

RESPONDING TO PEOPLE LIVING WITH HIV/AIDS FROM A NARRATIVE THERAPY PERSPECTIVE

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ABSTRACT

HIV/AIDS affects millions of people and in particular many young people in South Africa. In my work at the Cape Peninsula University of Technology (CPUT) from 2006 to 2008 as the HIV/AIDS Counsellor at the Bellville campus Health Clinic, I was faced with the daily task of counselling students before they had an HIV test; giving them the results and providing HIV positive students with ongoing support. My experience of giving an HIV positive result was traumatic each time I had to do it. How much more traumatic must it have been for the person receiving the result? In this presentation I hope to consider the effects of an HIV positive diagnosis as a potentially traumatic event. In particular, I would like to focus on the impacts that this diagnosis could have on the person's sense of identity – taking into consideration the view in Narrative Therapy that a person's sense of self is socially constructed.

I would also like to engage participants in thinking about ways we as practitioners of Narrative Therapy can support people who live with HIV/AIDS. In particular I would like to explore how the narrative practices of outsider-witness work and re-authoring conversations can be used as ways to support individuals and groups of HIV positive people. In my presentation I will make use of case studies from my work at CPUT to reflect on some of my learnings about how to integrate Narrative Therapy into the area of HIV/AIDS counselling. Psychology has sat on the sidelines when it comes to the HIV/AIDS pandemic in South Africa. It is my hope that this presentation will create a space for psychologists and other mental health practitioners to begin to think about ways that they can get involved in supporting people living with HIV/AIDS.

INTRODUCTION

HIV/AIDS is one of the biggest health challenges South Africa has ever faced. In the face of this challenge there are opportunities for practitioners who are trained in the field of Narrative Therapy to make use of their unique knowledges and skills to offer support to people living with HIV/AIDS. The purpose of this paper is firstly to explore the potential traumatic effects of an HIV positive diagnosis this will be done by way of a case study. Secondly the paper seeks to examine possible ways in which the narrative practices of re-authoring conversations and outsider-witness work may be used to support people living with HIV/AIDS. And finally

the paper serves as a way for the author to reflect on her work in the field of HIV/AIDS counselling at the Cape Peninsula University of Technology (CPUT).

CONTEXT / SETTING THE SCENE

It is no secret or surprise that HIV/AIDS affects millions of people in South Africa. The Actuarial Society of South Africa (ASSA) provides us with the following statistics:

- 12% of the total population is infected with the virus;
- approximately 500 000 people (1% of the total population) are infected each year (new infections) and
- each year approximately 400 000 people (0,8% of the total population) die due to AIDS-related illnesses this accounts for 50% of all deaths in South Africa.

(Actuarial Society of South Africa 2003 <http://assaids.eu1.rentasite.co.za/ASSA2003-Model-3165.htm>)

The World Health Organisation have identified adolescents and young adults (15 – 24 years) as a population at higher risk of contracting HIV and have set a global target of reducing new HIV infections in this group by 20% by 2015 (HIV & AIDS and STI National Strategic Plan (NSP) 2007 – 2011). In South Africa the ASSA model seems to suggest that the female HIV positive population is five times larger than that of the males within this age group.

So this is the context that I stepped into at the Health Clinic on the Bellville Campus of the Cape Peninsula University of Technology (CPUT) in July 2006. During those early days I was relatively unaffected by my work and conducted about six pre- and post-test counselling sessions a day. These were after all just clients and I was just doing my job. However, as the months progressed and I started giving more and more women (it is interesting to note that it was mostly female students who came to test for HIV and as such mostly female students to whom I needed to give an HIV positive test result) the news that they were HIV positive I realized that this was hard work and that my news about an HIV positive diagnosis affected them in ways that I could not really understand fully. It is only now more than six months after leaving CPUT that I think I am really able to comprehend how devastating an

HIV positive diagnosis is for a young person and also how much I was affected each time I gave a positive diagnosis.

