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WORKING WITH AMBIVALENCE: FINDING A POSITIVE IDENTITY FOR HIV/AIDS IN SOUTH AFRICA

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Biographical Notes

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Soskolne, T. (2003). Moving Beyond the Margins: A Narrative Analysis of the Life Stories of Women Living with HIV/AIDS in Khayelitsha. *CSSR Working Paper, No 33*. Cape Town: CSSR, University of Cape Town.

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Stein, J. (2003). Editorial: Tackling Stigma Through Treatment and Advocacy. *AIDS Bulletin* 12(1).
Stein, J. (2003). What's News: HIV/AIDS Advocacy in the South African Media. *African Journal of AIDS Research 2003* 2(1), 1-9.
Stein, J. (2003). HIV/AIDS Stigma: The Latest Dirty Secret. *CSSR Working Paper No. 46.* Cape Town: AIDS and Society Research Unit, Centre for Social Science Research, University of Cape Town.

Kerry Gibson is a senior lecturer in the Department of Psychology also at the University of Cape Town. She is collaborating on the HIV/Stigma research project. Her primary area of publication is in the application of psychoanalytic ideas to community problems. Her most recent publications include the following:
Gibson, K. & Swartz, L (2000)**.** Politics and Emotion: Working With Disadvantaged Children in South Africa**.** *Psychodynamic Counselling* 6, 133-153.
Gibson, K. & Swartz, L. (2001). Psychology, Social Transition and Organizational Life in South Africa: 'I can't change the past but I can try.' Psychoanalytic Studies *3(3/4), 393-404.*
Gibson, K., Swartz, L. & Sandenbergh, R. (2002). *Counselling and Coping*. Cape Town: Oxford University Press.
Swartz, L., Gibson, K. & Gelman, T. (eds). (2002). *Reflective Mental Health Practice: Using Psychoanalytic Ideas in the Community.* Cape Town: Human Sciences Research Council.

Working with Ambivalence: Finding a Positive Identity for HIV/AIDS in South Africa

Abstract

Psychoanalytic theory draws attention to the way in which a positive identity can be asserted as a defence against underlying anxieties. Focusing specifically on the South African context, this paper highlights the way in which people attempt to forge a positive self-concept in the face of a stigmatised and self threatening HIV identity. In-depth interviews were conducted with twelve women living with HIV in a black South African township. Discursive and psychoanalytic understandings were used to explore the emotional experience of HIV/AIDS and its impact on both the participants of the study and ourselves as researchers. We elucidate the process by which our interviewees vacillated between conflicting notions of health and sickness; empowerment and disempowerment; strength and weakness; purity and contagion; and death and continuity. We argue that a more resilient self can be formed through recognition of both the positive and negative implications of an HIV diagnosis. We also maintain that it is necessary to move beyond the individualising tendencies of mainstream psychology to recognise the social context and discursive practices which exacerbate stigma and influence the experience of those living with HIV/AIDS.

Introduction

This paper is concerned with the effects of stigma on the identity of the stigmatised person and follows recent research in arguing for active 'identity work' as central to the construction of the self (Crawford, 1994; Goffman, 1968; Lee & Craft, 2002; Park, 2002; Tewksbury & Mcgaughey; 1997). In the field of HIV/AIDS, stigma has been highlighted as perhaps the main barrier to dealing with the epidemic on the levels of prevention, care and support (Goldin, 1994; Mann, 1987, Parker & Aggleton, 2002,). The potential of the stigmatised person to actively construct a positive identity is seen as a strength on which public health intervention programmes can be developed. This approach is also widely used in AIDS activist strategies that have aimed to transform the public perception of HIV/AIDS.

As this paper will suggest, however, this emphasis on 'positive identity' may have unintended and problematic consequences in silencing some of the more painful emotional aspects of HIV/AIDS. Firstly, the depiction of an HIV/AIDS identity as primarily 'positive' may prematurely foreclose an acknowledgement of the very real losses inherent in a diagnosis of HIV. Further, the identity work involved in constructing an HIV positive self may overshadow other and equally important aspects of the person's identity both connected to and outside of the disease itself. The argument of this paper is that an acknowledgement of the positive and negative consequences of an HIV positive diagnosis for identity may help people with HIV/AIDS to ultimately forge a more resilient and integrated sense of self.

This paper draws from a series of interviews conducted with a group of South African women who have received a diagnosis of HIV/AIDS. These women live in Khayelitsha, a sprawling black urban township on the outskirts of Cape Town. Although anti-retrovirals are still not provided to HIV positive patients at South African public hospitals generally, this group of women has access to the Médecins Sans Frontières antiretroviral programme in Khayelitsha. They have also been part of an intervention programme called the Memory Box Project, first as participants and then as facilitators who assist with the work of the project. The Memory Box Project uses a narrative art therapy approach to help participants to make meaning of the experience of living with HIV/AIDS. Twelve in-depth interviews were conducted in order to explore how an HIV positive diagnosis impacted on the women's relationships with others and how they negotiated a stigmatised identity. This research is part of a broader research and income generation project in which this group of women are participating, not only as research subjects but also as fieldworkers, interviewing members of the broader community about HIV/AIDS and stigma. In preparing the women as researchers who would intentionally be attempting to elicit stigmatising attitudes, we needed to address their own experience of stigma.

Making Sense of Contradiction in Illness Accounts

Our questions to the women elicited descriptions of their lives and interactions with others insofar as these touched on their identities as people living with HIV. Their accounts often included details of how they experienced their current relationships and whether and how they felt these had changed since their diagnosis. They spoke about their decisions regarding disclosing to, or concealing their status from, others. They also described the impact of

HIV/AIDS on how they felt about themselves as mothers, lovers, daughters and friends. Initially, we made sense of the interview material by establishing some of the narrative devices used by the women to construct their life-stories. We were struck by the tendency for them to give unexpectedly positive accounts of their lives in the period since adjusting to their diagnosis. The accounts we elicited from the women were essentially stories of transformation. The temporal structure was such that painful or difficult experiences around their HIV status were situated in the past, when they were first diagnosed. Joining a support group or entering into the Memory Box Project was posited as the moment of narrative transformation where the women spoke about their lives making a turn for the better. In the present the women emphasised having accepted their HIV status, having constructed a strong, positive identity and experiencing some degree of improvement in their lives following their diagnosis.

However, during the course of the interviews it became clear that the accounts we were eliciting were not free from ambivalence or contradiction. There was a sense that the women were using language to actively resist questions that were threatening to their construction of self. As we probed deeper, we became aware of feelings of vulnerability and uncertainty beneath the image of positivity and self-assurance that the women presented. As we engaged with this material we were forced also to interrogate our own reluctance to move beyond the optimistic views we were being given and to challenge our complicity in facilitating this reassuring portrayal of what it means to live with HIV/AIDS. On the other hand, we were cautious of pathologising the women's discourse unnecessarily and of projecting our own concerns onto the interview material.

