

# **Caring for Caregivers:**

## **The role of alternative practices in weaving new threads of meaning within the South African HIV/AIDS and TB context.**

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**Abstract:** *Waldegrave (2003:8) describes that Just Therapy ... "in essence, concerns the movement from problem-centred stories of pain, to stories of resolution and hope; new meaning is given to experience, by the skilful weaving of new patterns." This has been my quest ever since engaging with the work of caring for caregivers within the HIV/AIDS & TB context. In this paper I will describe some of the practices other than the usual structured conversation, that help weave the new patterns of meaning which gives caregivers hope and provide them with the necessary skills to deal with compassion fatigue.*

*I will describe the context of the work; firstly giving a background of the different communities I am involvement with (the broader communities as well as the caregiver communities), then describing the nature of the standardised mentoring programme, lastly focusing on the issues that complicates the work and contribute tremendously to difficulties and compassion fatigue for caregivers: poverty, gender issues, cultural practices and taboos, substance abuse and domestic violence.*

*I will share how Narrative Therapy has enriched my practice and opened up new possibilities of engaging with this work that sometimes feel like wandering in a wild landscape of loneliness and despair. I will also share how practices like mindfulness-based meditation, working with music, art and movement and the practices of Capacitar have further enriched my work and how it helps in the weaving of the alternative story-line and elicits narratives of hope.*

### **Introduction**

"From across the water he stepped out, among the broken reeds ... and he laughed silently with white teeth showing – crouching, waiting ... and the great beast emerged suddenly and quietly from the warm slime. And finally Koki's heart recognised that he had come to a boundary – that he was enclosed by something dark and dull and strong."

I find it greatly significant that Alta van Dyk uses this translation of NP van Wyk Louw's poem, "*Raka*", in the opening pages of her book "*HIV/AIDS: Care & Counselling*" (2005). Working as therapist and caregiver in the field of HIV/AIDS, the words of this poem resonates so strongly, stirring the deep waters of one's soul with the realisation that this is such an appropriate metaphor to describe the HIV/AIDS landscape. It puts our experiences into words of such rich imagery. Maybe it even languages the material of our nocturnal nightmares as our psyche tries to process the impact of our daily experiences...

With the presentation of this paper I want to honour all the counsellors and health care professionals that I have worked with as mentor and trainer over the past eight years, some's names and faces I might have long forgotten, but their contribution to clients living with HIV/AIDS will remain lasting and invaluable.

I will now proceed to describe the nature of my work as mentor to counsellors and other health care professionals in the field of HIV/AIDS/TB and how Narrative Therapy and practices like mindfulness-based meditation, working with music, art and movement and the practices of Capacitar have further enriched my work and how it helps in the weaving of the alternative story-line and elicits narratives of hope.

## **1. Context of the work**

I have been fortunate to have gained a very rich experience of working in the field of HIV/AIDS/TB by being able to work in various diverse communities in the Cape Town area over the past eight years. My longest involvement still remains with the HIV/AIDS counsellors of Lifeline in the Xhosa-speaking community of Khayelitsha. I mentor approximately 40 counsellors in 5 groups as well as a group of coordinators every second week in 90-120 minute sessions. My work as mentor and coach for the Desmond Tutu TB Centre (DTTC) linked to the University of Stellenbosch and City Health clinics are centred in largely Afrikaans-speaking coloured communities like Mitchell's Plain and Kraaifontein. For DTTC I mentor 25 people in 5 different sites comprised of nurses, counsellors and field workers. I see them once or twice a month for 60-120 minute sessions.

For City Health I mentor in the Tygerberg District all levels of staff in two clinics, the environmental health office and the Parow Training Centre twice a month in hourly sessions. Once a month I coach a group of 14 facility managers, whom I also see individually twice a year. Although the focus of the work for City Health is largely capacity building, debriefing around and management of HIV/AIDS/TB forms and important part of the work.

I also work with three nursing professionals at I&J Fisheries, whom I see twice a month, and although their debriefing focus on general needs, managing HIV/AIDS also form and important part of their work.

On a different level I work as supervisor in the Department of Practical Theology where I train M.Th. students specialising in HIV/AIDS counselling. They gain their practical experience through placements in various health care clinics spread over the Cape Peninsula, where I oversee their clinical work.

