

University of Cape Town



CENTRE FOR
SOCIAL SCIENCE RESEARCH

**MOVING BEYOND THE MARGINS: A
NARRATIVE ANALYSIS OF THE
LIFE STORIES OF WOMEN LIVING
WITH HIV/AIDS IN KHAYELITSHA**

Talia Soskolne

CSSR Working Paper No. 33



Published by the Centre for Social Science Research
University of Cape Town
2003

Copies of this publication may be obtained from:

The Administrative Officer
Centre for Social Science Research
University of Cape Town
Private Bag
Rondebosch, 7701
Tel: (021) 650 4656
Fax: (021) 650 4657
Email: kforbes@cssr.uct.ac.za

Price in Southern Africa (incl. VAT and postage): R 15.00

or it can be downloaded from our website
<http://www.uct.ac.za/depts/cssr/pubs.html>

ISBN: 0-7992-2177-5

© Centre for Social Science Research, UCT, 2003

CENTRE FOR SOCIAL SCIENCE
RESEARCH

AIDS and Society Research Unit

**MOVING BEYOND THE MARGINS: A
NARRATIVE ANALYSIS OF THE LIFE
STORIES OF WOMEN LIVING WITH
HIV/AIDS IN KHAYELITSHA**

Talia Soskolne

CSSR Working Paper No. 33

March 2003

Talia Soskolne is a research assistant in the AIDS and Society Research Unit, Centre for Social Science Research, at the University of Cape Town.

The supervision of Adelene Africa in the writing of this working paper is hereby gratefully acknowledged. She is a clinical psychologist and lecturer in the Department of Psychology at the University of Cape Town.

Moving Beyond the Margins: A Narrative Analysis of the Life Stories of Women Living with HIV/AIDS in Khayelitsha.

Introduction

Women, AIDS and Africa: A Marginal Voice

Statistics about the devastating impact of the HIV virus on the African continent, where more than 23.5 million people are infected (Poku, 2001), are widely known, and are bandied about in both social and academic speak. Within mainstream biomedicine (biomedicine dominates research and regulation of the epidemic, and permeates popular understanding), the spread of AIDS in Sub-Saharan Africa remains relatively unproblematised, with biological and behavioural models of aetiology remaining uncontested (Crewe, 1997). However, within a wide range of disciplines, such as anthropology, sociology, psychology and political science, waves of critical consciousness (post-modernism, social constructionism, post-structuralism, Marxism and feminism) are actively wearing down antiquated modes of thought that fail to take into account social constructions of the disease, and its intersection with constructions of race, gender and class, and are working to unveil the institutions and ideologies (e.g. patriarchy, capitalism, democracy) that these social discourses serve (Crewe, 1997; Durrheim, 1997; Foster, 1999; Peterson & Benishek, 2001). Of notable interest are feminist critical theorists who unpack cultural notions of disease, and seek to understand their particular impact on women's illness experiences (Peterson & Benishek, 2001). For women, the social construction of HIV/AIDS cannot be torn apart from the oppression and regulation of women under patriarchy, and from gendered constructions of masculinity and femininity. Furthermore, feminist theorists pay special attention to the articulation between class, race and gender; black women, especially those living in Africa under conditions of incessant poverty, carry a vast burden and, when it comes to HIV/AIDS, are particularly vulnerable to projections of risk, where they are seen as 'carriers' of the disease, and are feared as dangerous (Fleishman, 1995; Joffe, 1999; Strebel, 1995).

Women's experience of HIV/AIDS is intensified because of their subordinate role in society. Women have less access to economic and political power, are

usually poorer than men, and are more likely to work in the informal sector or be unemployed, and are thus often economically dependent on men (Strebel, 1995). This is heightened in Africa, where the intersection of colonialism and traditional culture has precipitated large-scale urbanization and migration, disrupting family and community ties, and exacerbating poverty. In Africa there are vast numbers of impoverished women who, although they earn a lower income than men, are often the chief provider for their household, as well as for extended networks of kin (Lawson, 1999; Strebel, 1995). South Africa is a particular case as, even after the collapse of the Apartheid regime, many blacks continue to live in conditions of chronic and unreceding poverty. In townships, income is insufficient to cover basic needs, unemployment and illiteracy are high, sanitation is exceedingly poor, housing in shacks is overcrowded and rundown, education is limited, and government funding to supply and maintain a basic infrastructure trickles in rather than flows (Head, 1993; Le Clerc-Madlala, 1997; Poku, 2001).

Apartheid's violent legacy has manifested itself in escalating violence, crime and abuse, often directed at women, who usually occupy the lowest rung of society (Gilbert, 1996). The impact of poverty on the spread of AIDS is inestimable. Malnutrition, stress, inadequate hygiene and medical care, and increased susceptibility to TB, leads to reduced immunity increasing the risk of HIV infection (Head, 1992; Strebel, 1995). Women, who are uniquely impacted on by poverty, are particularly vulnerable. Further, for those living with HIV/AIDS, poverty means that they have limited access to resources that would help sustain health and life. Women typically carry the burden of care, and with HIV/AIDS are expected to care for others, even though this may mean that their own health is at risk (Lawson, 1999; Strebel, 1995). Poor women, especially, have minimal access to health resources and to others (nurses, health-care workers, home carers) who can share the burden of care. Fleischman (1995) talks about the 'triple jeopardy' of women in Uganda, arguing that they "suffer as mothers, as care givers and as human beings" (p.56). Likewise, women in South Africa bear the burden of caring for the sick and must confront the horror of potentially passing the virus onto their babies. They are likely to be the one's blamed for transmitting the virus, whether or not the man was engaged in unsafe practices, and thereby risk losing all support and finding themselves chased out of home, destitute (Fleishman, 1995).

Women, in sub-Saharan Africa, constitute a vast percentage of those infected, where studies have found the rate of infection in women to be greater than that of men (Strebel, 1995). Women are often infected at ages up to ten years younger than men, and frequently have a poorer prognosis, and die sooner. The chief mode of infection for women is heterosexual, and there is evidence that women are more likely to become infected through heterosexual than are

heterosexual men. The women who are most at risk usually belong to marginalised groups (Strebel, 1995). HIV/AIDS thus constitutes a critical problem for women and, as a field of study, has received notable attention in the last decade (Strebel, 1995), yet interventions typically ignore critical issues, failing to address women's precarious role in society.

Strangely, the onus has fallen on women to take preventative action, either by abstaining, remaining monogamous, or negotiating condom use (Strebel, 1995), even though women often do not have control over their own sexuality, and are frequently coerced or forced into unsafe sexual practices. Women are particularly vulnerable physiologically to infection, but also, because of the subordinate role they occupy in society, are at risk in that they have scant power to negotiate safe sex and condom usage (Strebel, 1995). They are readily positioned as objects, subject to the whims of men's desire (Irigaray, 1993), such that heterosex has been elucidated as 'the eroticisation of women's subordination' (Jeffreys, 1993: 243) and often occurs within a matrix of violence, coercion and domination. This is intensified in South Africa where violence against women, particularly in the townships, is widespread, and is normalised (Straker, Mendelsohn, Moosa & Tudin, 1996), so that violence can be argued to be one of the most insidious and fundamental ways that women continue to be oppressed (Gilbert, 1996). Black women, living in conditions of poverty, are particularly vulnerable to sexual and physical violence, rarely having social or political voice and, because of their economic dependence on men, have little room to maneuver, to the extent that violence is accepted as a normal part of heterosexual relationships (Shefer, Strebel & Foster, 2000).

Sadly, constructions of black women's 'out-of-control' and enticingly exotic sexuality still persist, and it is promiscuity that is posited to precipitate the spread of AIDS in Africa (Head, 1992; Strebel, 1995), rather than stiflingly oppressive gender relations. Black women are constructed, in multiple contexts, as dangerous. This amplifies violent forms of social control and regulation that seek to reign in their sexuality and voice, and intensifies their marginalisation, so that black women as the ultimate 'other' carry projections of risk and danger not only for whites, but also for black men (Joffe, 1999). Conversely, are discourses that construct black women as victims: victims of violence, victims of abuse, victims of poverty and victims of AIDS. These discourses, while acknowledging the precarious position of black women in society, also work to destroy their agency and silence their voices. A victim is seen to uncomplainingly accept her oppression: why should she speak out; she is acted upon and has no agency in altering her abuse? She becomes the object of research that describes or quantifies the things that happen to her, rather than exploring her subjectivity. There is no acknowledgement that violence is deeply felt by the 'victim', becomes part of her experience as much as it is 'inflicted' on

her, and is not always passively and unthinkingly accepted. Likewise, black women are positioned as the victims of AIDS, and as a marginalised group, in the face of studies that seek to quantify and medicalise suffering, their experience of living with the disease becomes unimportant. AIDS, as it affects black women, particularly in Africa, becomes something 'out there' to be studied and controlled, rather than something to be explored and understood. What is needed is a method of research that allows black women's voices and stories to be heard, that moves them beyond of the margins of society, and that transcends the narrowness of biology and behaviour.