Most of the students who received an HIV positive diagnosis only came for one or two sessions following the pre- and post-test counselling session and as such it was really difficult to engage with them around how the diagnosis had affected them. For the most part I was seen as the person to come to when they had questions about their health or when a crisis hit. So my work with HIV positive students often felt frustrating as I longed to connect with them at deeper levels beyond the times of crisis. In my work at CPUT I had a deep desire and longing to use the skills and knowledges of Narrative Therapy but this sadly never seemed to happen the way I wanted it to. So this paper is about “what if”. What if there was space to engage with HIV positive people in more creative ways from a Narrative Therapy perspective? What might this look like? How could we position ourselves as counsellors? Which narrative practices or ideas might be useful in our engagement with HIV positive people?

AN HIV POSITIVE DIAGNOSIS AS A POTENTIALLY TRAUMATIC EVENT

In the diagnostic criteria for Posttraumatic Stress Disorder the DSM IV describes a traumatic event as having occurred when both of the following criteria have been met:

- 1. the person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others*
- 2. the person's response involved intense fear, helplessness, or horror.*

(American Psychiatric Association, 2000, p. 467)

In the case of an HIV positive diagnosis it would seem to me that this meets the DSM IV criteria of a traumatic event. A person diagnosed HIV positive is confronted with a perceived threat to his or her physical health as well as threatened death. Furthermore, the person receiving this diagnosis is often confronted with a sense of overwhelming fear and helplessness as they contemplate life with a chronic disease which is highly stigmatised.

But in my experience the trauma of an HIV positive diagnosis is more than just the individual's experience of the event and his or her response to the event. The person receives this diagnosis not in isolation but in a particular context and in relation to others. "Narrative practice is based upon the belief that our sense of self is socially constructed and exists in relationship to other people" (Carey & Russel, 2003, p. 68). It is this notion of the socially constructed self and the ideas that one's sense of self is relational and contextual (Bird, 2002) that got me thinking about richer and "thicker" meanings of the possible traumatic nature of an HIV positive diagnosis. To help us with this I would like to tell you Marcia's story.

Marcia's story

Marcia is a 21 year old final year education student about to embark on her teaching career. I first met Marcia at the clinic in April 2007 when she came for her first HIV test after an unprotected sexual encounter which happened after a party where she had had too much to drink. Marcia is the eldest of two children and she is the first member of her family to attend university. She lives with her younger sister and mother in the Boland town of Worcester – a relatively small tight knit community. Marcia is a bright young woman who had been awarded a bursary from the Department of Education – to get this particular bursary one needed to be achieving top marks during your studies and so it was evident to me that Marcia was a top achiever and that she had ambitions to be a teacher and a role model in her community.

Marcia's first HIV test in April 2007 was negative but she was in the window period and as such she needed to repeat the test in three months in order to get a final result on her HIV status. My second meeting with Marcia was in July. This second testing session normally goes quite quickly if the test result is negative. This was not to be on this day. Marcia's second HIV test indicated that she was HIV positive. The news was a huge shock to her. I remember vividly her reaction to the news. She jumped out of her chair and started screaming and crying hysterically. I had never had a client react in this way to a positive diagnosis before so this was a shock to me. Marcia proceeded to sit on the floor in the corner of my very small office. She pulled her knees into her chest and rocked herself as she continued to cry. I went over to her and held her. A moment that will stay with me forever. In this moment I connected with her pain. This moment of connection gave me a fresh insight

into the devastating nature of HIV/AIDS. At that moment I felt hopelessness and despair. At that moment I grieved with Marcia for the things she had lost in this diagnosis. At some point Marcia calmed down and we were able to continue the counselling session. To this day I will never forget this encounter with Marcia and the affect it has had on me.

The impact of the HIV positive diagnosis on Marcia

Let's examine what Marcia's reaction and what this says about the traumatic nature of an HIV positive diagnosis. For Marcia this positive diagnosis presented a perceived threat to her physical health and wellbeing. She knew that she would be living with HIV for the rest of her life and that once her immune system started deteriorating she would need to be taking medication forever. She was now living with a chronic disease for which there is no cure.

Marcia lives in a small, close knit community where everyone knows everyone else and so the fear of others knowing about her status was a real concern. For Marcia one of her biggest concerns was the stigma associated with HIV/AIDS. HIV/AIDS is highly stigmatised because it is associated with deviant sexual behaviour; it is often tainted with various religious beliefs about immorality; it is perceived as contagious and threatening to the community and it is not well understood by the broader community (Alonzo & Reynolds, 1995). Furthermore, in South Africa the social discourse about HIV/AIDS illness has for the most part constructed HIV/AIDS as a deadly disease and has created the impression of hopelessness and despair. This is in spite the fact that chronic illnesses represent the most prevalent form of illnesses that are treated (Malgas, 2005). This stigma leaves Marcia vulnerable to rejection and isolation and it is this fear that weighed heavy on her as she contemplated life with the virus.