Lastly in my private capacity I offer retreats for caregivers once or twice a year, providing an opportunity for them to engage on a deeper spiritual level with some of the alternative practices I will describe later on.

## **2. Nature of the mentorship programme**

The Provincial Health Departments annually pay a lump sum of money to NGO's to manage the HIV/AIDS counsellors working in health care facilities. These counsellors include Voluntary and Testing (VCT) counsellors, Mother-to-Child-Transmission (MTCT) counsellors and the more experienced adherence counsellors working long-term with patients on Ante-retrovirals (ARV's).

The NGO's then also contract professionals to mentor the counsellors. The counsellors' contracts stipulate that they must receive mentoring at least twice a month. This is how my relationship with Lifeline started, the NGO that manages the HIV-programme in the Khayelitsha district. My task is to take care of the general well-being of the counsellors, to help them with case work, stress management and to give attention to their training needs.

The work with Desmond Tutu TB Centre (DTTC) and City Health is basically the same, although the focus is largely on team-building and stress management, while time is also provided for debriefing around workload.

## **3. Issues complicating the work**

### ***Compassion fatigue***

I borrowed this term from the designer of the Capacitar work, Pat Cane (2005) – which I will describe later – since it aptly describes what I experience almost every time I meet with my groups, especially the two groups of adherence counsellors in Khayelitsha. A rising demand in the work, more and more people falling sick and needing ARV's, dealing with defaulters, being unable to trace clients (they sometimes give false addresses), all contribute to the experience of compassion fatigue. In the clinics a lack of especially human resources results in an overload of work that contributes to experiences of demoralisation and chronic fatigue amongst nursing staff.

## ***Poverty***

As more and more people flock from rural areas to Cape Town, especially those who are HIV+ and needing the better health care the province provides, more and more pressure is put on the city's infrastructure and service delivery. Lack of housing and work increases people's poverty situation. Heart-rendering stories are often heard of people who have nothing to eat, since they are too sick to work, but in order to take the medication they need to treat TB and HIV, they need to eat properly! It thus becomes clear how HIV/AIDS and nowadays TB increases poverty (Whiteside & Sumter, 2000). The stories of poverty in a context of inefficient social welfare support leave counsellors and clinic staff alike feeling helpless and hopeless.

Linking poverty with gender issues, we nowadays find that more especially young women are leaving school to move in with older mostly employed men who can provide for them. Their focus is usually to have babies so that they can either secure the man's hand in marriage or get a child support grant. "Pre-occupied with survival, and with limited access to information and health services, the risk of infection and options to reduce risk are not priorities for these women" (Q Abdool Karim in Karim & Karim (eds) 2005:247). These stories lead to feelings of desperation amongst counsellors and staff at the youth clinics in Khayelitsha.

## ***Gender issues and domestic violence***

This is an area that is largely overlooked in the work with HIV/AIDS, but it is my personal opinion that gender relations is one of the biggest contributing factors in the failure to stop the spread of the virus in Southern Africa. Especially at the Maternity and Obstetrics Units (MOU's) counsellors often feel they have failed in their work when HIV+ women sometimes return for even a third time with yet another pregnancy, some of them desperately ill, putting both themselves and their babies at risk. When asked why they didn't make use of condoms to prevent further pregnancies, the answers are usually that they were not ready to disclose, or they found themselves in a new relationship and scared the partners might leave if they did disclose, or the partner refused to use a condom.

Despite our progressive constitution, women in South Africa still have very little negotiating power when it comes to sexual relationships, and this is particularly noticeable in the Xhosa-speaking community. Mostly men claim free reign to engage in multiple sexual relationships, but women are normally blamed and rejected for bringing the virus into relationships. At the health facilities mostly women are seen, and men often refuse to come out for testing.

Add to the scenario the enormous rate at which women are abused by their partners, and one can understand why it is almost impossible for women to engage with risk-reducing practices. The fear of violence is mostly used as an excuse for not disclosing and therefore increasing the HIV risk. It is highly frustrating for the caregiver on the other side though, since it feels like so little can be done about this.