Narrative: Moving Beyond the Margins

Narrative has been posited as the preferred method of research for working with people with AIDS and other chronic illnesses (Crossley, 2000a; Crossley, 2000b; Davies, 1997; Del Vecchio Good, Munakata, Kobayashi, Mattingly & Good, 1994; Ezzy, 2000; Garro, 1994; Grossman Dean, 1995; Mattingly & Garro, 1994; Viney & Bousfield, 1991) and also for documenting women's stories. A narrative approach arguably gives voice to those who have been otherwise marginalised. A critical feminist view would argue that women's voices have been silenced, and their stories suppressed: men's stories have been enshrined through much of history, while women's tales (and lives) have been relegated to the realm of the private with its connotations of insignificance and mundanity – women have been sidelined (Gergen, 1997; Reinharz, 1994). When women's stories break through, it is through a phallogocentric lens that omits experiences that do not fit in with a view of what it is to be a woman (Reinharz, 1994; Sands, 1996), where women are 'positioned' (Hollway, 1984) in particular, essentialising ways (Walkerdine, 1997) that constrict women's stories and their construction of self in those stories. Black women are triply constrained - through racism, sexism and elitism - and are rarely heard, as others forcibly speak for them. Narrative, used as a feminist tool, allows women's voices to be freed, keeping their lives and stories at the fore of its analyses, and is thus empowering for women (Gergen, 1997).

Social constructionism seeks to deconstruct fixed notions of womanhood, unveiling the discourses and ideologies that underlie cultural and historical constructions of femininity (Malson, 1998; Malson, 1999), as well as breaking down staid constructions of race (Foster, 1999). Likewise, a narrative analysis challenges singular, essentialist, homogenous and fixed constructions of 'woman' (and of 'black woman'), arguing that women have multiple identities and multiple selves, yet acknowledging that, while women draw on the dominant cultural narratives offered to them, they do so in a reflexive way, making the narratives uniquely their own, and actively positioning themselves

within social discourses in ways that are meaningful in terms of their life stories (Sands, 1996).

A narrative approach patterns a space for thinking about women who transform their life stories and their constructions of self in those stories, who reject or transcend the dominant (and ultimately limiting) social discourses that saturate society, and who are subversive in their everyday lives. Further, a narrative analysis, while able to unveil the universal aspects of storytelling, can also separate out women's voices, so that it can be acknowledged that under patriarchy not all women have had the same experiences. Also black women's tales may diverge in essential ways, which need to be recognised and heard, from those of their white sisters, though this is not to suggest that all black women share the same experiences either (Alleyne, 1998).

Narrative psychology is concerned with the stories people tell that allow them to make meaning of their lives and to construct an evolving sense of self – a storied existence (Denzin, 2000; Ochberg, 1996). Narrative, while it is argued to fall into a constructionist category because of its emphasis on a reality that comes about through language, is discernible from other discursive approaches in that it acknowledges the human quest for meaning where people conceive a sense of unity, coherence and significance through the stories they tell about themselves, others and the world (Crossley, 2000a; Crossley, 2000b). While social constructionism emphasizes the disorderly, chaotic, changeable and fluctuating nature of existence, narrative seeks out the congruity and continuity of human lives, where stories of self give a sense of significance and purpose to self-experience (Crossley, 2000a; Lieblich, Tuval & Zilber, 1998). They engender a sense of 'knowingness' which ascribes meaning to one's being in the world: knowing that there is a god/ humanity/compassion/ connection/ future/ evolving meaning. Holding onto cherished beliefs constructed in 'knowingness' allows us to exist purposefully and securely in the world. As in other discursive approaches, the focus is still on language, and a self envisaged through language in the recounting of the narrative but, in telling a story, that self is seen to be situated within a framework of meaning and temporality, where there is a profound connection between different events recalled in the narrative, as well as an interrelationship between the self and others in the account.

A life narrative situates the narrator within a web of time, space and identity, as well as culture and community, where connections and relationships described by language ascribe each thread with significance. So, for example, narrative psychology theorises an inextricable connection between time and identity (Bruner, 1991), as the temporal, sequential framework of stories is argued to lend significance to self-experience, in which each incident is imbued with meaning through its relation to, and intertwining with, other incidents in the

account. It is thus the chronological timeline that narrative researchers turn to, to uncover meaning in the accounts they are given (Gergen & Gergen, 1997). Further, individual life stories are embedded in and emerge from cultural and community narratives, and draw meaning from these by situating themselves within a context that is imbued with history, continuity and connection (Andrews, Schlater, Rustin, Squire & Treacher, 2000; Rappaport, 2000). However these may also be constraining, limiting what can be said (Frank, 1995), and ensure the re-enactment of suppressive ways of being in the world. Narrative psychology, like other discursive approaches, seeks to uncover the dominant cultural narratives that inform our personal stories, unveiling their ideological consequences, and bring their unspoken assumptions to the fore, but also recognises that people do not always unthinkingly accept these discourses and may in fact actively subvert their meaning.

Narrative theorists argue that chronic illness, such as HIV/AIDS, signifies a juncture or disruption in the life narrative, whereby the sense of temporal connection, and relatedly purpose and meaning, is lost (Crossley, 2000a; Crossley, 2000b; Davies, 1997). Chronic illness dissolves our basic framework for being in the world, which consists of a sense of time, space and identity and thus has the capacity to ‘unmake the world’ (Scarry, 1985). The chronically ill person becomes painfully aware of each aspect of her existence, and time and identity take on new, previously unimaginable meanings that complicate her ability to live in the world. She becomes painfully aware of each action she makes, annihilating the ‘practical consciousness’ (Giddens, 1991: 36) that enabled her to just ‘be’ in the world and, consequently existential questions about death and the nature of reality are brought to the fore, and may signify the disruption of long-held and cherished beliefs and dreams:

‘When a person receives a terminal diagnosis, they are immediately shocked out of the complacency of the assumed futurity of their existence, and their whole conception of themselves, their life and their world is likely to undergo radical changes’ (Davies, 1997: 562).

Chronic illness destroys the ‘destination and map’ (Frank, 1995: 1) that the ill person had previously used to guide her, and the relationship between time and self becomes fundamentally altered through the dissolution of her ‘routine temporal orientation’, where she ‘projects into the future’ (Crossley, 2000b: 539) and where her current self should not be that different to the self she recognises in the past. With a diagnosis of chronic illness, for example being diagnosed HIV positive, a juncture or tear occurs in the life narrative, and the ill person can no longer be guided in a practical existence by a foreseeable future and a connecting past, and instead there is a sense of ‘living in the empty

present' (Davies, 1997: 569). Heidegger's (1962) concept of 'angst' (an intense anxiety or dread) can be used to understand the sense of dissolution that occurs when all facets of a chronically ill person's life, and her sense of 'being-in-the-world' (p.182), unravel. Crossley (2000a) describes 'angst' as similar to the experience of vertigo, where the ill person is brought 'face to face with the abyss' (p.56), and experiences a sense of groundlessness in the absence of any bearings (of time or space), holding them in place. Time no longer anchors the person in the present, and she is faced with a screaming abyss of past, present and future, where nothing makes sense, and there is no feel of the mundane to ground her.

Clearly, the crisis of chronic illness, and of living with HIV/AIDS, is one of meaning and the challenge is to make new meanings that enable the person to override the narrative juncture and to 'mend the [narrative] tear' (Honwana, 1996). There is a need to rewrite the narrative in a way that is meaningful, that links the person as they are now to who they were before, and that revives hopes and dreams. This is not to say that the experience of chronic illness is not something terrible and senseless; but rather it can be argued that people seek to empower themselves through reclaiming their active voices, instead of embracing the sick role ascribed to them (Frank, 1995). Crossley (1999: 1686) explores whether illness stories can in fact be liberating, or if they merely function as 'repressive technologies of the self' in the Foucauldian sense, convincing people to effect practices that affirm the dominant order. She concludes that value judgements cannot be made about illness stories without 'an adequate appreciation and understanding of the individual's life world' (p.1695) where in a narrative approach there is a necessity to recognise the intertwining of personal life stories with cultural and community narratives, rather than regarding individual stories as purely dictated, on a subliminal level, by oppressive social institutions and by unwittingly internalised ideologies and discourses. So, for example, while personal illness stories may draw from, and be shaped by, the rhetorical expectations internalised through witnessing popular illness accounts, these stories may still set themselves in opposition to, and seek to subvert, the dominant biomedical narratives that require an ill person to be passive, and the illness experience to remain in the body (Frank, 1995). The ill person, for example living with HIV/AIDS, is able to claim her active voice, situating herself as more than a disrupted body, and thus is able to elucidate the full illness experience in which all aspects of the self, not merely the physical, are involved. In this way she reclaims the self she was before she became ill, and while this self may be irrevocably changed, it is more than a shell of illness.