In making sense of the material, we were drawn to theoretical ideas that could accommodate the ambivalence we detected in the women's accounts of themselves and in our own responses to these. Hollway and Jefferson (2000) argue for the use of a theory of the psychosocial subject, which draws together strands of both psychoanalytic and discursive psychology to offer a means of delving beneath the surface of interview material.

Discursive approaches such as social constructionism suggest an alternative understanding of the self, where language is seen as the most potent tool for organising experience and ultimately for constituting reality (Bruner, 1986; Crossley, 2000). Discursive psychologists reject the notion of a distinct self, arguing that self is 'constructed when people refer to themselves, speak about each others' selves, and respect each others' right to express themselves' (O'Connor & Halam, 2000: 240). In this view, the way we experience being in the world is largely socially constructed and is mediated through language, and self is seen to reside within the social, historical and metaphorical realms where

shared meanings create 'what it is to be a self' (*ibid.*). Shared discourses seep into our constructions of self, so that, for example, the experience of living with HIV/AIDS cannot be separated out from the social construction of HIV/AIDS as a stigmatised disease (Peterson & Benishek, 2001; Sontag, 1989). A discursive approach would argue that people have an identity investment in drawing on certain discourses, and in incorporating these into their repertoire, particularly discourses that bolster or affirm their self-identity. The discursive subject is situated within a social matrix where there is a need to guard against discourses that threaten one's construction of self and to hold on to discourses that protect and maintain self-identity.

Psychoanalysis complements discursive psychology by calling attention to the meaning carried in the powerful emotions that lie beyond words (Frosh, 2002). In itself, a discursive approach is not able to capture the intensity of emotions evoked when delving into the terrain of HIV/AIDS. Psychoanalysis argues that threats to the self generate anxiety, and that there is an investment at an unconscious level in protecting or inoculating the self against these threats. In Kleinian theory there is a focus on defensive positions that are initiated in infancy and come in and out of prominence throughout the individual's lifetime, with their use intensifying in times of duress (H. Segal, 1981; J. Segal, 1992). In the 'paranoid-schizoid' position, when faced with internal or external threats to the self, there is a strong need to protect against anxiety through splitting: seeking to hold onto and internalise 'the good', and to split off or locate the bad outside of the self. Arguably this is a tenuous position to maintain. There is always the threat of contamination by the bad since splitting does not destroy or ameliorate the bad but rather allows it to lurk ominously in the dark corridors of the psyche. The constant vigilance needed to keep up this defence can also become a source of stress in itself. In the process of splitting, the self becomes divided too, and what becomes defended against are aspects of the self that are felt to be terrifying, destructive or unmanageable (Klein, 1921-1945/1975a). Klein suggests that a more constructive way of coping with threats to the self is achieved in the so-called 'depressive' position. In this position 'the good' and 'the bad' can be held together in the mind, contained in the same object, and it can be acknowledged that 'the bad' need not contaminate or destroy that which is felt to be good. It becomes possible to hold ambivalence and this forms the basis for a less defended, more integrated self (Klein, 1932/1975b; H. Segal, 1981).

As researchers, it is predominantly through language that we are able to access a sense of our participant's inner world. In this regard, two difficulties present themselves. Firstly, we were severely hampered by our own inability to speak Xhosa, the first language of our interviewees. Secondly, the idea of the psychosocial subject should warn against reading the verbal accounts we elicit

as transparent or self-evident. Through investing in particular discourses that affirm the self, the subject is able to defend against anxiety, to protect vulnerable aspects of self and to disown those aspects that feel unbearable or unmanageable. This means that interviews which probe for accounts that reveal painful issues or areas of vulnerability may generate anxiety and have the unintended consequence of activating our interviewees' psychic and discursive defences (Hollway & Jefferson, 2000). This is not to say that we as researchers cannot gain access to what we are looking for, but rather that it is necessary to read into the defensive discourses that are mobilised by our interviewees in order to gain a sense of the anxieties that underlie them. Here, an understanding of the fluidity of the psyche in Klein's conceptualisation, in which the separation between conscious, preconscious and unconscious mental life is not really made distinct, would be useful (Mitchell, 1986). Klein elucidates a dynamic interplay between reality and phantasy where that which is defended against threatens intermittently to seep into conscious awareness. Following from this we can look for, and expect, contradiction and inconsistency in our interviewees' accounts as they move back and forth between acknowledging vulnerability, and mobilising defences against anxiety when emotions become too threatening or painful. In order to understand these emotional complexities more fully, our own counter-transference becomes a useful mechanism for tracing subtle emotional shifts through our response to them (Hollway & Jefferson, 2000).

While the two different approaches of discursive psychology and psychoanalysis offer the potential to highlight social aspects of the illness experience, there is a danger of losing sight of the actual social context in which these particular women are situated, especially as the unique socio-economic deprivations of township life in Khayelitsha throws aspects of the South African context into relief. Theories of discursive psychology vary in the extent to which they read 'reality' as socially constituted, but in this case the very real consequences of social inequality need to be highlighted (Foster, 1999).

The illness experience of the women we interviewed is mediated and intensified by the day-to-day struggle for survival. HIV/AIDS is a very tangible threat in their community where poverty is endemic and sickness an unsustainable financial and emotional burden. Khayelitsha is the township with the highest prevalence of both poverty and HIV in the Western Cape (Shabodien, 2003). It has been estimated that in South Africa, HIV/AIDS accounted for 40% of deaths in adults aged 15-49 in the year 2000 (Dorrington, Bourne, Bradshaw, Laubscher & Timaeus, 2001). In this context, a diagnosis of HIV still resonates as a death sentence rather than a chronic manageable disease, although this is slowly changing with the gradual introduction of anti-retrovirals. Here, as elsewhere, discrimination intensifies when people are sick (Stein, 2003a).

The illness experience is exacerbated for women living in a township context. Women living in conditions of poverty, even if they are ill themselves, are often expected to carry the burden of care for others, and may be the chief providers for a whole family (Lawson, 1999; Strebel, 1995). They are generally targeted by campaigns to take responsibility for practising safe sex and for using condoms, even though they live in a highly patriarchal, sexist society and often do not have the power to negotiate their own sexuality and may be coerced into unsafe and unwanted sexual acts (Strebel, 1995). One of the most blatant ways in which women continue to be oppressed is through violence, force and subjugation (Gilbert, 1996; Irigaray, 1993; Jeffreys, 1993). As 'underprivileged' black women, the group we interviewed are particularly vulnerable to repressive sexist practices and in some cases the consequences of disclosing their HIV status could be devastating. In South Africa, violence against women is widespread and normalised (Straker *et al*, 1996) and poor black women living on the 'margins of society' have little social and political voice (Crewe, 1997). In disclosing their HIV status, they risk being labelled as bad, dirty or damaged (Lawless, Kippax & Crawford, 1996; Nack, 2000), experiencing violent retribution as a measure of control, and potentially losing all social support and being left destitute (Fleishman, 1995).