### ***Cultural practices and taboos***

Through the years of my involvement with the counsellors in Khayelitsha, most of them women, I have been privileged to hear some of the most interesting stories relating to the Xhosa-culture. Counsellors will often tell how certain cultural practices can contribute to the uncontrolled spread of the virus. For instance, the traditional role of the woman in the Xhosa culture where her position is sometimes submissive and she has little negotiating power in the sexual relationship. The practice of paying “lobola” (bridal dowry) for a wife is often nowadays interpreted as a man’s right to treat his wife as a possession, although the counsellors would also tell that this has not been like this in the past.

Often superstitious beliefs will surface where the presence of HIV will be interpreted as a curse, for which the traditional healer will be consulted. Often the advice of not very responsible practitioners are sought, who will give their clients potions to drink to get rid of the “poison” that will make them vomit, very dangerous for an HIV+ person. Unfortunately the superstitions has also crept into the Christian culture, where certain pastors through the laying on of hands proclaim their parishioners free of HIV, only to be re-tested again at the clinics. Both situations are highly frustrating for counsellors.

There are also cultural taboos where teenage heterosexual relationships are not acknowledged and sometimes children are forbidden to bring their boyfriends/girlfriends home. Sex education for children is strongly frowned upon.

Fortunately though stories of change in all of these limiting cultural practices are told, especially amongst the younger generation as awareness increases and ideas around marriage and gender relations as well as culture start changing.

### ***Substance abuse***

It seems that the abuse of substances, especially alcohol, has rapidly increased amongst the poor over the last few years. The link between substance abuse and domestic violence has also been noted and needless to say, HIV risk-taking. Particularly when it comes to adherence to ARV’s the abuse of alcohol becomes a huge issue. People cannot be given ARV’s when they abuse alcohol, since the risk of defaulting and untimely death is too high.

All of the above need to be seen as highlights in the intricate fine web of the very complex South African situation that contributes to the difficulty of this work. Since this situation also results in a feeling of ultimate heaviness, I sensed that it is sometimes too much to talk about in mentoring for caregivers. I personally reached a point where it felt like I'm wondering in a wild landscape of loneliness and despair, sometimes not knowing what I am going to offer my clients next. My ideas dried up. I needed alternatives. I sensed an urgency for a richer approach to this work, partly to preserve my own sanity, but also realising that the HIV/AIDS/TB scenario is in itself becoming a problem-saturated story, a thin description of our lives as caregivers. I realised there is much more to who we are. I needed to engage with the alternative story, the richer, thicker description of who I am. I also realised that it is my obligation as mentor to help my clients engage with their own alternative story, and in the process help them weave narratives of hope.

#### **4. Searching for the alternative story**

Gradually through the development of my professional life and through my involvement with the Western Cape branch of the South African Association of Marriage and Family Therapy (SAAMFT) I found myself drawn to the practices of Narrative Therapy. I'm deeply grateful for the input Dr. Suzanne Shuda had on my work at the time. The richest formative influence though came through the workshops and courses of Elize Morkel that I eagerly attended at the time of my search. My work was further enriched by the workshops of Johnella Bird as well as Jill Freedman and Gene Combs presented on their respective visits to South Africa.

The impact of this work was liberating to say the least. I no longer had to succumb to the limiting description of my clients as sometimes struggling human beings desperately in need of coping skills within the minefield world of HIV/AIDS/TB. Knowledge and skills I transferred where needed, but for the most I from now on respectfully engaged with my clients as knowledgeable human beings with rich life experiences. I worked hard on decentralising my position as the "expert". Instead my role as mentor became a compassionate journeying with my clients. My clients became my cultural consultants (a term I borrow from Elize Morkel), informing me about little known aspects of both the Xhosa and Coloured cultures I work with, therefore enriching my understanding. Sometimes the mentoring sessions would become in itself a landscape of rich story-telling, sometimes jaw-dropping shocking and at other times extremely funny and entertaining. I would witness some individuals suddenly transform into skilful and extremely entertaining narrators, complete with animated re-telling and enacting of their experiences. The usually problem-saturated and miserable stories all with the same plot would transform through humour and theatrical antics and alternative possibilities of viewing the situation would open up. I realised that in Waldegrave's words, we were moving towards stories of resolution and hope, giving new meaning to experience and skilfully weaving new patterns (2003). This would sometimes happen through something as simple as a sense of relief.

