of psycho therapy namely narrative therapy), and
- the apparent focus on memories which makes it more like reminiscence work
- the assortment of containers which are deliberately created to hold and store and shape the memories and stories, which makes it more like ethnography or oral history or archiving.

Thus memory work might be defined as the deliberate setting up of a **safe space** in which to contain the telling of a story. This **space** might be a **room**, or the **shade under a tree**, or a **memory box**, or a **memory book**, or a **body map**.

Alternatively memory work might be defined as any endeavor involving elements of remembering, retelling, recording, counseling and sharing.

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**.

The question then arises, how can memory work be focused on the future?

Memory work can be future or non-past orientated in that remembering has the purpose of organizing one's thinking which is a form of orientation. Orientation as we all know is future focused in its purpose. We ask ourselves -where was I- , because we want to know -where to go and what to do next. In Narrative Therapy terms memory work may be defined as the restory-ing or reviewing of historical events, and the finding of a plot that can take one forward into the future with renewed energy or a new perspective. In a conscious way, one then begins to tentatively perform this alternative and hopeful story about oneself. One attempts to begin to notch up and lay down a string of "positive" experiences. Memory work then becomes the gathering and notching up, and then the laying down, of new positive memories. One is remembering how one is ok, how one is not all that bad, and one is remembering how to proceed.

Hopefully we can turn two basic and related assumptions on their heads. One – memory work is about death. Two – Memory work is about the past.

What is meant by treatment?

In the same breath as HIV and AIDS, when we speak of treatment, it is of course ARVs that most often spring to mind, as the ultimate powerful treatment. Almost a cure. Those terribly expensive drugs that can reduce viral load to undetectable levels.

Then there is the treatment of opportunistic infections with antibiotics and antifungals. Then there is traditional or herbal medicine. And there is home based care and palliative care. In an ideal world, all these are forms of treatment might co-exist and be integrated into a holistic and comprehensive service. In the real world, the TAC has raised all of our awareness about how little HIV and AIDS treatment is available, and how costly the gaps and delays are in terms of human lives and human suffering.

Having defined some of the terms and the territory, we are now in a better position to return to the question - how treatment might combine with memory work.

I have attempted to do this in a systematic way considering a whole range of possible combinations and permutations.

The question for me has now become, - how to tailor memory work to the needs of the client, and where might one find the appropriate tools.

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 (National Association of Women Living with HIV and AIDS) in Uganda, and the core manual developed within the Memory Box Project in the Aids and Society Research Unit, up to 2003. This manual has been further developed with a stronger psychological focus within MAP.

This client might wish to:

- 1) Find his or her own reason for engaging in memory work (see “Why” exercise MAP manual)
- 2) review and restory his or her life and come to terms with his or her impending death (see Windows and Plot exercise, MAP manual)
- 3) do some succession planning (the NACWOLA module might have more to offer here)
- 4) map out his or her lineage and support system so that surviving children will know their roots and know who to turn to (see family tree exercise MAP and NACWOLA manuals)
- 5) Open up communication with family members including children (see Disclosure exercises, MAP manual)

Scenario 2:

Client: An adult with early or middle stage HIV illness. She has no access to ARVs. She needs to hang on to her good health, or reverse the course of the illness via self care and becoming knowledgeable about treatment options in the absence of ARVs.

Her needs are well described in the language of treatment literacy and narrative therapy in which she will be encouraged to find her own power, knowledge, skills and agency in the face of this formidable challenge. Before HIV becomes AIDS, and indeed to delay onset, there is much that can be done and under the umbrella of memory work

This client might wish to:

- 1) 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 and record and reinvent the ways in which she pictures her body and her life. Body maps can capture the marks life leave on our bodies (laugh 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 dreams). It is a chance to engage in life drawing and full length projective instrument. As art works and communication tools, body maps are message, and in a support group the witnessing and exchanges of encouragement can be massage.

Body mapping was central to the project “Long Life, positive HIV stories” now published as a book (Jonathan Morgan and the Bambanani Women’s Group, Double

Storey Books, 2003). This began as a participatory media project in which 13 women with access to ARVs first told their stories using memory boxes and books, intended for the ears and eyes of their support group members. They then decided that their stories deserved a wider audience and told them as an advocacy document aimed at the AIDS dissidents and those who think universal access to treatment is a misguided pipe dream.