This study, working from within a narrative psychology framework, informed by a feminist perspective, and drawing on the methodological tools of grounded theory, immersed itself in the life stories of ten black women living with

HIV/AIDS in Khayelitsha, a South African township, seeking to develop a rich, contextualised understanding of the impact of an HIV positive diagnosis on their life narratives. A particular focus was on the connections made, or the severing of connections, between ‘myself before the diagnosis’ and ‘me after the diagnosis’. Drawing on the narrative literature, it was theorised that an HIV positive diagnosis would constitute a juncture in the women’s life narratives and the researcher was concerned to explore whether, and through what means, the juncture was resolved. However, it was acknowledged that in South Africa, particularly for women, the trauma of HIV/AIDS intersects with other socio-cultural and economic disparities in ways that seem to suppress any sense of meaningfulness, and that the women’s personal stories would interweave with the narratives of their culture and community, as well as with dominant social narratives. In documenting the life stories of township woman living with HIV/AIDS, it was seen to be insufficient to focus on HIV/AIDS as an experience of overriding significance, and it was considered that the woman were likely to have experienced other significant transformatory or traumatic experiences that impacted on their life narratives, and thus were asked to recount their entire life stories, allowing them to outline and explore for themselves the significance of an HIV positive diagnosis within the context of their accounts as a whole. In so doing it was hoped that the women would be given voice, and their stories moved beyond the margins.

Methodology

Sampling

In sampling, I drew on the comparative case study approach recommended for narrative research by Franklin (1997), where participants with relevant areas of similarity are purposefully selected, as it allows for individual voices to be separated out and heard, but also provides a basis for comparison, and articulation of convergence and divergence, across accounts. My sample consisted of ten black women, between the ages of 19 and 33, living with HIV/AIDS in Khayelitsha. The women were approached by a gatekeeper through the Memory Box Project, a voluntary organization, with a setup in Khayelitsha, that works from a narrative framework with people living with HIV/AIDS. Accessing women through the Memory Box meant that the women would be loosely familiar with a narrative approach, having constructed cardboard memory boxes of their lives, which would be helpful in conducting the interviews. Having already shared part of their stories, and having experienced some form of intervention, meant that the women would be more open in exploring clearly traumatic material. All the women attended a support

group, which meant that they would have a further space to work through any difficult material that was evoked. It was recognised that having gone through the Memory Box intervention, and having attended a support group, would differentiate them from other women living with HIV/AIDS, as they would have had an opportunity to work through their concerns, and to integrate an understanding of HIV/AIDS into their life narratives. However, I was interested in accessing stories where the women had in some ways integrated the experience of living with HIV/AIDS into their accounts, and had in some sense worked through the narrative juncture (if there was in fact a juncture), so that I could document the process of transformation and explore how meaning was revived in their accounts. The women mentioned that, while they had discussed their experiences of living with HIV/AIDS, they had not shared their entire life stories before, which meant that their stories would not be contrived. By limiting the sample to black women in Khayelitsha, who had shared similar experiences of support and intervention, it meant that in some sense these women would share the same cultural and community narratives, thus increasing the internal consistency of the study, and allowing for me to draw out similarities (and divergence) across accounts. Black women, living in township areas, are one of the most marginalised groups in South Africa, and are most vulnerable to poverty and violence. It was felt that separating out their voices would allow for them to be heard, and experiences particular to their life world to be better understood and explored.

Method of Data Collection and Procedure

Material was gathered through in-depth life history interviews, situated within a narrative framework. The interview schedule was adapted from an approach advocated by Crossley (2000a) to access the participant's life story. The participants were first asked to see their lives as stories with different parts (Crossley used a book with chapters) and to recount the story of their lives as fully as possible, articulating the changes from childhood to adulthood. This part of the interview was loosely-structured, allowing the interviewee to lead the way in constructing their own life story, and stimulating the emergence of rich, in-depth material. The second part of the interview was more structured, and the participant was asked to focus on certain aspects of their experiences such as significant events, stressors, plans for the future and overall message or theme. This was designed to uncover more fully the connections that stretched across the narrator's life story and enabled me to gain an intricate understanding of the impact of an HIV diagnosis on their life accounts and to explore its interweaving with other life incidents. In-depth interviews, because of their openness and flexibility, engender a more human, empathic relationship between researcher and participant, allowing them to work reciprocally towards a sense of meaning

and understanding (Fontana & Frey, 1998; Kvale, 1996) and pattern a space for the emergence of detailed, coherent narratives (Chase, 1995; Riessman, 1993). In this way, there is an emphasis on exploration, rather than hypothesis testing, and I was able to adapt the interview format to delve into emergent material that enriched my analysis, in line with a grounded theory approach. However, in-depth interviews, contrary to the view that would have us believe that they are a 'soft option', are particularly challenging, and it was necessary for me to monitor my own processes (reflexivity) through the duration of the study, to adapt to the needs of my participants, and to deal with issues of translation, transcription and recording as they arose (Etter-Lewis, 1995; Cresswell, 1988).

The interviews took place in a small room which made up the Memory Box office in Khayelitsha. The participants were debriefed before and after the interview by the interviewer, they were assured of their confidentiality, their voluntary informed consent was obtained, and they were given a contact number in case they had any queries or problems. Interviewees were paid a small amount, in line with the principals of the Memory Box Project. A translator was present for all the interviews, since most of the women chose to speak in Xhosa. Three of the women spoke to me English. Each interview lasted for between 45 minutes and an hour-and-a-half, with an average of an hour. The interviewees were accessed through the translator who proved to be a valuable gatekeeper, informing me on any areas of uncertainty. She too was a black women living with HIV/AIDS in Khayelitsha, and worked for the Memory Box project, having been through the intervention herself, and thus helped to ease the interviewees through the process. The interviews were tape recorded and later transcribed.

Method of Analysis

Interviews were analysed using a narrative approach, but drawing on the tools of grounded theory. Franklin (1997) talks about a theme/plot orientation in which the focus is on uncovering the underlying timeline, as well as reading into the generated content and pulling out relevant themes. These can be later reworked into a cohesive narrative, with a meaningful sequence, that draws together multiple accounts. This formed the basis of my analysis and I was particularly interested in the process of transformation that occurred in the accounts, where meaning was made and the narrative juncture overcome. Crossley (2000a) recommends looking for connections across a life story, and this became important for unearthing the interweaving between the experience of being diagnosed HIV positive and other significant experiences in the account. Narrative theory recognises that stories are told as cohesive and integrated wholes, rather than a series of meaningless incidents, except in cases where

meaning is disrupted by trauma. Seeking out integration allowed me to witness the process of making meaning in overcoming the narrative juncture.

Grounded theory provides useful tools for developing or generating an emergent theory (Charmaz, 1990), and was thus suited to the exploratory nature of this study. In using grounded theory, the researcher is able to break out of old structures of thought, to develop new ways of seeing (Pidgeon & Henwood, 1997), which is useful in undertaking local research where it may not be wise to transfer theory generated in more western settings onto a South African township context. Grounded theory provided a more thorough, methodological approach to doing the analysis, since narrative authors are notably scant on providing outlines for narrative analysis. While a narrative approach resists breaking the text down into unrelated parts, it was impossible not to explore and dissect the constituent parts before weaving them into a more elaborate narrative, and the tools of grounded theory - coding, categorisation and memo writing - allowed for me to do this (Charmaz, 1990). I made use of time-ordered matrices (Miles & Huberman, 1994) which enabled me to condense the material and to gain a clearer idea of the interview structures, and to develop a general timeline. Open coding was used to capture the detail, complexity and variation of the material, and these codes were included in the matrices. Comparison within and between categories, using the visual matrices, allowed me to develop stronger, more encompassing core categories, and to draw meaningful links between categories, which tied in with the narrative aim of making connections within and across accounts. These were later integrated to form a more cohesive analysis that tied together the different stories into an overarching narrative.

Analysis

In using a narrative approach I have chosen to allow the analysis to unfold in chronological order, moving from childhood through adolescence and then adulthood, to the current experience of living with HIV/AIDS, in the way that made most sense in terms of how the stories were recounted. Since narrative theory posits an HIV positive diagnosis as a juncture in the life account, and since the impact of an HIV positive diagnosis on the women's stories was a particular focus of my research, I have divided my analysis into three sections: living in the past (before an HIV diagnosis); being diagnosed HIV positive; and living with HIV/AIDS in the now – specifically seeking to make connections across the life story. This will hopefully resonate with the way the accounts were told to me, as well as reflect the culmination of meaning that emerges with the unfolding of each story and with the accreting establishment of connections across an account. Since many of the women chose to speak in Xhosa, the language they were most comfortable with, and since their accounts were

translated during the interview and were not back-translated (Swartz, 1998), some quotes may appear in the third person, or in a rather unwieldy mix of first and third person. However, it is hoped that this will not detract from the poignancy and immediacy of the stories. All of the women except one, who chose 'Cinderella' as her pseudonym, consented to having their first names used in the text, and seemed to feel that it was important to claim ownership of their own stories.