Following the onset of an HIV positive diagnosis HIV/AIDS can at times consume a vast amount of time and energy for the person living with this chronic illness. The person is suddenly faced with more tests that need to be conducted, lifestyle changes that need to be considered, people that need to be told, doctors that need to be consulted, stigma that needs to lived with, and so the list could continue. This seems to suggest that an HIV positive diagnosis could result in what Michael White (2004) refers to as the shrinking of the territory of a person's identity and a sense of losing touch with a "particular and valued sense of who they are – a 'sense of myself'" (p. 47). This shrinking of the territory of identity and losing

touch with a sense of myself occurs due to the fact HIV/AIDS represents more than just another chronic illness for which one needs to take chronic medication. HIV/AIDS has been described as “the ultimate biopsychosocial phenomenon” (Schider as cited in Lindegger & Wood, 1995, p. 8) this perhaps encapsulates the very overwhelming nature of the impacts of living with HIV/AIDS and best describes the fact that HIV/AIDS affects the person living with the illness at so many different levels and it is this multidimensional impact that results in the shrinking of the person’s territory of identity and that feeling of losing touch with that valued sense of who they are (White, 2004). Given this possible explanation of the impact of an HIV positive diagnosis, Marcia’s response to the news of her status is perhaps more understandable. She was now faced with task of making sense of what this news means for her, for her family, for her work, for her health and for all the hopes and dreams she holds for her future. Perhaps the biggest challenge for Marcia is how to live with the virus and not to be overwhelmed by the multidimensional nature of the challenges that living with HIV/AIDS presents.

RE-AUTHORING CONVERSATIONS

Re-authoring conversations seek to assist with the “identification and co-creation of alternative story-lines of identity” (Carey & Russell, 2003, p. 60). It is during such conversations that the therapist seeks to help people bring to light some of the potentially significant experiences and events that may have been neglected and are “out of phase” with the person’s dominant storyline (White, 2007, p. 61). It is the belief that “no one story can possibly encapsulate the totality of a person’s experience” (Carey & Russell, 2003, p. 60) that guides us as we embark on such conversations. We believe that no matter what a person has experienced and no matter how dark the problem story-line is that there is always more to the person than the problem or the trauma. So in the case of HIV and AIDS we need to hold on to this belief and know that there is more to an HIV positive person than the virus. It is our role to open up possibilities within our conversations with HIV positive clients which point to life and living with HIV in a different way.

When people experience a traumatic event such as an HIV positive diagnosis, they “experience their lives to be single storied, perceiving themselves trapped in a single

dimension of living, one that predominantly features a sense of hopelessness, futility, emptiness, shame, despair and depression” (White, 2004, p. 60). My guess is that if Marcia were here today this quote would resonate with her experience of discovering that she is HIV positive. Michael White’s words sum up for me what I experienced as I witnessed Marcia’s reaction to her diagnosis – I experienced that sense of utter hopelessness and despair as Marcia sat on the floor of my office and wept. I remember driving home at the end of the day and crying my own tears of despair and hopelessness and thinking about how unfair this situation felt. And yet there is more to Marcia’s life than the fact that she is HIV positive. I remember a comment made by another one of my clients which seems to sum up this notion of the multistoried nature of an HIV positive person’s life “I’ve got the virus but I’m not the virus” (Marchelle, as cited in Malgas, 2006).