As stories of experiences were told, we were also busy re-membering. I think I experienced something of what Michael White (1997) writes: "Re-membering practices provide persons the opportunity to engage in the resurrection and rich-description of the knowledges and skills of living that are co-generated in the significant relationship of their lives" (p57). Also, in especially the groups of mixed cultures, people were invited "to celebrate their differences and to develop and perform narratives that they prefer around the particularities of their lives" (Freedman & Combs, 1996:33). This could happen during lively discussions around values and the management of controversial issues.

However, numerous times there was a need to be quiet. The level of compassion fatigue or secondary trauma would be so high that even a conversation of the lightest nature would just seem to be too much of an effort. The need for non-verbal work that honoured the same principles as narrative therapy was needed. I will now describe the alternative practices that I employ in my mentoring work and that proved to be invaluable in the weaving of the richer story-line.

## **5. Alternative Practices**

### ***Mindfulness-based meditation***

Jon Kabat-Zinn (2005) writes about mindfulness: "Mindfulness ... has a rich and textured capacity to influence the unfolding of our lives. By the same token, it has an equal capacity to influence the larger world within which we are seamlessly embedded, including our family, our work, the society as a whole and how we see ourselves as people, what I am calling the body politic, and the body of the world, of all of us together on this planet" (p23-24). Although mindful meditation involves the teaching of certain techniques, like deep breathing, and although there are different ways of meditating, the importance of this very simple practice is that it allows awareness, life itself, to emerge. I would notice that as a group start meditating, the energy starts shifting in the room. The atmosphere sometimes loaded with the heaviness and difficulty of the work, would become lighter, the room would become a safe and gentle space for the body to rest in the present moment, and awareness would surface that would in the end result in rich narratives of hope.

For some this space would merely allow the over-exhausted body to rest and fall asleep, awaking later feeling a little refreshed. For others awareness of body aches and pains would arise, the body's own language calling for attention and presence. Some would experience profound imagery and insights while being present in meditation, returning to their work with renewed strength, mindful and aware of the present moment.

I would sometimes also use guided imagery, often involving the use of colour, and these meditations would often evoke stories of re-membering, fond childhood memories or stories involving significant guides, mentors or meaningful life experiences.

The important point of this practice is that it, at least for some, succeeds in teaching awareness, being mindful and present in the moment. One fieldworker at a DTTC site where my journey with this particular group came to a conclusion recently reported that this work taught their team respect. They became aware of the disrespectful way they related to one another, and became mindful of being together as a team in a different way, respectful of the other's uniqueness and learning to value each other through listening.

### ***Music***

"Music is the most subtle of the art forms but probably has the greatest influence on our psychic centers and sympathetic nervous system" (Bassano, 1992:10). Music has become for me an extremely powerful tool in the work that I do. Music of all kinds vibrate energy, and utilising music specifically designed for healing in group settings transports clients to an almost meditative state of mind, where they start engaging with a different landscape, a landscape that opens up opportunities to view their lives differently. I would sometimes have a session where I use music of different types evoking different feelings and energies and allow clients to respond to it. The most wonderful imagery and stories of memories, positive or sad, associated with the music would emerge. Almost always at the conclusion of such a session people would say they feel renewed and refreshed, able to go back to their work with a different perspective.

Music, art and movement form an important part of the retreats that I present. I gradually over time became interested in the link between colour and music and found a powerful tool in the work of Mary Bassano (1992). I designed a meditation based on the colour-music key link and used it to great effect. I have noted what she writes: "The proper use of color and music lifts us beyond the material world into a place that is more universal" (p 99). It is from this universal place that clients would gain new insights and enrich their lives with stories of hope and renewal.

### ***Art***

Sometimes after a guided meditation I would ask clients to make a drawing of their experience. On my retreats participants have a choice of paints, pastels or crayons to draw with, or they can make collages or work with clay. This being done in a meditative space while listening to gentle music. Once people have overcome their initial resistance to the creative process and they start engaging with the work, even the simplest of drawings would become the most powerful landscape of the alternative story. Not once would a person return from such an engagement unchanged.