Narrative Lives: Living In The Past

In recounting their life stories, all the women began in childhood, and their accounts of self as children were enmeshed with their experience of family life. Talking about childhood evoked vivid recollections of significant others, mostly parents and caretakers, and the import of their relationships with those others. While childhood, when talked about through the framework of adult life, was seen as a time of immaculateness where there was a 'freedom from knowing', many of the women in reviving the immediacy of childhood talked about disrupted lives and particular hardships that reverberated in their families. Often parents were absent for long stretches, while seeking or engaging in work in other cities, and children were left to the care of grandparents or other extended family members, or found themselves moving back and forth between different caretakers (the phenomenon of migrant labour in South Africa can be argued to have an immeasurable impact on personal as well as community story lines). Some relationships were recalled for the quality of care and affection, while others were remembered for their harshness, and for the obstacles they placed in the way of 'dreaming about the future'. Poverty placed a particular strain on family life, in that childhood was recounted by some as a time of struggle, with parents burdened by a lack of money, and where the desire to attend school was overshadowed by the humiliation of arriving without shoes or a jersey, or was shattered by a lack of resources. It is in childhood that 'dreaming about the future' emerges and the harshness of some of the women's lives is contrasted with the vividness of their dreams:

Nomonde: 'I am not growing up fine because of my father...He didn't treat them nicely, he was very difficult to them, he just, I can say he was abusing them to just like hit them ...(Talia: Difficult childhood) they still thinking about that, it's still sad to them... because her father didn't give them money, each and everybody at home didn't finish matric...Okay to her father's family...all the children, all the kids are educated you see, it's only this family's not, so she want to [...] to her aim she just want to be one of the [...] who educated at school, but didn't go back...'

Eunice: ‘She grow up without her father, there are eight kids at home (T: Where was her father?) passed away when she was young... Okay eh her mother was not working that time when her father passed away... It was very difficult, they were struggling very much, but the eldest kids they dropped their studies, they didn’t finish studies (T: To go work?) to go work so that the kids they can support them... it was hard, and sometimes they sleep without food, so it was a sad sad time... when she was young she’s still, she’s going to learn and she’s going to study all to the matric and she want to be something, whatever, a nurse or whatever, a doctor, but she want to be [.] she want to be educated.’

Many of the women, in retrospect, described childhood as a carefree time, untouched by the awareness of ‘big problems’ and where childhood was seen to be about ‘just doing things [and not] experiencing many [bad] things’, however this contrasted with the reality of some of the women’s lives where losses experienced in childhood, often the death of a parent or caretaker, resonated in later experiences, and were remembered, and recounted, with an intensity of feeling that suggests that these are wounds that have not healed but have been carried with the storytellers as narrative scars, and are intrinsic to their stories and to their construction of self in these stories:

Nomalunga: ‘Okay her mother was nice, she was a good person. She grow up with her mother and when she was 10 years old her mother passed away (T: Oh shame, what happened) (*Nomalunga cries*)... While she was still sitting on the chair outside, when she go outside and see her mother outside she find that her mother fell her from the chair and she was vomiting blood, they start crying and they calling her grandfather and the other people. When they come at home, when they look at her mother, she’s dead (T: Shame) it was the last.... The very very important thing, she’s missing her mother cause she was staying very happily with her mother and father. She say that memories still in her mind.’

Adolescence seemed to be characterised by a diffusion of family life, with the women experiencing the erosion of the protection that childhood offered. It was during this time that the storytellers saw themselves becoming women, and talk about boys, love and sex seeped in alongside stories of family life. It is through an awareness of an opposite sex that desires a woman’s body, and through an experience of sexual contact, wanted or unwanted, that womanhood emerges from the wake of childhood. For many of the women there was a poignant, and sometimes painful, reminiscence of the naivete with which love and sex were

first approached, and many experienced the consequences of a womanhood defined by sexuality to be life altering:

Victoria: 'When I grow up I was in the high school I was know everything now and have the boyfriend... Now when you meet a boy you know you know you going to do a sex. So I was still not so bright, I was stupid (*laughter*)... Mummy, what's he going to do to me? He's going to rape you...I just keep quiet, keep quiet, when I was in standard seven, I meet this boy...I know I see mos outside the people making love, so I make love me too. The other day I came at home, I just told my mother there's blood coming underneath so what must I do? My mummy say to me okay, okay you old now.'

Many women talked about how they were violently thrust into 'womanhood', and detailed the reverberations of traumatic and painful initiations into love. Bongwiwe, for example, describes a brutal rape which still haunts her:

'...1995 the most terrible year that was, that was terrible year for me, 1995, I was raped ... It was terrible. I started to scream, but there was no help, because it was at midnight ... there's no houses near that there, it's far away. So they hit me with a glass of beer, I had a something here and I was bleeding, bleeding, I was bleeding and so they left me there, but I was fortunate because ...why I say I was fortunate because I was raped by one person, although there were five, but I was raped by one person, the other one was tried to kill me with a knife... I sometimes even now I sometimes think of it. (T: And how does it make you feel?). I feel very sad when I think of it...It was a very bad time.'

Pricilla recounted how, as a teenager, she was kidnapped from her home in the Transkei and taken to Johannesburg by a man who forcibly initiated her into heterosexuality:

Priscilla: 'She sleep with that man because there was nobody she knows, but she was scared, it was the first, he was the first person, first man (T: Okay) that sleep with her. Oh she was very young, fourteen years...'

For others teenage pregnancy meant the loss of a dream of studying further or the loss of a carefree self. Three of the women talked about losing their babies and the devastation that this caused. The tragedy of losing a child seemed to carry through their accounts. The years between adolescence and adulthood are

ones of increasing difficulty and the accounts are scattered with traumatic experiences that mar this time. There is often a dissolution or shattering of family life as children move away to find jobs, fall pregnant, lose a parent or caretaker, or are taken away, or violated, by men. For many, it is during the later years of adolescence that the dream of education is lost, and the (often unsuccessful) struggle to find work begins. 'Dreaming about education' is painted as the possibility of having a better life, and the loss of the dream of education emerges as a moment of deep sadness and disappointment, where arguably there is a sense of grieving for a future self who could have been if the life story had unfolded as was wished. What stands out in these accounts is a sense that there are traumatic or transformatory experiences, other than receiving an HIV positive diagnosis, that impact on the life story. For some women these experiences constituted a juncture in their life narrative, where the event impelled them to re-evaluate cherished beliefs (for example where trauma annihilated the 'immaculateness' of childhood and of 'not knowing'), where their sense of self was irrevocably changed, and where certain experiences were described as a turning point from which their state of being in the world was altered:

Cinderella: 'I can say that I'm a different person and that's because when I was a child I didn't experience what I experienced, like I don't know if [...] if someone dies how you could feel. So I saw that when my child died, the pain that I felt. (T: ...How has that pain made you different...). It shows me that I'm growing up now, I'm no longer a child.'

A Narrative Juncture: Being Diagnosed HIV Positive

The stories the women told of being diagnosed HIV positive indicated that this did signify a juncture or disruption in their life narratives, and they elucidated the altering of family and community ties, as well as the tearing of temporal connections, where their previous constructions of self were no longer tenable, and where they struggled to hold onto a sense of meaning and a sense of an unfolding future. An HIV positive diagnosis for some symbolised the loss of freedom, and they described being unable to engage in activities they used to enjoy, either for fear of stigma, or because they needed to 'look after' themselves more carefully. Others talked about how the diagnosis precipitated the collapse of treasured dreams and hopes, and shattered their images of self:

Nomonde: 'Okay, to the community I always do the beauty contest. When I hear my results come positive, I just fell down because I was picturing when I'm standing to the stage then

maybe the people they gonna know I'm HIV positive so I was scared to go to the beauty contest...I just go down, I didn't do anything to my community ...Maybe I was dead now because I didn't know nothing, I just collect myself when they told me I'm HIV I must stay at home, look after my future.'

Many of the women described being washed over by a dreadful recognition of the immediacy of their death, which seemed to override all other concerns with a staggering cognisance that 'when a person is HIV she's supposed to die':

Bulelwa: 'Since I heard that when a person is HIV she's supposed to die...so I was thinking of those things, dying or what...Oh it was bad...and the counsellor told me everything, that this isn't the end, this is not the end of the world, I can live for as long as (.) I mean for a long time, I can live for a long time, all those things, but I didn't accept it at that time.'