Michael White suggests that when therapists are faced with clients who have experienced trauma that they adopt a stance of “double listening” (White, 2004, p. 28). This double listening asks us to listen for the pain of the trauma but also to listen for “expressions of what people have continued to accord value to in their lives” (White, 2004, p. 28). These “double-storied conversations” provide the person the space to reflect on the traumatic event and its consequences but it is the therapist who listens for and highlights those expressions which point to the things that people accord value to. In the case of Marcia I was amazed at how very concerned she was about her family and the impact that her HIV positive status would have on her family. Had I had the opportunity to have a re-authoring conversation with her I guess this is one of the things I would point out to her – i.e. the value that she places on people and relationships. I would ask her what this says about her – the values that she has; her hopes and dreams and her principles of living. In listening doubly we listen for the pain and trauma of the effects of HIV/AIDS but we also listen for those “intentional states of identity” (Carey & Russell, 2003, p. 65). These intentional states of identity include: (1) intentions or purposes that shaped a particular action; (2) the values and beliefs that supported the action; (3) the hopes and dreams associated with these values and (4) the principles of living or commitments represented by these hopes and dreams (Carey & Russell, 2003, p. 65). By listening for clues that point to these intentional states of identity we will be shifting the focus of the conversation to the person rather than focusing solely on the

problem. Furthermore during such a conversation we will hopefully be strengthening the person's sense of self.

In working with people who have received an HIV positive diagnosis it seems to me that one of our aims should be to "restore that valued sense of who they are" and in so doing to reinvigorate their "sense of myself" (White, 2004, p. 47). It is in the double listening that the therapist will gather clues about what the person gives value to. This listening doubly does not mean that we try to minimize the effects of the pain of the trauma. Rather we should give careful attention to these expressions of pain as "the felt intensity of this pain is a testimony to the intensity to which what they held dear or held precious what was violated or dishonoured" in their experience of the trauma (White, 2004, p. 61). In Marcia's case she felt very disappointed that she had let her mother and her family down by being HIV positive; the sense of disappointment left her feeling extremely sad. The question that could be asked is what this says about what Marcia holds dear. This listening doubly may be easier said than done. It calls on the therapist to rise above the overwhelming nature of the trauma and to remain curious for words, comments, questions or actions that point to the things that the person gives value to. One of the things I believe that can assist a therapist to not get sucked into the despair and hopelessness of HIV/AIDS is to be equipped and armed with up to date knowledge of HIV/AIDS. Such knowledge could include the following:

- knowledge about the disease progression of HIV/AIDS and what happens at the various stages of the disease;
- knowledge about healthier lifestyle options that can encourage a healthier immune system;
- knowledge about treatment options – i.e. when does a person qualify to start antiretrovirals and how does this process work; and
- knowledge about support groups or people that might be able to support the person living with HIV/AIDS.

By being equipped with up to date knowledge the therapist will be able to empower the client with such knowledge and this will hopefully provide the client with some much needed tools to fight the seemingly overwhelming, multidimensional impacts of HIV/AIDS. Another benefit of being equipped with such knowledge is that the therapist will be able to adopt a more hopeful

stance in relation to HIV and AIDS because this knowledge will counter the despair and hopelessness.

“Problems are often extremely successful at separating and isolating people from others, and so a key aspect of re-authoring work is to open spaces of connection and reconnection” (Carey & Russell, 2003, p. 68). HIV and AIDS are no ordinary problems. By their very nature they separate people living with the illness from others. The fact that HIV/AIDS is still highly stigmatised and that the messages about its “deadly” nature still abound contribute to the sense of isolation that people living with HIV/AIDS experience. In my work at CPUT I was often the only person who knew about a student’s HIV status. This was true in Marcia’s case. The fear of stigma and possible rejection prevented many students from disclosing their status to their family and friends. Various theories suggest that social support could play a role in helping people cope with the stress of living with HIV/AIDS and that there is a relationship between the social support received by an HIV positive individual and his or her immune functioning (Malgas, 2005). This finding in itself points to a need to open up those spaces of connection. So part of a re-authoring conversation in this context would involve the gentle exploration of relationships that the HIV positive person has and which people might the person be willing to risk disclosing his or her status to.

OUTSIDER-WITNESS GROUPS

As part of the process of supporting students who were HIV positive we ran a support group on campus which was facilitated by the Health Promoter – an ex-CPUT student who was HIV positive. The group was a safe space for students to talk about living with HIV and to provide emotional support and encouragement. My role in running this group was that I provided support and supervision to the group facilitator. My experience of having attended the group was that people felt safe and comfortable but that conversations tended to be superficial and often did not really touch on the real issues that faced a person living with HIV. Granted the students needed some diversion and distraction from constantly thinking about being HIV positive. I was left wondering about how an outsider-witness group might work in this context. What might the effects be of interviewing one person and having the other group members be outsider witnesses? How could intentional listening for the four categories of outsider-witness

response i.e. identifying the expression(s) that caught your attention; describing the image that this expression evoked; what is it about the expression that resonated with you (embodying responses) and acknowledging how you have been moved on account of witnessing these expressions (White, 2002) impact the person being interviewed as well as the outsider-witnesses?