Within this context the physical, social, discursive and metaphorical significance of an HIV diagnosis is heightened. The women's construction of an HIV identity as a 'positive' one cannot be separated out from what it means to be HIV infected in their social world; which is both the local socio-political and economic context of Khayelitsha, and the broader social arena, where shared discourses and practices impact on the experience of HIV/AIDS.

A Positive HIV/AIDS Identity

Our first and strongest sense of the women we interviewed was that they had somehow come to terms with their diagnosis. From our initial readings of the interview material we gained the impression that many of the women, in spite of their difficulties, were surprisingly accepting of their HIV status:

> 'I think at first it changed my life totally, but now just because I'm used to it, so I see no problem… It's like as I said like before, I was told I am HIV positive, my life changed totally, but now I am free, I've got no problem.'

Some seemed not only reconciled to their diagnosis, but came across as actively positive about their new identity:

> 'No Jo, I am not scared. I am not scared anymore because I am
> proud because I know my status. I know that I am HIV positive so
> things I was doing when I didn't know, I am not doing them now. I
> am taking care of myself. I know where to go. I know what to do.
> So, I'm proud of that.'

While we had expected to find the participants struggling under a burden of stigmatisation, which we had been led to believe was rife in their community, many of the women talked about how they were unafraid of disclosing to others and would be immune to negative reactions. The same woman went on to say:

> 'So I didn't before, I didn't want to hear anything about HIV
> because I didn't accept it yet. But now as you see me wearing this
> t-shirt (she points to her t-shirt with the slogan 'HIV positive') I
> can say umm I did accept it, I accepted it Jo. In such a way that I
> can even talk to (.) I can even disclose to the community that I am
> HIV positive because I am from being sick – but now I am well. I
> am like umm (.) (Interviewer: strong?). Yes, I am strong now, I am
> strong!'

> 'I am so free with my status, I can disclose everywhere and I don't
> mind what is my stigma or which one is stigmatise me. I don't
> mind. I don't care. And I didn't, everyone at police station they
> shout me about my status, I don't care… I don't mind because
> many people have the HIV positive. It's not mine all of HIV is not
> mine only.'

A closer reading of the interview material, however, helped us to understand that our initial impressions were perhaps only part of the women's experience. While on one level there was a real sense that they had come to terms with aspects of their status and would actively resist stigmatisation, there were still areas that they struggled with. These experiences seemed harder for the women to articulate and because of their distressing content, harder perhaps for us to foreground in our own understanding. As we immersed ourselves in the material we became increasingly aware of painful aspects of living with HIV/AIDS.

Strategies for Constructing a "Positive" Identity

Our analysis of the interview material suggests that most of the women at various times disavowed the difficulties inherent in living with HIV/AIDS. Their way of speaking about their status seemed to suggest that they had come to terms with living with the infection and even that it had brought about

positive changes in their lives and in their sense of selves. They drew on discourses of activism and empowerment, in terms of which HIV became the basis for an uplifted identity. In all the interviews, however, there were moments where vulnerability seeped into the women's accounts of their experience. At these times they seemed better able to articulate the areas of their lives that had become more complicated or distressing since they had been diagnosed positive. There seemed to be movement between their representation of themselves as strong and capable and an acknowledgement of themselves as more vulnerable. In between these two representations, it was possible to track something of their attempts to protect themselves against feelings of fear and uncertainty.

Health and Sickness

The women we spoke to seemed intent on emphasising their good health, regardless of the extent to which HIV had, in some cases, already compromised their immunity or manifested in illness. They described themselves as 'strong, positive and healthy', actively resisting the idea that they could be perceived as ill:

> '… most of the people used to say, 'Phew, [that] time you were sick, we thought you had AIDS! … but now they can see that I'm gaining weight, I look just like them. So even if I can tell them [that I have HIV], they won't believe what I'm saying.'

For many of the women, the fact that others in their community saw them as healthy was a source of pride and affirmation. We were regaled with numerous tales about how their disclosure had led to ongoing disbelief among family, friends and community members who would not accept that they were HIV positive because HIV was associated with serious sickness, weight-loss and other bodily manifestations. This collective denial performed the function of affirming the identity the group had constructed for themselves, as people who were HIV positive, but who were healthy and who were not unduly affected by the disease. The women's talk paradoxically suggested a deep pride in their HIV status and yet they also took great pleasure in being able to pass as 'normal' or 'healthy'. In Khayelitsha, losing weight is associated with poverty as well as illness and the women revelled in being seen as 'fat' as this is a signifier not only of radiant health but also of wealth and beauty:

> 'She said her boyfriend the thing [that] make him doesn't believe because …she was losing weight before she started getting sick. But now when she go back to Durban to him she's fat, she's beautiful.'

The fact that so many of the women were proudly declaring their good health stimulated an uncomfortable response in us as researchers. It was reassuring to believe that the women were exceptionally healthy and that, as they were suggesting, they could live free from the harsher physical aspects of the disease for many years. However, this sat uncomfortably with the recognition that some of these women looked quite unwell.

We found ourselves wondering about the real state of their health and whether in fact they might be as well as they claimed. We considered that maybe we were projecting our own anxieties about the illness and that the women really were amazingly well and could live for ages untouched by the disease. Increasingly, however, we discovered that health issues were affecting the group and were causing more alarm than the women were letting on to. We learned, both through monitoring the group, and through interviews with the Memory Box facilitators, that it is not unusual in a normal week for one or more the women to be suffering from some minor but distressing complaint such as stomach aches, diarrhoea, flu and nagging tiredness. While these are not major health problems they point to the uneasy fluctuations inherent in managing HIV on a day-to-day basis. There were also, in some cases, indications of more serious illness. One of the women in the group, Nandi[1] has eye cancer and she often wears sunglasses to hide her eye, which is now almost completely closed. Another woman stopped her anti-retroviral treatment and has since experienced unpleasant bodily manifestations including marks on her skin and hair loss. She wears a hat to cover this. Although most of us would choose to hide physical imperfections, it seems likely that these women are also hiding what these symptoms represent to others.