In their body maps,

Nomawhetu painted the virus in her body but not in her uterus or in her embryo. She also stands on the huge snake that sleeps in the water and rises like a hurricane to destroy houses and trees and villages. The snake is the Pandemic. Itchy skin. Pocked skin. A burn on the abdomen where the candle in the shack set fire to the blanket and almost to the baby that died later. A knife taken out a bra to stab men who knife and rob. Dog bites (lots) and corrugated iron cuts. A sore heart – my sister drank paraffin then set herself alight. A breast bitten by another woman. Little feet that led Babalwa into a police van at age five, a heart that refused to be intimidated, the beginning of her career as a TAC activist. The HI virus dividing in the body. ARVs destroying the virus. Thobani's empty body map, he started well then he faded, emblematic of men's poor participation in support groups and poor compliance with ARV regimens?

Not to lose the plot, we were thinking about the client, an adult with early or middle stage HIV illness, who has no access to ARVs.

She might also want to:

- 2) understand her own condition and prognosis intricately and locate herself on a graph which tracks CD4 cell count and / or various symptomatic indicators of the different stages of HIV illness (see MAP manual exercise called finding yourself on the graph)
- 3) develop a personal narrative in which she is not a passenger or powerless victim on the inevitable pathway to death's door. Rather with healthy lifestyle / diet / abstention from substances etc, she has the ability to be the driver and not the passenger of HIV, and is able to slow down/delay/keep at bay the onset of AIDS (see MAP manual exercise called "Driver not Passenger")
- 4) Become treatment literate (knowledge is power) that draws on folk wisdom and traditional remedies, things that worked for others in her support group, as well as what western medicine has to offer around the management of opportunistic infections. The key is that with a compromised and hard to recover immune system, it is vital to hang on to manage ones good health while one has it.
- 5) Keep tracking her wellness/illness, keeping current with her own emotions around this, and keeping communication channels open with significant others, including health care professionals (see tracing books, MAP manual and next client scenario)

Scenario 3:

Client: This client has HIV but he has access to ARVs.

On one level, the needs of this client perhaps center most strongly around adherence. ARV regimens demand that patients take the drugs several times a day (usually 3), every day for the rest of their lives.

Missing very very few dosages per month (less than 5%) puts the patient at risk around building resistance to the medication which renders it permanently ineffective in the fight against the virus. Once a patient has developed drug resistant strains of HIV, he is no longer a candidate for entire categories of ARVs, and has to face the illness without these powerful lines of assistance. He will then succumb to a host of opportunistic infections which will kill him.

Thus the importance of adherence to the regimen becomes a priority. While this might seem like a bio medical problem, it is also a psycho social one. 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 meal times. 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 and the nurse and the social worker and other support group members need to know about in order to offer help.

It is against this backdrop that Tracing book as Patient Held File was developed.

This part of the paper will be presented in a similar format to a poster that has been recently developed to be exhibited at the SAHARA conference in Cape Town.

Overview, Jonathan Morgan, Narrative Therapist and Clinical Psychologist

Tracing Books are an extension of body maps which are life sized human form tracings that can be described in the languages of art therapy, participatory research, anatomical charts, psychological projective instruments, and more. They are a form of memory work in the context of ARVs, where strict adherence and compliance is key to the success of the HAART (Highly Active Antiretroviral Therapy), in that they help patients to remember and not to forget to take their ARVS which can be fatal.

One scaled down version of the life sized body map and a sheaf of blank pages made of transparent tracing paper, make up the hand bound 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 2, 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 onto the 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 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.

Tracing books have been piloted amongst a group of patients at Masiphumelele Clinic and are in an early stage of development.

Contribution by Anya Subotzky – Artist and Psychology Student

In 2003, Anya completed a fellowship within the MBP and as an artist began to explore memory work in a stronger visual and artistic way than had been done previously. Building on the body mapping work of Jane Solomon, she and Nondumiso Hwele – a Khayelitsha A team member - facilitated a group of Masiphumelele men and women from the Living Hope Support Group to each complete a body map. I was present at the final workshop in which the 15 body maps were hung up on the walls of the Living Hope community room, and in which the women and men that Anya had been working with, explained their body maps.