Eunice: 'Okay, she said she's very worried about her status because when she heard somebody passed away she know that she's got HIV and she passed away. She's very worried about that...she stay two weeks without sleeping thinking about this problem.'

Concerns and ambiguity around disclosure reflected the women's anxiety that they would be stigmatised, rejected or abandoned by their families and communities, and some of the women chose not to disclose their status, which meant carrying the burden of 'knowing' alone and signified an intrusion in the intimacy of interpersonal relationships. The torment of 'keeping it to myself' was counterbalanced by the risk of 'losing all' if their status was known. Disclosure is arguably the tie between self and the community, and the decision to disclose alters the unfolding of the narrative. Shared stories about other women living with HIV/AIDS who had been chased out of home, left destitute or treated inhumanely, amplified anxiety around disclosure, so that community tales intertwined with personal story lines, and complicated the decision 'to tell or not to tell':

Victoria: 'I get upset when people telling me the lot of stories you see...the people told them bad stories (T: Like what?). Sad stories, like the other one when I told my mother, my mother chase me out. I am staying with my parents and my boyfriend hits me and my boyfriend sex me without condom, and I'm not working and running out of money, you see...I get upset...I'm

matching my story to the other peoples stories, sometimes it's one and the same...'

There are also dangerous stories that circulate, telling of others who have committed suicide in desperation, or who have died of AIDS. These stories instill a sense of despair and hopelessness, since there is a 'matching [of] my story' to 'theirs' and acknowledging that 'I too can die soon'. Some women related their anguish at the thought of dying without seeing their children grow up, and without seeing their dreams for their children realised. Many of the women received an HIV positive diagnosis during pregnancy, and their stories thus became entwined with those of their unborn babies, and their fears for themselves were often overshadowed by concern for their children.

Being diagnosed positive often occurred within the context of other traumas, which had an impact on how the diagnosis was received, and how it was incorporated into the life story. For example, Bongiwe talked about how her mother's AIDS death intertwined with her own diagnosis, so that she was terrified that she would die a similarly painful and traumatic death. Initially however, the horror of her own diagnosis was overshadowed by her mother's sickness and by her resolution to care for her. For Cinderella it is the death of her daughter by AIDS that constitutes a traumatic juncture in her account, and not her own diagnosis, and it is an awareness of resounding loss that annihilates any sense of meaning. An experience that has been incorporated into the life account can arguably be talked about philosophically, in terms of its significance, in a way that distances the narrator from the experience, and that distances 'me-now' from 'me-then'. Cinderella's graphic descriptions speak of raw, unmediated pain that tears apart narrative connections, and that destroys the temporal framework, where the past, seeping into the now, is experienced as vividly as if it were the present:

'And we go to the hospital its where I saw my daughter, she was [...] like, [...] (T: Just take your time) (*she cries*). Okay, by the time I was looking at her I didn't believe that it was my child, just because the nurses were putting a drip on her head, when the drip was finished they didn't took it out, so her head was sore ne, and when they tried to pull the needle the needle couldn't come out, so they cut it here. She didn't have all this, all this part of his head, I saw that. I didn't know that a person has 3 layers before you reach the scalp, I saw that on my child's head, (*crying*) ... (T: We can stop for a while if you want) (*she cries for a long time*)...on the Easter Monday, it was 1st of April 1998, my daughter, her mouth, we had to move then to this part and her eyes were like this, they were not looking straight as they used to,

and she was like [...] she seemed as if he was a cripple just because he was trying to speak but that time she couldn't speak, she couldn't sit, and her hand wasn't straight she was like this, but the time she was born, she was a normal person. So on Monday she passed away...'

Some women hinted at how the losses and traumas they had experienced as children and adolescents were re-evoked when they were diagnosed HIV positive. These were the scars that they had carried with them, and that were intrinsic to their stories, and which thus resurfaced when they were faced with the prospect of death. In Bongiwe's account, the inability to determine her own wellbeing emulated the powerlessness she had felt when raped, and the stigma of a positive diagnosis paralleled for her the humiliation of rape, where she talked about being the receptacle for the community's hatred and derision:

'So, so you know when people hear of a raped girl...they talk about you a lot, "She's no longer a girl, she's no longer..." So they say all those bad things about you...[...] you know, when I'm with people I feel, I feel embarrassed especially to people I didn't disclose...(T: Okay, and what do you think they'll say if they know?). They are going to say all those disgusting things you know, terrible things like you did not keep yourself, you did not look after yourself, you a rubbish.'

For others the losses (of self, of freedom, of an imagined future, of a long life, of work, of a role as carer of others) inherent in an HIV positive diagnosis evoked earlier losses: the loss of the 'immaculateness' of childhood, the loss of innocence in entering womanhood, the death of a loved one or child, the end of a relationship, and the loss of dreams. It was through carrying these losses and through incorporating them into their life accounts that the women were able to 'mend the (narrative) tear' (Honwana, 1996) and through telling alternative stories and through constructing alternative identities they were able to override the narrative juncture and 'come to terms' with their status.

Living With HIV/AIDS In The Now

While an HIV positive diagnosis seemed to represent a juncture in the women's narratives at the time when they received it, their talk about 'living with HIV/AIDS in the now' was qualitatively different. These are arguably transformatory accounts where the women were able not only to override the narrative juncture, but also to construct a new, positive sense of self. Although at the time of the diagnosis there was an overwhelming fear that 'I am going to die', in 'living in the now' the women acknowledged with sadness that they

might die sooner than hoped, but did affirm that, if they looked after themselves, they could still live a long life, and many clung to the hope of living to see their children grow. When asked what the difference was between themselves as children and themselves now, many women talked about a sense of 'knowingness', where growing up had meant an initiation into a world of adversity, where they were confronted with difficult and painful experiences, and where it became them, and not their parents and elders, who witnessed with sadness the harshness of the human condition. 'Knowingness' thus signified a loss of the symbolic 'immaculateness' of childhood - a loss of perceived innocence/naivete - and the women talked about how they were no longer carefree, but rather burdened by responsibility. 'Knowingness' also meant accepting the repercussions of an HIV positive status, acknowledging the limitations it imposed, and confronting one's mortality:

Nomalunga: '[.] She say when she was young she didn't think anything, she didn't have any problems...but now she's old, now everything she's thinking and everything she see with her eyes, but when she was young somebody tell her, she doesn't care about that, but now she's old now, there's a difference now.'

Bulelwa: 'See, I'm getting sick when I was a child...I was taken by my mother to the doctor and I [.] but now when I' sick I'm thinking of many things and I know that I'm sick, I am HIV positive maybe I can die I don't, I mean thinking of all those things.'

However, 'knowing' was also constructed as freedom from ignorance, an ability to have 'control over my life' since 'I know my status' (looking after myself, taking care of my family). 'Knowingness' precipitated a humane consciousness where the women saw themselves having a positive responsibility to help and care for others, and to share the knowledge they had garnered about HIV/AIDS. In this way, 'knowingness' formed the foundation for an alternative identity, and was used to solidify a positive sense of self. The women's stories spoke of constructing alternative identities in opposition to the restrictive 'positions' (Hollway, 1984) offered to them by their community. They talked about coming to realise that HIV did not mean the end of their lives, although HIV/AIDS as a 'death sentence' dominated social speak, and urged others to care for themselves and know that 'they could live long'. For example. Victoria, drawing on the compelling discourse of resistance used by freedom fighters during apartheid, sends out this message:

Victoria: 'Eh, this message I want to tell all the people about HIV is not killing people, look after yourself, use your treatment, *long*

live comrades...if you sleep on the bed, it's not the right way, you must wake up and do some jobs and do the washing, clean the house, so you must get strong and not always lying on the bed, it's not going to make you well.'

While the women talked about the diagnosis irrevocably altering their lives, what came through strongly in their stories was a sense of coming to terms with the limitations that HIV/AIDS had imposed, and accepting (and even subverting) their status. 'Knowing my status' was favourably contrasted with the blind ignorance of persecuting community members. There seemed to be a juncture between the way the women saw themselves and how they were perceived and spoken about in the community which impelled them to construct their identities, and to tell stories, in opposition to community narratives and, in so doing, subvert the meaning of their HIV/AIDS status. Contrasted with the women's 'knowingness' is the communities' unwillingness to know; the women talk about the ambiguity with which their status is received and the furor that wearing an 'HIV-positive T-shirt causes. They spoke about being positioned as 'dangerous' by community members who suspected they carried the virus, which was ironic as they were often not believed when they did share their status, and they alluded to subverting constructions of their status as 'risky' by pointing out that those that feared them did not know their own status and were likely 'to be next in line'. Some of the women acknowledged that it was an oppressive fear that 'if you are HIV, I may be next' that amplified hate speak:

Priscilla: 'Even the other people when they saw the sweater...the other woman saw the T-shirts in her line at home, she say who got this T-shirts, I hate this T-shirts...and [Priscilla's] mother came out and said why you hate this T-shirt, because you don't know what is the meaning. The other people they don't know the meaning of that name, they just say they hate it but they don't know their status...'