A psychologist who facilitated the running of the project recounted how the death of an HIV positive woman well known to the group had thrown the group into disarray because the woman concerned had also been on anti-retrovirals:

> '… and maybe some denial about the fact that they might die. Like X, she had access to ARVS and she died – and that's caused huge waves of panic and hysteria in the group. Like they thought: Well, if she could die with access to ARVS, well then, they think, that could be us.'

A careful guarding of the boundary between HIV and AIDS enabled the women to hold on to a sense that they were physically well and that their health could be maintained for a long period of time. This allowed the women to distance

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[1] The participants' real names have not been used in this article.

themselves from the anxiety that acknowledging the possibility of sickness generated. Separating out HIV and AIDS means that one's identity need not be tied with AIDS as a signifier of serious illness and ultimately death. Instead, some of the women drew strongly on the popular representation of HIV as a period of relative freedom from physical symptoms to suggest that in fact their experience of the disease was not complicated by the struggle against illness. This was problematic however as it denied the reality of the women's experience whereby for some, their health had already been compromised by the disease, and others held onto wellness through taking anti-retrovirals. While most of the women resisted talking about a potential outcome of illness or death, they seemed to vacillate between the hope that they were somehow protected from AIDS and doubts about whether this were so.

Uncertainty regarding the progression of HIV to AIDS is partly reflective of increasing gains in medical knowledge. Likewise, the wider discourses around HIV/AIDS in South Africa are unclear as to its status as a terminal, or chronic but manageable, disease. Public health campaigns suggest that people with HIV are able to live long lives and maintain good health indefinitely if they monitor and manage their own health correctly. In South Africa, the activist campaign for access to anti-retrovirals has also helped to foster a belief that with appropriate medication, HIV infection does not necessarily lead to death. These hopeful kinds of ideas contrast with other powerful discourses which continue to represent HIV/AIDS as a killer disease. In South Africa, both poverty and limited access to treatment reduce the possibility of self-care while at the same time making illness and death more visible. In this context, a disclosure of HIV positivity, especially together with an outward appearance of poor health, continues to stand as a signifier of imminent death.

Empowerment and Disempowerment

The women emphasised that their HIV status had brought them a constant income through disability grants and employment, as well as considerable opportunities for skills-development and learning. Arguably, with the exception of the disability grant, these advantages are a result of their involvement in the Memory Box Project rather than a function of the HIV diagnosis itself. Nonetheless, in a context where the broad unemployment rate is 46.3% (Nattrass, 2002) being employed registers as a significant advantage, and indeed appeared to almost override the obvious disadvantages of being HIV positive:

> 'People who are not HIV positive they have no jobs, but me I'm getting disability and on top of that I'm employed, you see. This HIV gave me a lot of jobs. No, really there are people who are not HIV positive who are just sitting at home doing nothing.'

This expression of the positive benefits of HIV is particularly salient given that the women have conceded so little regarding its costs in terms of illness. These concrete advantages may offer a way of helping to deny the more negative consequences of having HIV/AIDS. Within the group, however, there remained ongoing concerns about the financial stability the Memory Box Project offered to the women. Essentially these concerns were realistic, given that loss of income would certainly affect the women's access to health treatment and self care. Moreover, access to income had in fact given them special status within their own families and in the broader community. Thus the women's concerns about financial insecurity may also have gained further emotional significance insofar as loss of income could mean losing a vital aspect of their positive new identity.

Education, like employment, was seen as an empowering force. The women seemed to take considerable pride in their growing knowledge about HIV/AIDS and in their position as educators within the community. Many of them used their unique access to information about the disease to position themselves as experts in relation to others. This adoption of an expert role afforded the women a sense of personal control, which may have counteracted feelings of vulnerability and helplessness. Yet while the women embraced their expert role as HIV/AIDS counsellors and educators, some of them preferred not to disclose the fact that they were HIV positive themselves in case this undermined their newly found status as 'experts':

> 'But now to my family, I did educate them. Because I told them I'm a counsellor who came to clinics. … they are very happy about me because I am working, I am helping people. But they didn't know I am also one of those people living with this virus.'

Self and "Other"

In order to reinforce and assert the advantages of their own position, the women utilised a representation of a less capable and less worthy 'other'. While much has been written about how people with AIDS may carry the projections of society's anxieties about illness and contagion (Sontag, 1989; Joffe, 1999), less has been said about the 'othering' strategies of people who themselves have HIV/AIDS. Interestingly enough, the women we interviewed did not speak about HIV negative people as the obvious 'other'. Instead they situated themselves in opposition to people who they regarded as ignorant of their status. They distinguished between people like themselves, who had been tested for AIDS and had taken responsibility for their illness, and those who were possibly

also HIV positive, but did not yet know this. This conceptualisation afforded a sense of difference, not in being HIV positive but rather, in *knowing* it. Those who ostracised them need not be taken seriously because they were likely to be HIV infected themselves, or if not, soon could be:

> 'I was not worried because I said to myself (.) I said to myself that HIV is everywhere and everybody is going to have HIV – so I told that to myself. So that I was not worried. Even if somebody is not HIV, he or she is going to get it. That's what I thought.'

While it may be true that HIV/AIDS is widespread through the community, this participant appeared to find some comfort in the idea that she is not alone in her suffering. As one of many with HIV/AIDS she also need not be singled out for particular stigmatisation. This representation actively resists the marginalisation of HIV positive people as a group and works against possible stigmatisation.

The women were also very quick to separate out people with HIV like themselves – who had chosen to disclose and seek appropriate care and support and were seen to be healthy, empowered, productive and educated – from others who were ill, ignorant, isolated and home-bound:

> 'The people are sitting at home, they are getting sick, but they don't tell… they don't tell even anyone.'

Through locating illness, and all that was undesirable to the self, in unhealthy or ignorant 'others' the women were able to maintain a sense of personal wellbeing (Crawford, 1994). 'Othering' in this way distanced the women from stigmatising social discourses in which an HIV/AIDS identity is overridden by illness concerns and where HIV positive people are positioned as being incapable of contributing to society. While this 'othering' is strategically useful, it may make it harder to acknowledge more painful aspects of their own HIV identity and may lead to feelings of acute shame or humiliation in times of sickness or when they are in fact reliant on others.

Strength and Weakness

The interviewees emphasised self-care as critical to good health. This included knowing the prerequisites for health as an HIV positive person such as eating well, avoiding stress, taking your medication regularly, and being able to implement these in your daily life. In their talk, the women associated health with both physical and emotional strength and good health was seen as proof of personal resilience.