I was struck by how similar and completely different these body maps were to the Khayelitsha ones. The work had begun in mid 2003 before Masiphumelele had begun their roll out of ARVs, and this sense of “no access to treatment” was highly apparent in these body maps and the explanations offered by the participants. What struck me more than anything else was how traumatic the painting of these huge beautiful body maps had been for so many of the participants.

Listening to the explanations alerted me to how, in itself, body mapping can well be counter therapeutic. There is no doubt that it is a very evocative and maybe too powerful projective and diagnostic tool. What remains to be worked on is clearer guidelines how what is evoked can be contained.

On one level, we had given the Masiphumelele HIV positive support group, an opportunity to project onto the big screen, in multi colour, and with “sound around” (having to tell/inviting them to tell) their stories in the group with outsiders like myself present. As I listened to some of the explanations, I felt chilled that through this process we had elicited and captured layer over layer of pain, and that we had been party to further and re- traumatizing many of the participants.

Here are a few examples.

Examples of how the process was mostly painful:

- I see a hopeless person because of these problems of my wife dying and my son being HIV positive, I have lost my job, I see a person without future.
- In this picture I wanted to be a teacher, but now I see someone who is HIV.
- When I look at this body map I see an unhappy person

An example of how the process was mostly therapeutic

- Liziwe who drew a herself in the shade of huge sunflower.

I love my body map because I am a fighter of HIV. I am a driver of HIV and I don't want HIV to drive me. I feel I'm growing and breathing, I got fresh air direct from flowers and plants.

Examples of how the process was at first difficult and elicited pain but helped to work through some of this pain and to express some hope

- This is me Dena, sorry for not finish the body map. I had some problems, my baby's father passed away. The virus run through my body. I was raped in 1996 in Durban. The two boys who raped me stabbed me in the thigh. This is my future to be an interpreter a qualified one. And to help people who have been raped. Black is the virus, Red is the cell, Blue is the soldiers fighting for bodies

When I look at my body map I see a person who is very strong and don't let anyone take myself for nothing. I feel very confident about myself like all group members. About doing this I feel just like me. I feel very important like others who don't have this virus

- First time I did my body map I was angry with Anya we were sick and she was making us tired. I had shingles in my face see the red mark inside my lungs feel pain. Now when I see my body map I see someone who is strong and who has hope
- I don't want to talk too much because of laugh. This is the way you see me. On top is my angel wherever I go it looks after me dove also shows I'm a church goer. I see a very beautiful person used to lock myself in the house now I can come out

After one or two very painful listenings, I stepped in and asked that each teller, at the end of their telling, say (1) what they themselves see when they look at their own body map and (2) tell us what this process was like for them. Following this we went

round the entire group and completed the following sentence: “When I look at X’s body map and when I listened to her story, I see a person who

When Nobantu said,

- I’m not going to talk too much because I am someone who has HIV. This is my belly button, red is the pain that goes down the womb and leg how I see the virus. My twins died so I had another baby which is when I found out I was HIV. When I did my body map I chose a position like the way I chose I, free of HIV. It gives me a lot of pain because it talks about my life story.

the group including myself, Any and Nondumiso said, “When I look at Nobantu’s body map and when I listened to her story, I see a person who is looking directly into the future, who is so brave to face it, who has her hands raised like she is toyi toying, who can choose to change her body and be free.”

It was hard to know if any of this washed with Nobantu but something felt different in the room and the body map had alerted all of us how she felt, something we never knew before, not even the Living Hope counselor, and this conversation could be picked up on in individual counseling.

And when a group members said,

I love this mark on my face, it’s my culture, and my brothers and sisters have scars like this on their face. I have also drawn pneumonia on my lungs, I am coughing a lot, here are lines across my ribs. The virus starts here on my vagina, pain, a bad smell and discharge. This birthmark I like it when I bathe myself I see it and like it. I am tired in my legs. For the future I have drawn having a cup of tea together.

The group said,

- I see someone who is very strong and will never give up hope, a fighter for life
- Looking at your face I see someone full of hope and who is so determined
- Looking at your hopes – tea at the table, I think its beginning already, when I visit you I see you having everything with your family
- I see your hands up having hope you are faithful to the end and you are going to get the crown
- You live each day to the fullest

This extra process added onto body mapping, seemed to us to be very containing and therapeutic. It directly countered situations in which the body mapping had seemed just to elicit and evoke only painful and negative thoughts and feelings.