Victoria: '...if somebody point at you outside telling you bad stories about HIV you mustn't worry about that, but how you gonna stand for those things...if you point at me, you don't know the wheel is going down, next time it's going to be you.'

While community members position them contradictorily as sickly and passive, yet dangerous, the women do not position themselves as AIDS 'victims' and construct a positive identity around their HIV status by talking about how it connects them to other people, extending interpersonal lines of narrative; they are actively supported by a network of friends, family and others living with HIV/AIDS, and are able to distance themselves from ignorance, passivity and

hatred by aligning with a community that is informed, caring and active. 'Knowing your status' is elucidated as the foundation for a purposeful, caring, humanitarian subjectivity. Through joining support groups, through caring for others, through holding onto meaningful lives, and through telling alternative stories about HIV/AIDS (stories of affirmation, acceptance and expanded possibilities) the women were able to transform limiting, socially constructed identities, to take on new, dynamic selves. In rejecting the destructive and restrictive stories told by their communities, these women created alternative story lines, which enabled them to expand their narrative possibilities, to revive dreams, and to retie the threads of the past. However, many still talked about lives that were hard, worried about their children, were immersed in poverty, lived under the shadow of sickness and struggled to find work. In coming to terms with their status they could not transcend the reality of lives that were difficult, and of living in a township where possibilities were inevitably limited, but they were able to find a space for dreaming, and were able to tell stories that were meaningful.

Cinderella: 'I said we have to sit down, then she came into my room and I told her that I'm HIV positive. She closed her eyes then kept quiet for a while and after some time she just opened her eyes and said, "No, it's fine, there's no problem...but you have to look after yourself." So I felt relieved when she accepted me when I am positive.'

Discussion

Exploring the impact of the social construction of cancer, Petersen and Benishek (2001: 75) argue that women diagnosed with cancer are given the label of cancer before having symptomatic physical experiences, and that this is 'uniquely disempowering for women', for the stigma of cancer, and medicalised practice, alters their definitions of self and limits their way of being in the world:

'Furthermore, the label is imposed on her by the medical system and the meaning is initially imposed on her by the prevailing cultural expectations for the disease. Therefore the internal experience is one of unwanted intrusion on her life by the cancer and often experienced as an intrusion from both the diagnosing system and cultural images' (Peterson & Benishek, 2001: 77).

AIDS, like cancer, carries the label of 'death sentence', and because of its sexual transmission arouses intense contagion anxieties and, correspondingly, stigma

(Bolton, 1989). Women, because of their precarious and subordinate role in society often carry projections of risk for the entire population (Joffe, 1999) and, as nurturers, are expected to hold or in some way contain, in a psychoanalytic sense, the fears evoked by the epidemic. Ussher (1989; 1991) talks about the 'Madonna-Whore split' where women are placed in the unenviable position of having their sexuality defined by men: as the 'Whore', while woman may explore her sexuality, she is reviled and debased, and her sexuality subject to the whims of men's desire; and as the 'Madonna' she must stifle her sexuality and hand over her autonomy to her husband, finding an unsatisfactory solace in the sanctity of marriage and in childbearing and rearing. This becomes further polarised under the threat of the AIDS epidemic, where women, in the guise the 'Whore', are seen to precipitate their own infection and are feared as dangerous while, as the 'Madonna' are positioned as victims of men's rampant sexuality, and are pitied. Both of these subjectivities are limiting for women diagnosed HIV positive and limit the tales they can tell about themselves. Restrictive discourses about women's sexuality intertwine with constructions of AIDS as a death sentence, so that women are painted either as carriers of death, or as victims doomed to die.

What came through strongly in my interviews was a sense that, rather than chronic illness in itself constituting a juncture in the women's stories, it was the social construction of HIV/AIDS as a death sentence, alongside a recognition of the limitations that the stigma would impose, that precipitated the narrative tear. The women struggled to make meaning of the illness and to incorporate the experience of living with HIV/AIDS into their accounts because the stories that circulated about the epidemic were so horrific, and thus they could not draw on available cultural narratives to make sense of their illness experience (Farmer, 1994). It was these stories that in fact solidified a sense of despair and disruption. In the face of stories that sought to position them contradictorily as both dangerous and victims, the women were compelled to tell their own stories about living with the disease that allowed them to construct a positive sense of self, but that positioned them in opposition to community members. This limited their sources of support, and often meant bearing the burden of 'knowing' alone. There was little space to tell stories that enabled them to interweave their story lines with that of the community and, in so doing, to construct a positive way forward for the community as a whole.

Interventions that use scare tactics, with underlying messages such as 'HIV/AIDS kills' and 'sex is dangerous' reinforce contagion fears, and subsequently intensify projection, denial and dissociation. If sex is constructed as dangerous, then it is 'woman' as 'the other', and particularly 'black woman' as the ultimate 'other' - whose sexuality is seen to be dangerous and 'out-of-control' (Ussher, 1993) - that is feared. The increase of forms of violence and

abuse against women can be read as desperate attempts to rein in women's sexuality, and as men's disassociation from their own vulnerability. Strangely, although almost all interventions reiterate the importance of condom use or recommend abstinence or monogamy (Strebel, 1995), there are few that advocate alternative expressions of sexuality that do not have penetration as the pinnacle of eroticism. It can be argued that the fight against AIDS has been hindered by a refusal to look at worn constructions of sexuality, particularly heterosexuality, and at gendered constructions of masculinity and femininity, and an inability to move beyond these. Instead, interventions that take place within a matrix of domination and power, without directly addressing these issues, are doomed to fail, since 'above all else, AIDS is a highly political epidemic' (Bolton, 1989: 100).

Narrative research that posits chronic illness, particularly HIV/AIDS, as a juncture in the life narrative is clearly useful, acknowledging the tremendous impact of HIV diagnosis, and its potential to disrupt lives. However, reading HIV as a complete fissure in the account can be argued to obscure other oppressive forms of violence and trauma, often political in nature, that intersect with the disease, and that intensify the ordeal of diagnosis. For the women in my sample, for example, already living in conditions of poverty, an HIV diagnosis could potentially exacerbate existing economic disparities, where, because of their subordinate status as women and because they carried projections of danger, they were at risk of losing their jobs, of being thrown out of home, and of losing all material support. The ambivalence they experienced around disclosure cannot be read independently of their positioning as women, where disclosure was likely to evoke negative constructions of women as dangerous, would potentially intensify forms of violence and abuse against them, and could leave them destitute. Arguably, looking at an HIV diagnosis as if it is significant in itself, obscures the social and political matrix within which it occurs.

Further, the women described many traumatic experiences that they had had before being diagnosed HIV positive: deep experiences of loss: exposure to gender violence, and disheartening struggles to be educated or find work. It should be recognized that, while an HIV positive diagnosis is likely to be traumatic in itself, it potentially re-evokes past traumas and losses, intensifying pain and precipitating a massive loss of meaning, where the struggle is not only to make sense of the experience of living with HIV/AIDS, but also to come to terms with experiences that originate in the past. The losses intrinsic to an HIV positive diagnosis (of an envisaged future self for example) are likely to resonate with past losses, retraumatizing the person, and prolonging grief (Herman, 1992). For women, the stigma of HIV/AIDS, where they are constructed as sexually dangerous and frequently disparaged and debased, may summon forth

buried memories of gender violence, further disrupting their constructions of self, where they are forced to see themselves through the eyes of men as sexual 'objects' (Bartky, 1993; Irigaray, 1993), and increasing their vulnerability to a narrative breakdown. This is intensified for black women, who have been sexualized historically, are particularly prone to gender violence and, because of their marginalised position in society, are especially vulnerable to projections of risk. Reading HIV/AIDS as a juncture in the life narrative, without considering its interweaving with other traumatic experiences, and with suppressive constructions of class, race and gender, can thus function as form of social regulation, obscuring forms of oppression that interact with HIV/AIDS to heighten the horror of diagnosis and that complicate the process of making meaning in coming to terms with the disease.

On the other hand, narrative can be used as a potent feminist tool, because it does open up a space for thinking about women who reject the restrictive positions forced upon them (Hollway, 1984) and who subvert the meaning of the discourses underlying these, and because it is able to consider that women actively position themselves within these discourses in ways that make sense (Sands, 1996). In my interviews, the women, although they spoke of terrible experiences of gender violence and of being disparaged as 'whores' when it was known that they had contracted HIV, did not position themselves as victims, and instead actively constructed subjectivities in opposition to the stories that were told about them in the community. Instances of violence and rape, although clearly horrifically traumatic, were related as experiences that had become intrinsic to the women's construction of self in their stories, but that did not trap them within discourses of victimized, passive femininity (Tiefer, 1997). Instead, these discourses were subverted by the interviewees who chose to position themselves as strong women, who had pushed through hardship and carried on in the face of struggle; strength was seen to be gained through coming to terms with these experiences. Likewise, while AIDS is constructed as a death sentence in social speak, and an 'AIDS identity' is seen to be an essentially a negative one, the women positioning themselves in opposition to these discourses constructed positive identities around their status, and told stories about AIDS that subverted dominant meanings.