In the way Lupton (1999) and others suggest, the women take on a sense of personal responsibility for their health. This self-surveillance inculcates a sense of hope that they have control in monitoring and regulating their wellbeing. This ameliorates the sense of hopelessness and helplessness that is usually associated with chronic or fatal illness. Our interviewees commonly drew on the idea that strength of character, and an ability to hold onto positivity, would mitigate against vulnerability to illness:

> 'My mother was crying, also my brother was crying a lot, but I told them that I am not going to die. They must be strong because I am not going to die…they love me, they say, "You must be strong Sisi [Sister], because you mustn't think anything…you must think positively, all of that" ' (Interview 4).

While this comment suggests warmth and mutual support in this woman's family, there is clearly also a reluctance to think about vulnerability and death. These may be very painful issues for both the women and her family members to acknowledge. This monitoring of emotional well-being may offer some feeling of being able to control the disease, at least when the women are well. Conversely, however, an emphasis on personal responsibility for wellbeing may mean that illness is read as a failure for which they are somehow accountable. Illness may then make them feel as if something lacking in their core self has contributed to the onset of illness – that their emotional fragility has allowed the illness to manifest. This conflation of mental with physical wellbeing showed itself in areas of the interviews where the women held staunchly onto notions of themselves as strong and coping, as if this could protect them from feelings of vulnerability and uncertainty.

The tension between strength and vulnerability emerged particularly poignantly in our interview with Nandi, the woman who has eye cancer. She spoke about how starting a relationship with a man is more difficult as an HIV positive person because you are more vulnerable.

However, very soon after conceding vulnerability she resisted our questions following this train of thought. Our interviewer pointed out that it might be more painful as an HIV positive person to be hurt by a man. This instantly provoked a more defended response: 'No, uh just now, I am too strong now, I am not afraid for anything.' It is as if by holding on to this strength and this sense of immunity she could protect the parts of her that were felt to be more vulnerable. She appeared to use this idea of internal strength to make decisions that would protect her in areas where she was more fragile, for example, by being hyper-vigilant about accepting men into her life. In the beginning of the interview, she

talked about choosing to be alone, as if she could in this way protect herself from further hurt:

> '…I don't want to be frustrated anymore, because you see men are all the same, ja. So I want to stay alone.'

Later in the interview, however, she expressed strong desire to have a relationship and her initial denial of this gave us a sense of how deep the scars on her identity run. While taking on a discourse of strength may serve a valuable protective function, guarding parts of the self that are felt to be more fragile, in her case it meant that she felt her loneliness keenly without being able to acknowledge the source of that isolation. When the interviewer asks her why she holds back from starting a relationship with a particular man who has expressed interest in her, she finds it difficult to articulate the reason:

> 'Like, I don't, I told him that, just now I am not ready, but maybe when time goes on, just now I didn't trust him now…(and later in the interview) Ja I can trust him but …I am sure that we are going to fall in love. Also I know, I see that he love me, but I, he told me this, but I told him that no, we must wait.'

As a research group, we experienced a strong reaction to the contradictory images of themselves that the women were presenting to us. Some of us held fiercely onto the idea of the women as strong and capable, as being able to withstand far more than we could have imagined. Others felt that we were underestimating their vulnerability. These differences of opinion played themselves out in our discussions and it was only with some reflection that we were able to recognise in our responses to the material some of the fluctuation between disparate feelings of hope and despair, courage and fragility, that the women themselves must experience.

Contagion and Purity

The women emphasised how a positive diagnosis had enabled them to act responsibly, for example using condoms to protect others from infection. Their comments positioned those who did not know their status as dangerous – both to others because they were likely to be spreading the disease, and to themselves because they were unlikely to be taking the appropriate self-care measures. In maintaining a positive sense of self, the women projected contagion and irresponsibility, key elements of a stigmatised HIV identity, onto 'the other':

So I say thanks God. I don't care about the people who knows my status, but unfortunately some of them, they know my status but they don't know their own status. And I don't care about it – they kill themselves, actually.

However, there was a tension underlying this. Their pride in knowing their status occluded the recognition that in some ways it would be easier not to know their status. *Knowing* meant having to take on a responsibility from which those who do not know their status were free:

'Ja, it is different because now I know what I am going to do now. Before I didn't use the condom, ja. But now I know I must use the condom because my life is not like the same with other people.'

An overall analysis of the transcripts shows that while the women talked about how the infection had changed their lives for the better, they still wished for things that as HIV positive people, they were not supposed to have, and there was some resentment at the limitations that had been imposed on them. This came through strongly in talk about sexual relationships and condoms:

'Ja, just because before I don't have a condom, but now I know that I'm *forced* to use a condom.'

The women felt that they should take responsibility in ensuring that their partners wore condoms in every sexual encounter. However, some of the women had not disclosed to their partners. This made negotiating condom usage tricky. Either they had to develop elaborate and unwieldy excuses to explain their reluctance to have unprotected sex or they avoided relationships altogether:

'Ja, and the others they don't want to use condoms, something like that, so its better you stay alone.'

A small number of the women chose to have unprotected sex, rather than be 'found out'. However this was usually with partners they had been with before they were diagnosed and from whom they suspected they had contracted the infection in the first place. Nevertheless, they were aware that in disclosing they would be blamed for 'bringing' the infection into the relationship:

'I'm worried sometimes because I want to tell him, but we're not, sometimes we're not, when we not using the condom, I'm worried about that. But I am supposed to explain *why* I want to use a condom.'

A decision not to disclose put these women in a precarious position. In their roles as activists and educators they are expected to practice safe sex and to protect others from infection; but in their roles as partners and lovers they sometimes felt compromised by this responsibility. Most women felt they nonetheless had an ethical responsibility to disclose to a partner despite the possibility of rejection. One woman's comment highlights the enormous courage and risks involved in disclosing to intimate partners :

> 'Since I'm told like we must disclose to get over the problem you know because if …you're going to lie to that person and say no, you're fine, they're knowing there's something eating inside of you and you're like spreading it, understand. So I decided that every man that I meet, I will tell him that I'm HIV positive. I did – and I end up being rejected.'

Having to use condoms points to the fact that while the women construct a somewhat innocuous conception of HIV, they are in fact carrying a contagious disease – one that others desperately don't want and seek to protect themselves against. Because of the obvious link between HIV infection and sex, it is in their identity as sexual beings, and in their sense of themselves within intimate relationships, that they may feel damaged and where they may carry the most painful psychological scars. The same woman said:

> '…I was thinking maybe he run away because he said he is feel like there's nothing he get from me now, I've got the disease, I'm dirty, my body is dirty, what does he need from me. [He is thinking] I am also gonna be infected, you know?'

This woman holds a highly personalised sense of her body as dangerous and unclean. This is carried through an expectation of how others will see her, an expectation that reflects a broader social representation of an HIV positive body as wholly undesirable (Nack, 2000).