What struck Anya and I after this session was the fact that having unleashed such powerful feelings via the body map, there was no way that this could be the end of the intervention. We knew that we needed to develop a tool that was smaller/more containing than the huge body maps, and that could give bite sized pieces to work with. A tool that could track and trace changes and constants in body and mind over time.

We could also see that this might be useful from a counseling as well as medical perspective, which is when we began to talk to Eve, Anya's mother who is a doctor who works in Masiphumelele

Contribution by Eve Subotzky, Doctor Masiphumelele Clinic

When I (JM) first started working in the field of HIV and AIDS, or more particularly in a HIV and AIDS context where treatment was available, I knew almost nothing about ARVs. I was told to phone a Dr Subotzky. Due to her long working hours, extraordinary commitment, and busy schedule, I was able to reach her by phone late one night at her home. Eve spent an hour patiently explaining to me how long an HIV infected child might live without access to ARVS, as well as a million other things I needed to know.

When Anya and I began to think about tracing books, Eve was very supportive and explained to us that a typical consultation was very very short, like 3-5 minutes, and that the person had in all likelihood spent a long time in the queue. Add to this the fact that the patient often had no or little English. A tracing book was just the thing, Eve told us.

Anya asked her what would be useful information that a person might include in a tracing to bring to a time pressured consultation.

I joined in these conversations and this is how it ended looking in the tracing book:

THINGS YOU MIGHT WANT TO DRAW IN YOUR SMALL BODY MAP:

- **Your life and health this week**
 - Your health at the moment
 - Your illness right now
 - Things you have done this week to keep healthy [for example eating healthy food, taking your medicines, going to a support group or disclosing to a close family member]
 - Things you have done this week that may make your sickness worse [for example smoking or drinking alcohol or having unsafe sex]
 - Important happenings in your life this week
 - The things that are worrying you at the moment
 - Things you feel hopeful about right now

- **The virus**

- How does it look to you now?
- How much do you feel is in your body at the moment?
- Where in your body is it?
- How is the virus being fought by your cells or ARVs?
- You can also add your *CD4 count* or *viral load* if you know them

- **ARVs**

- How do they look to you inside your body?
- What happens when they fight the virus?
- Where in your body are they?
- What helps you remember to take your ARVs?
- When do you take your ARVs?
- Have you forgotten any doses this week?
- Have you had any side-effects? What? Where in your body?

- **TB**

- Are you coughing?
- Do you sweat at night?
- Are you losing weight?

- **Other symptoms in the rest of your body**

- SKIN: rashes, scars or marks
- STOMACH: diarrhoea, nausea or vomiting
- LUNGS: difficulty breathing, shortness of breath
- GLANDS: swollen, sore
- HEAD: headaches, pain
- STDs
- ANYWHERE ON YOUR BODY: Sores or Ulcers
- Pain, “pins and needles”, numbness, tingling, discomfort – where?
- Fever
- Not wanting to eat (appetite loss)
- Difficulty falling asleep
- Problems remembering things
- Times when you feel confused or disoriented
- Bad dreams or nightmares

From the word tracing, we talked about using actual paper so that when the person looked at any page, they were looking at a composite layered version of themselves, one that was made up of several documented memories.

Anya’s Fine Art sensibility and attention to detail then kicked in and she went on to make 18 tracing books which we handed out on the day the Masiphumelele members shared their body maps with us.

Eve has reported that every now and then, a patient brings a tracing book with them to the consultation. She also told me that even before tracing books, she often had the need to draw a little sketch to explain something or other to a patient, and that with the

permission of the patients who have brought in tracing books, she has drawn onto a page in or around the miniature body tracing. She also told me that the tracing books help her to see the whole person, not just their bodies and organs, but their thoughts and worries, things that are not really considered her domain as a medical doctor. In terms of family medicine which tries to see the patient systemically and not just as an individual, the tracing books were also helpful. Eve and I also spoke about how different these records/notes/files are to the ones held just by the clinic about the patient, and how the patient held dimension of them alter the whole treatment relationship. It as if they help patients to become more active and less passive in the management of their own health.

Lastly, I will give the last word on tracing books, to several patients who have made their own tracing books.