It is arguable that HIV/AIDS has not only disrupted individual story lines, but has also shattered community narratives, with social relations disrupted by the extreme threat of widespread chronic illness, and with community tales that situated members within a matrix of history, culture and meaning (Rappaport, 2000) becoming untenable in the face of massive, senseless loss. Farmer (1994) talks about how people draw on existing cultural narratives to make sense of the AIDS epidemic and to place it in a meaningful context, suggesting that this is valuable in that it revives meaning and restores community ties, but

pointing to the dangers of misperception, misinformation and the entrenchment of rigid thought inherent in this. Le Clerc-Madlala (1997) discussing an emergent youth culture in the townships of KwaZulu-Natal, South Africa, puts forward an interesting argument that the ethos of ubuntu ('a spirit of community and brotherhood') (p.371) - which was embraced in the liberation struggle against apartheid, when it was imbued with hefty political meaning - has been adapted and distorted in the post-apartheid era to precipitate the spread of AIDS among black youth. She argues that a cry of 'infect one, infect all' (p.370) has replaced the political 'pass one, pass all' (p.370) in the overwhelmingly oppressive space of the townships, where the 'lost generation' (p.370) of young black people grow increasingly frustrated see liberation as a dead or distant dream. Infection seems inevitable in this demoralising climate and the youth seek solidarity in death, in the same way that they would fall together under the 'bullets of apartheid' (p.370).

These are dangerous stories, uniting the youth in death, instead of life. They draw on pre-existing narratives of 'ubuntu' and 'fighting a common enemy' to imbue the illness experience with cultural meaning, in some ways seeking to make ties with the past, to override the dissolution of the present, where deep inequalities, the legacy of apartheid, are not only material, but have invaded the spirit of the townships, interlacing with the horror of the AIDS epidemic to instill feelings of overwhelming despondency. What is needed are new stories that retain the community identity, reviving temporal connections and frameworks of meaning, and that link the community as they are now to who they were before, while still allowing for the continuance of a practical existence. For example through embracing the notion of 'ubuntu' in the fight against AIDS, in banding together to demand outside assistance, in forming networks of support for community members including those living with HIV/AIDS, and through telling stories that inculcate community members with a sense of hope. In Uganda, Fleischman (1995) argues, women are banding together to confront the AIDS epidemic on multiple fronts, particularly by challenging talk and practices that perpetuate women's subservience and increase their vulnerability. Women need to contest archaic discourses and cultural practices that entrench their subordination, increasing their susceptibility to infection and heightening the trauma of living with HIV/AIDS, so that there is space for alternative stories that are empowering, and that engender connection, to emerge.

What is offered here is one particular reading of the life history interviews of women living with HIV/AIDS in Khayelitsha, informed by a narrative perspective, and drawing on the tools of critical feminism and grounded theory. Looking at the interviews from a different perspective and utilizing a different set of tools would likely render an interpretation that in no way resembles the

one given here. However, what is argued is that a narrative approach opens up a space for thinking about alternative stories that can be told, giving voice to women and those who have been otherwise marginalised. Narrative theory also suggests a way forward for those working in the field of HIV/AIDS, seeking to move those whose stories have been suppressed beyond the margins.

Further, narratives are constructed around 'social discourses and power relations, which do not remain constant over time' (Reissman, 1993: 55) making positivistic claims of reliability untenable; it would be unreasonable to assume that the stories that were shared with me would remain consistent across different settings. Likewise, qualitative studies question claims of generalisability and universality, where it is argued that specific meanings unfold in localised contexts (Durrheim, 1999; Kelly, 1999). Arguably, black women living in the township of Khayelitsha (especially as a small sample was purposively selected for this study) have specific experiences which are not generalisable to all women, and carry particular burdens with regards to the AIDS epidemic, which are intensified by poverty. However, a narrative perspective recognizes that there are universal aspects of storytelling (Gergen & Gergen, 1997), such as the transformatory capacity of stories and the human quest to imbue self-experience with meaning, which can be uncovered in a particular setting. It thus seeks to develop studies 'with detailed accounts of the structures of meaning which develop in a specific context' (Durrheim, 1999: 63) that can then be transferred onto new contexts to provide a framework for understanding the process of making meaning.

While an interpretive study does not necessarily seek to make claims of reliability of the research instrument, it is seen to be important for the researcher to monitor her own processes (reflexivity) and to explore the impact of this on the unfolding of results (Eagle, Hayes & Sibanda, 1999; Renzetti & Lee, 1993). It would be impossible for me to claim a neutral stance in working with women living with HIV/AIDS, as the very area of AIDS research is emotionally charged and, as a woman, issues of gender violence fall close to home. I have been aware of my own emotional investment in the study. Growing up in South Africa and witnessing the arbitrariness of inequality has entrenched in me a firm social consciousness. Documenting these stories was at times painful and stirred overwhelming feelings of sadness, guilt, grief and powerlessness, though more often I was in awe of the women's strength in dealing with what seemed to me to be tremendous hardship. Maintaining a reflexive awareness of my own processes made it possible to separate out my own 'stuff', from that of the women, and to stay close to the material that was given to me (Janesick, 1998). However, I cannot claim that my own interests and emotional investment did not push me in this research direction, and did not guide my unfolding analysis (and nor would I wish to).

If HIV/AIDS is seen to represent a juncture in the lives of those diagnosed positive, instigating the dissolution of meaning, then there need to be common stories that can be drawn on in reviving meaning, and those working in the field of HIV/AIDS need to consider how a space can be patterned for these stories to emerge and be sustained. Rather than fearing that these stories will precipitate the spread of the disease since they require the relinquishing of scare tactics, it should be considered that it is fear that propels the projection of risk and that intensifies the denial and disassociation that underlies risky behaviour. Interventions that do not have fear as their underlying tactic can begin to confront the epidemic in a realistic way, and can compel people to consider their own risk more effectively. Narrative theory provides researchers with a valuable tool to move those whose stories have been suppressed, and voices silenced, beyond the margins, and makes way for the weaving of alternative stories that challenge or even subvert the limitations of dominant social narratives - reviving frameworks of meaning, renewing community ties, and allowing for the emergence of alternative ways of being in the world.

References

- Andrews, M., Schlater, S. D., Rustin, M., Squire, C. & Treacher, A. 2000. *Lines of narrative: Psychosocial perspectives*. London: Routledge.
- Alleyne, A. 1998. Which women? What Feminism?. In I. Seu & M. Heenan (Eds.), *Feminism and psychotherapy. Reflections on contemporary theories and practices*, pp.43-56. London: Sage.
- Bartkey, S. 1993. Foucault, femininity and the modernisation of patriarchal power. In S. Jackson and K. Atkinson (eds.). *Women's studies essential reading*, pp. 227-231. New York: New York University Press.
- Bolton, R. 1989. Introduction: The AIDS pandemic, a global emergency. *Medical Anthropology*, 10, 93-104.
- Bruner, J. 1991. The narrative construction of reality. *Critical Inquiry*, 18, 1-21.
- Charmaz, K. 1990. Discovering chronic illness using grounded theory. *Social Science and Medicine*, 30(11), 1161-1172.
- Chase, S. E. 1995. Taking narrative seriously: Consequences for method and theory in interview studies. In R. Josselson and A. Lieblich (Eds.), *Interpreting experience: The narrative study of lives*, pp.1-27. Thousand Oaks: Sage Publications.
- Cresswell, J. W. 1998. *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks: Sage Publications
- Crewe, M. 1997. How marginal is a "marginalised group"?. *Social Science and Medicine*, 45(6), 967-990.
- Crossley, M. L. 1999. Stories of illness and trauma survival: liberation or repression?. *Social Sciences and Medicine*, 48, 1863-1873.
- Crossley, M. L.(2000a. *Introducing narrative psychology: Self, trauma and the construction of meaning*. Milton Keynes: Open University Press.
- Crossley, M. L. 2000b. Narrative psychology, trauma and the study of self/identity. *Theory and Psychology*, 10(4), 527-546.
- Davies, M. I. 1997. Shattered assumptions: Time and the experience of long-term HIV positivity. *Social Science and Medicine*, 44(5), 561-571.