It was through sex, often with a partner who they trusted, that the women were infected:

> 'I felt like if I didn't have a boyfriend before maybe I wouldn't get this infection, but just because I had a relationship and we have sex without a condom, so that's the reason why I became positive.'

In being diagnosed HIV positive, the women's sexuality was irrevocably altered. Even now, intimate sexual relationships must be constantly managed and

renegotiated. It is hardly surprising that during the interviews the subject of sexuality felt difficult to approach. In talking about these intimate issues we felt a sense of our intrusion into areas that were painful and difficult for the participants to discuss and for us to know about. In accessing our own feelings about our damaged selves, and our own imperfect bodies, we began to get a sense of how distressing these issues must be for these women. It was deeply impressed on us how difficult it must be to bring into the bedroom an identity that is often unjustly associated with shame, dirt and contagion..

Continuity and Loss

It was through working with the notion of loss that we began to get a real sense of how the women felt, in some ways, compromised by HIV infection. Loss came through in areas of the interviews where the women spoke about certain things they longed for, but which as HIV positive people they couldn't, or were not supposed to, have.

We have already pointed to complications in negotiating intimate relationships. Some of the women experienced the loss of aspects of themselves as sexual beings, while others felt that they would not be able to have intimate relationships at all:

> 'I am going to stay single for the rest of my life, that's what I am thinking sometimes.'

Other women feared losing their present relationships. Those who were in relationships seemed to resist the interviewer's probing for details: as if close scrutiny might jinx or taint these tentative bonds. One woman spoke about how her boyfriend had asked to marry her. It seemed that this was something she really wanted but at the same time she expressed great uncertainty. When the interviewer probed her on this, she struggled to articulate the fear that she might die as a result of AIDS and that in a sense then, it would be unfair for her to marry him. Yet she held onto a powerful hope that she could live long enough to marry him:

> 'I just say, "No, ok." I didn't want to tell him that I am afraid, "you can't marry me, you are going to be – ", I didn't say this. (Interviewer: Well, why would you want to say that? I mean do you feel that maybe that's true, that he shouldn't marry you?) I don't know, I am afraid, Jo, because I know that I am HIV positive. So, I don't know, maybe (.) am I going to go, I am going to live. I know I am strong enough now and I know I can live long

and I just, I didn't turn him down and say, "No you cannot marry me because of this and this." No, I just say, "OK".'

Two of the women expressed the longing to have children. They struggled to come to terms with the loss inherent in foreclosing on the option of motherhood and still clung onto the hope that they would be able to have children:

'… the problem is because I know where I am now, but I want another [child], yes. But the problem is that HIV. Maybe I can do that also, I can survive, maybe I can survive, I don't know... So I am scared also to have another one, but I want, I want.'

It seemed to us that it was actually quite painful for the women to think about some of these tentative hopes for the future. Once again the women seemed to deal with more difficult aspects of their status by situating these in the past:

'Since I was diagnosed, I was so lonely, sad and miserable. I was sitting at home lonely and I was not…thinking other things – the future. … And I am meeting P. She counselled me and then she took me to support group and I found many women there they got HIV and I (.) after I go there I feel very good.'

In the present, they spoke about their improved lives and their increasingly positive self-identity. Thus there was a degree of certainty in their talk about past and present. The future, however, is not as clear-cut, and considering a more distant future may generate considerable anxiety. While in the present they were able to hold onto a concept of health, this health is not assured in the future, and as we have argued, the sense of control inculcated by self-care is tenuous. Only one of the women spoke explicitly about knowing that she was going to die, while still asserting her identity as a 'survivor':

'From the time I was diagnosed, I was thinking of death … I know I am going to die, and I don't mind [that] I am HIV positive or not, but I am going to die. So, I'm feeling nothing about HIV, but I know I am going to die as all people they are going to die. … that's why I say it is my punishment from god. So I must go back to my creator, that's all I am feeling. Then the people… the people who are in the treatment, even in the anti-retroviral, they are going to die. But, I am a survivor.'

As researchers we found it hard to assimilate and make sense of the contradictions inherent in this account. As a society, generally, it is much easier for us to hear hopeful stories and the voices of those who are fighting for life. It

becomes almost unacceptable for an ill person to talk about the possibility of their death. It is arguable that by investing so much of their identity in the discourse of fighting for life, the women may have been foreclosing on an opportunity to talk about and work through the areas in which they experienced loss. This was apparent in their talk about not disclosing to children.

Only one of the women we interviewed had disclosed to her children. We recognised that disclosing to children is a particularly painful task. However, the Memory Box Project had initially been conceptualised in Uganda precisely so that mothers could disclose to their children and could help their children, and themselves, to come to terms with the losses inherent in an HIV/AIDS diagnosis and prepare for a potentially premature death. The women in our group seemed unable to do this. In trying to gain a sense of how the women might feel, we, as researchers, discussed how difficult it must be to hold together the paradoxical notions of fighting for life and coming to terms with death. Most of the women told us that they had not disclosed to their children because the children were too young and talked about a time in the distant future when they felt that they could disclose to them. The ages they chose for the moment of disclosure often seemed arbitrary. Nandi spoke about how she would wait until her eight-year-old daughter turned fifteen to tell her. She talked about how she wanted to wait until her daughter was old enough to understand that the disease need not be fatal:

> (Interviewer: Why is it so hard to tell your child?) 'You see that the other people think that if you are HIV you are going to die, you going to died. But it's not true. But before we tell our children, we must teach them first, we must teach them that HIV is not killing people. You can stay, yes, after that you can tell them that you HIV positive.'

This evoked a very uncomfortable response in us. We spoke about how this woman's health had already been compromised by the disease and how, if she waited those seven years to tell her daughter, she might die without having disclosed to her. Some of us felt guilty for acknowledging that she might die, when she herself was unwilling to do so. It was difficult for us to acknowledge that Nandi too, must hold an awareness that she might die. We felt guilt for challenging her wellbeing as though our thinking about her death would make this possibility real. This may have reflected her own fear that acknowledging the possibility of death may in some way compromise her health because it would mean relinquishing the discourse of positivity, which gave the women a sense of partial protection from serious illness. In spite of her attempt at positive thinking, Nandi appeared to struggle more than the other women with an awareness that her real state of health did not match the group ideal of wellness.

Discourses that emphasise living positively with HIV and fighting for life help many of the women to cope with the infection and to stand strong in times of less serious illness. These discourses, however, may not leave a space for working through the very real possibility of illness and death. For example, living positively for those women who were already experiencing painful losses meant that they felt that they had to carry their losses alone. To some extent, we felt, they hid their anguish from others, feeling that others would not be able to bear or contain their feelings of anxiety and pain. This is exemplified in this poignant quote by the project facilitator:

> 'Like, I saw Nandi yesterday. Like, one eye is closing but she is there, she is doing presentations – sort of dressing as well as she can, and sort of pretending like she is going forward.'