Noxolo Mqhobo – Patient and Adherence Monitor

On 20 December 2003 on my big body map I was feeling fine just some tiredness in my legs.

Then I drew this big body map smaller so it can fit into my tracing book.

The next week I drew myself coughing and sore lungs. I went to Dr Eve and she told me it was not TB just pneumonia on my lungs, I am coughing a lot, here are lines across my ribs. She also told me that my CD cell count was 147 and I filled it in on my tracing for week 2. I was given medication to take every day.

In week 3 I drew and I took my tracing book with me to Dr Eve and she examined me. I went home and drink lots of water every day and a glass of fruit juice. The next week she told me my cd cell count was up to 423 from 147. I was very very happy and I drew myself with my arms up but my legs were still sore and I was very itchy.

I was the first person in my community to disclose and I am an adherence monitor for CIPRA

On the first day of the new job I drew all 5 of us adherence monitors sitting around the table sharing things about training, having a cup of tea together. And the next week I drew me sitting and listening to our manager at the office. Nothing about my HIV, just me in my new job.

But the next week, in week 10, I drew myself lying in bed, feeling tired, dry cough, chest pains, always sleepy, always thirsty.

The next week, my hands are up again, I wrote I am free, feeling very strong, even though my cd4 cell was down to 255.

My book only goes up to week 12. On that last page, when I took my book to Dr Eve, and told her about my cough, she asked me if she could draw in my book. I was glad and with a very thin red pen she drew 2 lungs, one with little black dots in it, and she wrote damaged lung, easily infected again, and this made me understand easily. But with my cd only 255, it worries me a lot. I hope I can get ARVs when I need them.

These tracing books can help many patients because they can help people communicate to their doctor, to their children and to each other in support groups.

I showed my tracing book to Winnie my daughter and explained why I was not feeling well and couldn't help her with her homework. She understood me well.

On week 6 and 7 my tracing pages got burned when the paraffin lamp in my shack spilled over.

Liziwe Kweyama – also a patient of Eve who was a Memory Box Project intern graduate but who is now unemployed said this about her tracing book.

This is my tracing book, it has a little picture of my big body map on the cover. This little person is a counselor which is what I want to be. I am a driver of HIV and I don't want HIV to drive me. Since I stopped working last year things have been hard but this book has helped me a lot. I showed it to a friend of mine and used it to counsel her. On one page I have a photo of two of my friends. I call them my positive family. When I take this book with me to Dr Eve it is better than not taking it. Last time I took it I told her I am not HIV, because you can see every week except for one when I had flu I have been very healthy. Reason I say I don't have HIV because I'm eating healthy food and play sport so I get exercise. I control my life. I can see how long I have been healthy and what I am doing right by looking at this tracing book. Maybe I will not need ARVs for a long long time.

Xolisa Sijora – Patient and CIPRA adherence monitor

This is my body map. My son's name is Luthando. All my problems started when he was born, I took his mother to the day hospital but she passed away. As time goes by he gains weight, but he has the same problem as his mother, at the hospital they noticed her blood has HIV. Even though it is my tracing book, on the first page I drew myself and Luthando and both of our dates of birth. After the death of his mother. One hand shows that my heart is full of blood. One hand holds my son.

As you can see this is the virus, when we found out I asked my doctor lots of questions, the virus attacks the nucleus, the white cell, red cells. Tries to attack the nucleus and change cell to produce more HIV in the body.

Here is the stomach, the large and small intestine and the liver and ulcers.

When I drew my body map in 2003 I said, “I see a hopeless person because I have HIV and I lost my job, I see a person without future.”

Through this I have learned a lot and I was chosen to be an adherence monitor for CIPRA in Masiphumelele where the people will be getting ARVs in 2004.

I use this book to trace the health of me and my son and on ARVs we are both doing very fine.

On week 8 I felt so weak and tired and sore throat I took the whole week sick. I went to the clinic and Dr Eve gave me some tablet and some medicine.

On week 9 she told me about my viral load and cd4 cell count. I was worried for the news the doctor told. My cd dropped from 333 to 241. So that I can be on treatment very soon which is bad news for me because I don't want to be on treatment soon. Eve drew two graphs for me in my tracing book on the page for this week. She showed a line going down which explained when my CD4 goes from 600 to 241, it is only when it goes below 200 I will need to go on ARVs. Then she drew another graph with wavy lines like the sea which shows it does not just go straight down but up and down all the time.