“Outsider-witness practices challenge the isolating and individualising effects of problems” (Carey & Russell, 2003, p. 4). Whilst the traditional support group model does reduce isolation amongst members and does create a sense of belonging and safety it seems that perhaps more can be done to alleviate the individualising effects of the many challenges faced by people living with HIV and AIDS. For example what if the therapist chose to interview one of the group members on a particular challenge like stigma and its effects on the person’s life. I can imagine that using an outsider-witness group to discuss an issue like stigma will have benefits for both the interviewee, the witnesses and the interviewer. The interviewee will have the opportunity to tell his or her story to an audience who will be appreciative and respectful. The witnesses will be able to listen and reflect on their own experiences of stigma. The interviewer will be able to gain an understanding of the stigma experienced by people living with HIV/AIDS. Outsider-witness work can be seen as “a chance for the linking of lives around shared themes and values” (Carey & Russell, 2003, p. 8) and it is in this linking that “people experience their lives as joined around shared and precious themes” (White, 2007, p. 166). Other topics which might be explored in this way could include issues around disclosure, sexuality, spirituality, etc.

In South Africa where many people cannot afford the services of a therapist for individual counselling it seems that there is a need to make any sort of group intervention more meaningful for the participants of such groups. Perhaps the use of outsider-witness work within support groups for people living with HIV/AIDS could be one way of doing so. By creating spaces where this kind of telling and retelling takes place people will be encouraged to engage in positively witnessing each other’s lives and in so doing a greater sense of solidarity and collective care could be developed (Carey & Russell, 2003, p.15). I am not in any way suggesting that we should do away with traditional support groups for people living with HIV/AIDS. These support groups have a valuable place in the lives of many people living

with HIV/AIDS. Rather I am seeing outsider-witness work as a practice which can be incorporated into the current support group model.

Questions will arise about how this outsider-witness work could be implemented on a practical level. I would suggest that a therapist who has been trained to do outsider-witness work could be invited to a support group and do an outsider-witness group as one of the group meetings. The therapist who does this work need not necessarily be the same person who normally facilitates the group. The group will need to be briefed about how the process works and someone will need to be chosen as the person to be interviewed. The process can then proceed along the map for outsider-witness work (see White 2007, pp. 165 – 218).

Outsider-witness work often seems like such a mission to implement in practice. I know that I often shy away from this kind of work. But the more I think about applying Narrative Therapy in the context of supporting people who are living with HIV/AIDS the more I am struck by how outsider-witness work can benefit the wider community i.e. those living with HIV/AIDS and those people who are trying to understand the effects of this illness on peoples' lives and identities. And so the words of Carey and Russell present a challenge to me and to all of us as practitioners of Narrative Therapy – “Outsider witnessing is a key aspect of narrative practice. It is not simply an add on.” (Carey & Russell, 2003, p. 15).

CONCLUSION

This paper has provided a glimpse into the reality facing many people in South Africa who are living with HIV/AIDS and has given us as practitioners of Narrative Therapy with some ideas of how we can begin to use some of our unique knowledges and skills in supporting people who are living with HIV/AIDS. Marcia's story is not unique. There are many more such stories out there and many, many more “Marcias” who need our help. It is my hope that by reading this paper you have been challenged in some way to view HIV/AIDS as an opportunity to do something different rather than just sitting back and watching this huge catastrophe unfold and doing nothing. As practitioners of Narrative Therapy we are called upon to challenge issues related to social injustice and inequality. To me it seems that by not doing anything in the face of an issue which affects so many of our fellow human beings is a huge injustice. So I challenge myself and you to not be overwhelmed by the enormity of the

challenge that HIV/AIDS presents us but to rise up and find ways to creatively support people living with HIV/AIDS.

To end I'd like to leave you with these challenging words from well-known singer and AIDS activist Bono:

History will judge us on how we respond to the AIDS emergency in Africa. Whether we stood around with watering cans and watched while a continent burst into flames or not.

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