Discussion

The approach adopted in this research offers a view of the women interviewed as being actively involved in determining and asserting a positive identity. They construct their identity partly through the discourses available to them in the social world they inhabit. Importantly, however, their selection of particular discourses is motivated by an emotional need to protect themselves against anxiety. Our initial reading of the interview material tended to reinforce the primary message most of the women wished to convey – that it was possible to hold on to a positive identity while having HIV/AIDS. On closer examination of the transcripts, we began to recognise some of the complexities involved in constructing an HIV/AIDS identity.

Interviewees expressed a degree of ambivalence between positive and negative views of living with HIV/AIDS. The women's often conflicting ideas about themselves contained and expressed powerful and contradictory emotions. Arguably, it was difficult for them to reconcile the more vulnerable parts of themselves with their desire to hold onto an unspoiled positive identity. Sometimes, as researchers it was also hard to hold onto the connection between these different images of the women and the different feelings they evoked in us. Reflecting on this, however, made it possible to recognise how the women too may have struggled to hold together different experiences of self. We became aware of how their positive representations of self also seemed to serve a defensive function, limiting emotional knowledge of more frightening aspects of having HIV/AIDS.

There is considerable value in an approach that acknowledges the active, constructive element of people's capacity to engage with stigmatised identities.

It may be equally important to recognise how these processes are fundamentally influenced by emotion and the desire to evade anxiety. There is, however, a danger in repeating the individualising and reductionist tendencies of much of conventional psychological theorising (Durrheim, 1997; Foster, 1999). It would be all too easy to begin to suggest that what these women experienced was *only* 'emotional', *only* their own individual struggles with a disease. On this logic, all that is required is psychological intervention. The kinds of circumstances the women are facing are not, however, of their own making. They construct their own identity in response to anxiety – but the anxiety itself is a product of socially generated experience and circumstance. HIV positive people would, for example, have less need to formulate a somewhat idealised positive identity if they were not subject to very negative and damaging representations of themselves. In this sense, a positive identity serves as a necessary inoculation against stigma. Moreover, the broader society may also have an investment in the construction of an HIV identity as positive. While the processes of stigmatisation may help people to disown unwanted aspects of themselves, the belief that some strong individuals can survive the degradation of the disease may also ease anxieties about the threat it poses to society more generally. This need to minimise the threat of HIV/AIDS has been a part of public discourse in South Africa where the link between the virus and AIDS has been questioned, as has the need to use anti-retrovirals (Cullinan & Thom, 2000; Stein, 2003b). In South Africa, it may be particularly necessary to mobilise a 'positive' reconstruction of AIDS as, with one of the highest infection rates of any country in the world (Dorrington *et al*, 2001), it is no longer possible to cling to the illusion that the threat of HIV/AIDS is limited to marginalised risk groups. In Africa the media coverage of HIV/AIDS has emphasised the devastation wrought by the infection, and it is understandable that in witnessing images of unbearable suffering on an ongoing basis, it becomes desirable and even necessary to look for the light at the end of the tunnel. Still, the danger is that this focus places the responsibility for coping with 'positive-living' individuals and may play into a refusal by broader society to take accountability for, and constructive action in dealing with, the pandemic.

Furthermore, the struggle of living with HIV/AIDS in South Africa is compounded by the demands of surviving in a context of poverty and inadequate medical care. Given that there is little help available for people who are ill in poor black communities (Poku, 2001), death and dying are extremely visible in the stark landscape of Khayelitsha and it becomes essential to draw on positive thinking as a way of counteracting understandable feelings of helplessness and despair. In Khayelitsha, AIDS stigma has very real consequences, especially for women who, because of their precarious status in society, may be subject to projections of risk and blame (Joffe, 1999; Strebel, 1995). This adds to the arsenal of threat that these women encounter. Constructing a positive identity

around notions of health and strength partially performs the function of protecting them from discrimination and its subsequent costs.

Critical theorists highlight the role of the social context in constructing the experience of AIDS. The emphasis on the social construction of illness, however, may obscure the very physical nature of disease. While illness and death can be constructed quite differently in different contexts, the universal reality is that serious illness causes suffering and death. What critical theory offers is an elaboration of how this reality of terminal illness is mediated by social representations of HIV/AIDS. This creates a powerful combination of negative emotion, which precipitates the need for an assertion of a positive identity.

Focusing on good health rather than on the potential for illness is an effective strategy for dealing with or defending against anxiety. It enables the person to hold onto a construction of self not irrevocably tied to illness. However, this is likely to become less tenable as the disease progresses (Tewksbury and Mcgaughey, 1997). An HIV/AIDS identity constructed exclusively around a notion of positive health, while being reassuring for the infected person and others around them, does not leave a space to talk about the distress that sickness may evoke or to prepare for the disruptive physical dimension of an infectious chronic illness and the losses this entails. The denial of the negative impact of HIV/AIDS may also discourage appropriate attempts to mobilise the resources available to combat the effects of the epidemic. Further, on the part of those who are diagnosed with HIV/AIDS, the need to be seen by others as healthy can lead to a desire to hide signs of deteriorating health and the vigilance needed to 'pass' as healthy can cause considerable anxiety. At the same time, we do not wish to underestimate the strength and courage that is needed to hold onto a positive and productive sense of self, when threatened by serious illness. As we recognise the vulnerability of our participants, so we acknowledge their very real strength and positivity and the courageous way in which they engage with a reality that most of us would consider unbearable.

This paper raises some crucial questions about psychological models of intervention, which situate empowerment as a goal and set store by psychological strength as an important outcome of humanitarian work. The women we interviewed appeared to us at first to be stronger than we could have imagined and this seemed to be a product of a broader thrust in public health towards re-framing the experience of HIV/AIDS in terms of 'positive living'. This research suggests that it is important to give credence to both sides of experience – positive and negative, painful and uplifting – and to be able to hold onto contradiction and paradox in psychological work.

In asserting their strength and their will to survive, the women tended to neglect the more vulnerable aspects of themselves. In so doing, these aspects of self drifted, sometimes just below the surface of consciousness, emerging as disjunctive ideas and feelings in the primary narrative. As psychoanalysts recognise, these parts that are painful to know do not cease to have effects when they are disowned. In working with people living with HIV/AIDS we need to recognise that allowing for a space to think about the more painful aspects of the disease need not compromise their ability to fight for life and to hold onto a positive, affirming sense of self. This nuanced identity may in fact allow for greater resilience in dealing with all dimensions of the disease. It is in recognising and working through ambivalence in the illness experience that the groundwork can be laid for a more enduring and adaptable self-concept.