I only drew me and Luthando and wrote nothing on this page, I was too tired in the week. On the page when I explained Eve wrote, “in his heart he is worried about Luthando who has chicken pox and he is worried about drop in CD4 and that he would not like to start ARVs soon. Realizes it would mean treatment for life.” It felt good for me to have her understand this and to write it for me in my tracing book.

Scenario 4:

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

Living with the knowledge that your only caregiver, your mother has HIV is not easy. It is important that your caregiver/parent communicates with you to allay your anxieties and to have these issues out in the open, rather than as repressed fears and or as taboo topics.

The kind of interventions perhaps most suited to offer this child might be along the lines of play therapy, therapeutic interviewing, projective assessment, child focused narrative therapy.

This child might want to express some of these anxieties, communicate them to her mother/caregiver, be assisted in gaining mastery over particular challenges. 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 hand bound story book 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 projective drawing in the hero book process.

The challenges a child might want to take on using a hero book, include behavioral problems, emotional problems and social problems. Behavioral 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/witness 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.

Here is an example of a hero retelling retold by Jonathan Morgan and Helen Meintjies to a child and his caregiver both of whom participated in a Children’s Bill child participatory workshop.

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 7 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 6 other children. They are his brothers and sisters now but he has also not forgotten his sister 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.

The Ten Million Memories Project recognizes that the greatest service we can offer a child who has a parent living with HIV is to keep their parent alive.

Hero books are a current area of focus and research at MAP. Examples of hero books and a manual appear on the soon to be accessed MAP website.

Scenario 5

Client: Almost anyone in the HIV affected or vulnerable household

There is no doubt that the extent to which one is and may about to be HIV affected, as a person living with HIV, or a child in a household in which someone is HIV positive, or where a caregiver has died, or as a HIV negative teenager, is hugely mitigated by the income generating capacity of the household. In order for ARVs to work effectively, minimum levels of income which translate into quality of diet, shelter, access to clean water etc, have to be in place.

Memory work, however attractively it is packaged and marketed, in colorful body maps, in funky boxes, in neat little books, could be construed as an elitist art therapy and talking cure offered to people with empty stomachs.

Memory work cannot be everything at once or a stand alone solution. It is being differentiated into a range of products and interventions that address a wide range of needs. Its core business is psycho social support and not income generation. Having said this, the question of income generation has been addressed within the ambit of memory work.

The A team.

When Kylie Thomas and myself began memory work from within the Memory Box Project, Aids and Society Research Unit, the demand for memory box workshops far exceeded what Kylie and I were able to deliver. Kylie and I realised that, more than any one person, what we needed was an A team. A crack squad of helpers who could work on many different fronts. When we thought about what would most qualify this team to do the work required of them, the two things we came up with were that they should be Xhosa-speaking and HIV positive. Part of the motivation to develop this concept also

arose from the awareness that there is a very vibrant and healthy AIDS industry involving not only pharmaceutical companies, but a host of other AIDS profiteers (researchers, consultants, etc) as well, and that HIV positive people and HIV affected communities are often the last to benefit from all this business. In our work, we were always clear that what HIV affected communities seemed to need more than more condoms or counseling or awareness raising etc, was money, jobs, hope, a sense of future etc. It was not within our means or expertise to provide these but here, through the A team, there seemed to be some kind of an answer. Rather than recruiting our clients into yet another bead or craft enterprise, individuals here were being asked to deliver around their real area of expertise – their insider knowledge and experience as HIV positive people and their fluency in the language that is spoken in their own communities.

The concept of the A team has been quite successful. Since 2002, a group of 12 previously unemployed women all living with HIV, have been delivering a range of services (memory workshops into support groups, train the trainer workshops, and survey questionnaire field work). Their main clients are the AIDS and Society Research Unit at UCT and REPSSI. They have not owned by anyone, are self managed, and for 3 years have not only managed to survive in the deeply HIV intervention saturated Western Cape but have developed a range of skills including business skills, transcription and translation skills, published a book which is an advocacy document calling for access to treatment called Long Life and have travelled widely both nationally and internationally.