I would sometimes also show clients in a mentoring session different existing art works and ask them to respond to what the art evokes. I've always been awed after such a session about the stories told, associations with colour and images, what memories certain scenarios evoked, responses of fear and joy, numerous and rich experiences. Later clients would say how such a session opened their eyes to a multiple-layered view of art, other than just seeing a flat picture. In the process they are beginning to see their lives and work as a whole from a multiple-layered perspective, they are beginning to see more than just the problem-saturated HIV/AIDS/TB scenario they engage with everyday. Life itself is emerging as awareness (Kabat-Zinn, 2005). Jan Phillips (in Pearce Myers, ed. 1999) states about the effects of following the creative process to the inward landscape: "Life is no longer about time and demands and errands. It is about the extraordinary metamorphosis on one thing into another. What begins as cocoon emerges as butterfly. What once was sorrow may now be song. And as I am changed by the art that passes through me in the process of becoming, so I am changed by the creations of others" (p 127).

### ***Movement***

Due to space limits in the contexts I usually work, I don't use this practice very often, but during the retreats I present I would often make use of movement. The Capacitar practice (described below) taught me very simple Tai Chi movements that I often use even in limited space to great effect. As noted with the use of music, you sense energy shifting as people engage with the movement of their bodies. The movement itself becomes a form of meditation, a body prayer, during which awareness rises and rich experiences are evoked. "Doing the movements becomes a window into the body's wisdom" ... (Winston 2003:33).

I designed a movement and dance workshop based on Winston's (2003) ideas, called "Dances of Affirmation". Apart from the basic Tai Chi movements, I chose music for the themes I worked with and allowed participants to dance freely to how their bodies wanted to respond to the music. One participant wrote the most beautiful poem in Afrikaans to express her experience of this workshop. I translate a few phrases:

"A crate... keeping you enclosed from beneath and above.  
The corners holding you tight; it is dark, devoid of light  
Suffocating and stifling ...!

Get out, break out, break away!

....

Purified by life itself, you are more precious than gold.  
Human child, you can make a difference where ever you go.

Stretch wide your wings, fly like an eagle; free yourself from fear and anxiety.  
Nothing can hold you back. You are free to be yourself.

Look inward ... See how the gift  
of wisdom adorn your life.

....

This is the key Human Child!  
In our serving others, we can lose ourselves  
... and find ourselves.”

- Lorraine (01/09/07)

### ***Capacitar***

Capacitar is a Spanish word meaning “to empower”. Engaging with this work was like discovering a treasure chest filled with wonderful ideas and tools. Feeling excited like a child, I couldn’t wait to take these practices to my groups, and how powerful it proved to be indeed! Of everything we do in mentoring, my clients would always report on the usefulness of the exercises and techniques coming from this work and frequently ask for it to be repeated. Patricia Mathes Cane (2005) drew from a variety of wellness practices in her design of this work, including meditation, movement, reiki, Chinese medicine and Polarity Therapy in an effort to provide people on grass roots level who experienced trauma and compassion fatigue with practical tools that they can utilise in their own process of healing. I would hear numerous stories of how my clients implemented the techniques I demonstrated to them in their lives and how it assisted in facilitating new insights. They would tell how it assisted their bodies and even relationships to move from ailments and difficulties (problem-saturated stories) to release and healing (alternative story). I regard this work invaluable.

### **Closure**

Trying to find closing words for this presentation fills me with the fear that I might only end up with a thin description of my experience in my practice over the past few years. I therefore conclude with this poem by Fiona Almeleh (2002:14-15) that provides me with the rich descriptive summary I’m seeking:

“Chances were

A million wings would beat in rhythm  
spirit would rejoice and sing of life’s bounty  
and we would see the golden thread of connection  
appear from the mists of time

We each would become a kaleidoscope of faces  
a multitude of expressions and experiences  
and we would expand inwardly to embrace limitless realms

Past difficulties would invite new perspectives  
God would whisper of the greater plan  
and joy would dissolve fear and sorrow

The chameleon would inhabit us giving us wider vision  
the praying mantis would stand over us as it spoke  
the wisdom of our ancestors  
and the leopard's glance would melt all resistance  
as we surrendered to its will

Each meeting would call forth our soul's true colours  
the distance would become a blessing as it grew us  
and the spiritual intimacy would enhance us

We would release the need to understand the unknowable  
our separate paths in joining would again reveal great riches  
and we would remember to appreciate what we have

This moment – what you believe is true.”

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