References

Bruner, J. 1991. The Narrative Construction of Reality. *Critical Inquiry* 18, 1-21.

Crawford, R. 1994. The Boundaries of the Self and the Unhealthy Other: Reflections On Health, Culture And AIDS. *Social Science and Medicine* 38 (10), 1347-1365.

Crewe, M. 1997. How Marginal Is A "Marginalized Group"?. *Social Science and Medicine* 45 (6), 967-990.

Crossley, M. L. 2000. Narrative Psychology, Trauma And The Study Of Self/Identity. *Theory and Psychology* 10 (4), 527-546.

Cullinan, K. & A. Thom, A. 2001. HIV/AIDS Debate: Flirting with Death? *Health-e Online News Service*. Cape Town, South Africa. Available at: http://www.health-e.org.za.

Dorrington, R., Bourne, D., Bradshaw, D., Laubscher, R. & I.M. Timaeus. 2001. The Impact Of HIV/AIDS On Adult Mortality In South Africa. Technical Report. Cape Town: Medical Research Council. Available at http://www.mrc.ac.za/bod.

Durrheim, K. 1997. Social Constructionism, Discourse And Psychology. *South African Journal of Psychology* 27 (3), 175-182.

Fleishman, J. 1995. Living HIV-Positively. *Africa Report* 40 (3), 56-59.

Foster, D. 1999. Racism, Marxism, Psychology. *Theory and Psychology* 9 (3), 331-352.

Frosh, S. 2002. *After Words: The Personal In Gender, Culture And Psychotherapy.* Houndmills, Basingstoke, Hampshire and New York: Palgrave.

Gilbert, L. 1996. Urban Violence And Health – South Africa 1995. *Social Science and Medicine* 43 (5), 873-886.

Goffman, E. 1968. *Stigma: Notes On The Management Of A Spoiled Identity.* Harmondsworth: Penguin.

Goldin, C. S. 1994. Stigmatisation and AIDS: Critical Issues In Public Health. *Social Science and Medicine* 9, 1359-1366.

Hollway, W. & Jefferson, T. 2002. *Doing Qualitative Research Differently.* London: Sage Publications.

Irigaray, L. 1993. This Sex Which Is Not One. In Jackson, S. and K. Atkinson (eds) Women's Studies Essential Reading, 231. New York: New York University Press.

Jeffreys, S. 1993. Anticlimax. In Jackson, S. and K. Atkinson (eds) Women's Studies Essential Reading, 243-244. New York: New York University Press.

Joffe, H. 1999. *Risk and 'The Other'.* Cambridge: Cambridge University Press.

Klein, M. 1932/1975a. *The Psychoanalysis Of Children.* London: Virago Press.

Klein, M. 1921-1945/1975b. *Love, Guilt, Reparation And Other Works*. London: Hogarth Press.

Lawless, S., Kippax, S. & J. Crawford. 1996. Dirty, Diseased And Undeserving: The Positioning Of HIV Positive Women. *Social Science and Medicine* 43 (9), 1371-1377.

Lawson, A. L. 1999. Women and AIDS In Africa: Sociocultural Dimensions of the HIV/AIDS Epidemic. *International Social Science Journal* 161, 391-400.

Lee, D. L. & Craft, E. A. 2002. Protecting One's Self from a Stigmatised Disease Once One Has It. *Deviant Behavior* 23, 267-299.

Lupton, D. 1999. Risk. London: Routledge.

Mann, J. 1987. Statement at an Informal Briefing on AIDS to the 42nd session of the United Nations General Assembly. 20 Oct, New York.

Mitchell, J. 1986. The Selected Melanie Klein. London: Penguin Books.

Nack, A. 2000. Damaged Goods: Women Managing The Stigma Of STDs. *Deviant Behavior* 21, 95-121.

Nattrass, N. 2002. Unemployment, Employment and Labour-Force Participation in Khayelitsha/Mitchell's Plain. *CSSR Working Paper No.12*. Cape Town: Center for Social Science Research, University of Cape Town.

Available at http://www.uct.ac.za/depts/cssr.

O'Connor, K. P. & R.S. Halam. 2000. Sorcery of the Self: The Magic of You. *Theory and Psychology* 10(2), 238-264.

Park, K. 2002. Stigma Management Among the Voluntary Childless. *Sociological Perspectives* 45(1), 21-45.

Parker R. & P. Aggleton. 2002. *HIV and AIDS-Related Stigma and Discrimination: A Conceptual Framework and Implications for Action*. London: Brazilian Interdisciplinary AIDS Association and Thomas Coram Research Unit, Institute of Education, University of London.

Peterson, S. & L. Benishek. A. 2001. Social Constructions of Illness: Addressing the Impact of Cancer on Women in Therapy. *Women and Therapy* 23(1), 75-100.

Poku, N. K. 2001. Africa's AIDS Crisis in Context: 'How the Poor Are Dying'. *Third World Quarterly* 22(2), 191-204.

Segal, H. 1981. The Work Of Hanna Segal. New York: Aronson.

Segal, J. 1992. Melanie Klein. London: Sage Publications.

Shabodien, R. 2003. The Impact Of HIV/AIDS on Sustainable Livelihoods: Living with HIV/AIDS in Khayelitsha, South Africa. Development Action Group.

Available at http://www.dag.org.za/Livelihoods_and_Aids.pdf. [Accessed 2003.07.17].

Sontag, S. 1989 AIDS And Its Metaphors. Harmondsworth: Penguin Books.

Stein, J. 2003a. HIV/AIDS Stigma: The Latest Dirty Secret. *CSSR Working Paper No.46*. Cape Town: Centre for Social Science Research, University

of Cape Town. Available at http://www.uct.ac.za/depts/cssr.

Stein, J. 2003b. What's News: Perspectives On HIV/AIDS Advocacy in the South African Print Media. *African Journal of AIDS Research 2003* 2(1):1-9. Also available at http://www.uct.ac.za/depts/cssr.

Straker, G., Mendelsohn, M., Moosa, F., & P. Tudin. 1996. Violent Political Contexts and the Emotional Concerns of Township Youth. *Child Development*, 67, 46-54.

Strebel, A. 1995. Whose Epidemic Is It? Reviewing the Literature on Women and AIDS. *South African Journal of Psychology* 25(1), 12-21.

Tewksbury, R. & D. Mcgaughey. 1997. Stigmatization of Persons with HIV Disease: Perceptions, Management and Consequences of AIDS. *Sociological Spectrum* 17(1), 49-71.

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