This model that recognises that people living with HIV in affected communities can be more than research subjects and can be powerful partners in action research projects that at the same time educate academics, mitigate the effects of the pandemic, and provide them and their households with well earned income. Inspired by these Western Cape women (and one man) the A team memory work model has now been taken up by the University of Natal. The point here, in terms of treatment and memory work, is that a group of about a dozen women, all living with HIV, some of whom are on ARVs, and some of whom are not, most with infants who are HIV negative because of PMTCT, who consider themselves drivers and not passengers in their journey with HIV, are experts in memory work and in a position where they can implement the work and train others to do the work in their own and other communities.

A final example of a memory tool that addresses income generation is now presented before concluding this reflection.

The A-Z Masiphumelele Meander Tourist Guide –

When the second A team was recruited in 2003 in Masiphumelele, Anya and I wanted to make sure that not only the 5 A team members benefited through the project but also “the community.”

Other than the new A team, as part of their training, co-facilitating memory workshops in the support group, we dreamed up the idea of an income generating tour that would tread the tricky territory between AIDS tourism, township tours and study tours. The idea was

simply to make a huge memory book, which we would keep in the A team office. The A team would be on the look out for entrepreneurial tourist worthy residents in Masiphumelele, and help them to write up their life and business stories in their own memory books. Anya took up this project (as she did the tracing books) with amazing focus, commitment and creative energy.

Next thing the photographer from Venda with his studio in a shack on the “main” road had his story witnessed, acknowledged, documented, as well as a page in the A-Z. So did the hairdresser who had the client’s chair, perched at the top of a tower with a view over all the shacks and taking in both the Atlantic and Indian oceans, with stereo speakers close to each ear. He had built a double storey level above his shack and it was up here that he plied his trade.

This initiative was also conceived as breaking /bending stigma campaign. The idea was to showcase lifestyles in a HIV affected community, which use available resources creatively which can serve as an inspiration to others. Radiating out from the A team office (social entrepreneurs in their own right) and profiled in the big memory book Anya made with the A team, were a whole host of people who live positively, or are making a community contribution, or are using their home as an income generator, or as a resource in the community.

When I was leafing through this book the other day, I noticed on the visitors book comments page an inscription by Beatrice Were, who began memory work in Uganda in the early 90s.

She wrote, “I cannot believe that memory work has spread here, to Masiphumelele, on the furthest tip of Africa.”

Like in all things, especially in stories, in narrative work, in therapy and in memory work, the beginnings and ends are connected, and loose ends can be tied up.

Conclusion

This paper started off exploring how memory work and treatment might fit together. In too many countries the situation continues in which limited people who need ARVs have access to them. While we are waiting for and working towards the rollout ARVs, there remain millions of children who have lost, are losing, and will lose loved ones. In these contexts there remains a need for classical memory work, where the focus is on succession planning, dealing with loss and grief, the leaving behind of a legacy for surviving orphans, communication within families and across communities to break the silence and lessen stigma.

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. We are not advocating that organizations like hospice, who do excellent memory work, become activist organizations like TAC, or that they stop helping their patients die dignified deaths with as little suffering as possible. What is being advocated is that the assumption that HIV = AIDS = DEATH be questioned wherever possible.

This paper has sketched out how in hope zones, like Khayelitsha where through MSF and the Western Cape Provincial Government, where ARVs have been available, conditions have forced memory work in some ways to examine its own assumptions, and turn itself inside out. With treatment, HIV becomes just another chronic but manageable condition, and in these zones, memory work becomes more about fighting for life than preparing for death.

At a conference in Sussex, I was speaking about this work to a white English woman living with HIV, who is also a hardworking activist who has made real contribution to the struggle, and who was involved in memory work in its early days. She said, "You must not only stress fighting for life, but also celebrating life."

ARVs make this more possible, but just because a person might have access to ARVs, this does not necessarily mean they feel like celebrating their life. A host of other things might get in the way but once again memory work might have something to offer here.

Also, there is a continuum between "hope zones" (ARV contexts), and "wastelands" (no access to treatment contexts), which is showing signs of narrowing in certain countries like South Africa and Botswana. The cost of ARVs is dropping steadily and many individuals and organisations are working tirelessly to ensure that all who need treatment are able to access it.

Many people who are on ARVs, die of other things, motor car accidents, heart attacks not related to their HIV status, murder, etc. Preparation for death and memory work is for everyone.

The Ten Million Memories Project (10MMP) is a project whose goal it is to scale up innovative, replicable and sustainable **memory** approaches within integrated psycho social programmes.

Participant organisations comprise a deliberate mix of organisations, research institutions, faith based organisations, advocacy and activist organizations, etc (the Regional Psycho Social Support Initiative (REPSSI), the Red Cross, the Salvation Army, Save the Children, University of Cape Town, University of Natal, Madaboutart, South Coast Hospice.

The 10MMP is owned by no one organisation and our hope is that it will become a pan African people's movement that will reach at least 10 Million Children across Africa with Memory approaches by 2010.

The broad strategy at this early stage includes the development of simple training material, the establishment of pools of regional master trainers & national training teams, media and communications advocacy, the integration of memory work into education, as well as ongoing monitoring and evaluation.

This rich mix of partners is not only challenging but will ensure that memory work will grow and develop to address a wide range of contexts. Via peer review processes, and interdisciplinary collaborations, universities are well placed to provide critical thinking and to guide much needed research, including monitoring and evaluation.

Grass roots and front line organizations like the Red Cross, Save the Children, the Salvation Army, are well positioned to help arrange access for the research, ground it and keep it relevant.

Organisations like TAC and MSF keep on reminding us not to ever accept that people should die as a result of this completely treatable virus.

Programmes that offer psycho social support and memory work need to challenge the belief that millions of people need to die because they can't on a daily basis, access a few granules of a chemical. A kind of memory box that was not mentioned above were the ones that members of Khayelitsha support groups carried on broom sticks high above their heads during the largest ever TAC march through the streets of Cape Town in 15000 people mostly wearing HIV Positive T shirts demanded that the government roll begin to provide ARVs or a civil disobedience campaign would follow. Painted on their sides these memory boxes said, "ARVs now", and "Live don't die."

Through MAP, Memory Action Projects, a collaboration involving REPSSI and the UCT, Psychology Dept, currently housed in the Child Guidance Clinic, UCT has become a hotbed of current action research all around memory work.

It is hoped that this paper which has outlined how memory work needs to become more differentiated to meet different client needs, and the examples provided show what memory work has to offer and how memory work and treatment can co-exist and indeed be integrated.

As a second last word, the question, how vaccines and indeed a cure, might influence memory work, is posed. Is this the stuff of science fiction? Will a cure or a reliable vaccine, make memory work redundant? Not at all. Every one of us is both living and dying at the same time. Memory work in all kinds of contexts needs to be articulated into an art which holds central sharing, healing, documenting and containing.

As a last question, if memory work is not necessarily about death but about life, and if memory work is not necessarily about the past but about the future, should it still be called memory work?

My answer is yes. It is past experiences that are in the past, memory work is all about remembering, remembering is a verb, it is a doing word, and it helps us chart and map the paths we choose to lead us out of difficulty. There is a lot to be done. Every choice we make and every name we give something, both shuts down and opens up possibilities. The word memory is just fluid enough and evocative enough and pointed enough to embrace a diversity of thinking, feeling, imagining, art and science that make this work so rich. Quantum physics would also have us that all time is continuous, past, present and future, some would even say living and dying, life and death. This is the space into which memory works.

Acknowledgements:

- To Anya Subotzky for her amazing commitment as a Fellow within the Memory Box Project, Aids and Society Research Unit, UCT, in 2003, and for all she brought to this work.
- To Eve Subotzky for her input and participation in co-developing the tracing books.
- To Noxolo Mqobo, Liziwe Kweyama, and Xolisa Sijora and other support Masiphumelele members for the courage and creativity they have brought to co-developing the tracing books and other memory tools.
- To Pumla and Nelson
- To Masego Morgan
- To the hopefully eternally widening MAP and working group dialogues which thus far have included Sally Swartz, Sia Maw, Pumla Gobodo Madikizela, Johann Louw, Natalie le Cleuzier, Reygana Adams, Peter Schaupp, Anne Turner and the MA Clin students.
- To Helen Meintjies, Namhla, Lizette, Paula, and Solanje from the Children's Institute, UCT, and the children who participated in the Children's Bill workshop.
- To the NACWOLA women who inspired all us with their pioneering memory work
- To REPSSI and all its partners in the Ten Million Memories Project
- To Jane Solomon for bringing us body maps
- To the Khayelitsha A team