- Del Vecchio Good, M., Munakata, T., Kobayashi, Y., Mattingly, C. & Good, B. J. 1994. Oncology and narrative time. *Social Science and Medicine*, 38(6), 855-862.
- Denzin, N. K. 2000. Narratives moment. In M. Andrews, S. D. Sclater, C. Squire and A. Treacher (Eds.), *Lines of narrative: Psychosocial perspectives*, pp.xi-xiii. London: Routledge.
- Durrheim, K. 1997. Social constructionism, discourse and psychology. *South African Journal of Psychology*, 27(3), 175-182.
- Durrheim, K. 1999. Research design. In M. Terre Blanche and K. Durrheim (Eds.), *Research in practice: Applied methods for the social sciences*, pp. 29-53. Cape Town: University of Cape Town Press.
- Eagle, G., Hayes, G. & Sibanda, T. 1999. Standpoint methodologies: Marxist, feminist and black scholarship perspectives. In M. Terre Blanche and K. Durrheim (Eds.), *Research in practice: Applied methods for the social sciences*, pp. 438-461. Cape Town: University of Cape Town Press.
- Etter-Lewis, G. 1995. Telling from behind her hand: African American women and the process of documenting concealed lives. In R. Josselson and A. Lieblich (Eds.), *Interpreting experience: The narrative study of lives*, pp.114-128. Thousand Oaks: Sage Publications.
- Ezzy, D. 2000. Illness narratives: time, hope and HIV. *Social Science and Medicine*, 50, 605-617.
- Farmer, P. 1994 AIDS talk and the constitution of cultural models. *Social Science and Medicine*, 38(6), 801-809.
- Frank, A. 1995. *The wounded storyteller*. Chicago: Chicago University Press.
- Franklin, M. B. 1997. Making sense: Interviewing and narrative representation. In M. M. Gergen and S. N. Davis (Eds.), *Toward a new psychology of gender*, pp.99-116. London: Routledge.
- Fleishman, J. 1995. Living HIV-positively. *Africa Report*, 40(3), 56-59.
- Fontana, A & Frey, J. H. 1998. Interviewing: The art of science. In N. Denzin & Y. Lincoln (Eds.), *Collecting and interpreting qualitative material*. Thousand Oaks: Sage Publications.

- Foster, D. 1999. Racism, Marxism, Psychology. *Theory and Psychology*, 9(3), 331-352.
- Garro, L. 1994. Narrative representations of chronic illness: cultural models of illness, mind and body in stories concerning the Temporomandibular Joint (TMJ). *Social Science and Medicine*, 38(6), 775-778.
- Gergen, M. M. 1997. Life stories: Pieces of a dream. In M. M. Gergen and S. N. Davis (Eds.), *Toward a new psychology of gender*, pp.171-184. London: Routledge.
- Gergen, K. J. & Gergen, M. M. 2000. Narratives of the self. In L. P. Hinchman and S. K. Hinchman (Eds.), *Memory, identity and community: The idea of narrative in the human sciences*, pp.161-184. New York: State University of New York Press.
- Giddens, A. 1991. *Modernity and self-identity: Self and society in the late modern age*. Cambridge: Polity Press.
- Gilbert, L. 1996. Urban violence and health – South Africa 1995. *Social Science and Medicine*, 43(5), 873-886.
- Grossman Dean, R. 1995. Stories of AIDS: the use of narrative as an approach to understanding in an AIDS support group. *Clinical Social Work Journal*, 23(3), 287-303.
- Head, J. 1993. Behavioral assumptions about the spread of HIV infection in South Africa: Myth or reality?. *AIDS Bulletin*, 2(1), 11-15.
- Heidegger, M. 1962. *Being and time*. Oxford: Basil Blackwell.
- Herman, J. L. 1992. *Trauma and recovery*. London: Routledge.
- Hollway, W. 1984. Gender difference and the production of subjectivity. In J. Henriques, C. Urwin, C. Venn and V. Walkerdine (Eds.), *Changing the subject*, pp.227-263. London: Methuen.
- Honwana, A. 1996. *Spiritual Agency and Self-Renewal in Southern Mozambique*. London: University of London.

- Irigaray, L. 1993. This sex which is not one. In S. Jackson and K. Atkinson (Eds.), *Women's studies essential reading*, p.231. New York: New York University Press.
- Janesick, V. J. 1998. The dance of qualitative research design: Metaphor, methodolatry and Meaning. In N. Denzin & Y. Lincoln (Eds.), *Collecting and interpreting qualitative material*, pp.209-219. Thousand Oaks: Sage Publications.
- Jeffreys, S. 1993. Anticlimax. In S. Jackson and K. Atkinson (Eds.), *Women's studies essential reading*, pp. 243-244. New York: New York University Press.
- Joffe, H. 1999. *Risk and 'the other'*. Cambridge: Cambridge University Press.
- Kelly, K. 1999. Calling it a day: reaching conclusions in interpretive research. In M. Terre Blanche and K. Durrheim (Eds.), *Research in practice: Applied methods for the social sciences*, pp. 421-438. Cape Town: University of Cape Town Press.
- Kvale, S. 1996. *Interviews: An introduction to qualitative research interviewing*. Thousand Oaks: Sage Publications.
- Lawson, A. L. 1999. Women and AIDS in Africa: sociocultural dimensions of the HIV/AIDS epidemic. *International Social Science Journal*, Sept, 161, 391-400.
- Le Clerc-Madlala, S. 1997. Infect one, infect all: Zulu youth response to the AIDS epidemic in South Africa. *Medical Anthropology*, 17, 363-380.
- Lieblich, A., Tuval-Mashiach, R. & Zilber, T. 1998. *Narrative Research: Reading, analysis and interpretation*. Thousand Oaks: Sage.
- Mattingly, C. & Garro, L. 1994. Introduction. *Social Science and Medicine*, 38(6), 771-774.
- Malson, H. 1998. *The thin woman: Feminism, post-structuralism and the social psychology of anorexia nervosa*. London: Routledge.
- Malson, H. 1999. Womaen under erasure: Anorexic bodies in a post-modern context. *Journal of Community and Applied Social Psychology*, 9, 137-153.

- Miles, M. B. & Huberman, A. M. 1994. *Qualitative data analysis: An expanded source book*, 2nd edition. Thousand Oaks: sage Publications.
- Ochberg, R. L. 1996. Interpreting life stories. In R. Josselson (Ed.), *Ethics and process: The narrative study of lives*, pp.97-113. Thousand Oaks: Sage publications.
- Petersen, S. & Benishek, L. A. 2001. Social construction of illness: Addressing the impact of cancer on women in therapy. *Women and Therapy*, 23(1), 75-100.
- Pidgeon, N. & Henwood, K. 1997. Using grounded theory in psychological research. In N. Hayes (Ed.), *Doing qualitative analysis in psychology*, pp.245-274. Hove: Psychology Press.
- Poku, N. K. 2001. Africa's AIDS crisis in context: 'how the poor are dying'. *Third World Quarterly*, 22(2), 191-204.
- Rappaport, J. 2000. Community narratives: Tales of terror and joy. *American Journal of Community Psychology*, 28(1), 1-24.
- Reinharz, S. 1994. Feminist biography: The pains the joys, the dilemmas. In R. Josselson and A. Lieblich (Eds.), *Exploring identity and gender: The narrative study of lives*, pp.37-80. Thousand Oaks: Sage publications.
- Riessman, C. K. 1993. *Narrative analysis*. Thousand Oaks: Sage Publications
- Renzetti, C. M. & Lee, R. M. 1993. *Researching sensitive topics*. London: Sage Publications.
- Sands, R. G. 1996. The elusiveness of identity in social work practice with women: A postmodern feminist perspective. *Clinical Social Work Journal*, 24(2), 167-186.
- Scarry, E. 1985. *The body in pain: the making and unmaking of the world*. Oxford: Oxford University Press.
- Straker, G., Mendelsohn, M., Moosa, F & Tudin, P. 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.

- Swartz, L. 1998. *Culture and mental health: A South African view*. Cape Town: Oxford University Press.
- Tiefer, L. 1997. Sexual biology and the symbolism of the natural. In M. M. Gergen and S. N. Davis (Eds.). *Toward a new psychology of gender*, pp.363-374. London: Routledge.
- Ussher, J. 1989. *The psychology of the female body*. London: Routledge.
- Ussher, J. 1991. *Women's madness: Misogyny or mental illness?*. London: Harvester.
- Ussher, J. M. 1993. The construction of female sexual problems: regulating sex, regulating women. In J. M. Ussher and C. D. Baker (eds.). *Psychological perspectives on sexual problems: new directions in theory and practice*, pp.9-40. London: Routledge.
- Viney, L. & Bousfield, L. 1991. Narrative analysis: a method of psychosocial research for AIDS infected people. *Social Science and Medicine*, 32(7), 757-765.
- Walkerdine, V. 1997. Femininity as performance. In M. M. Gergen and S. N. Davis (Eds.), *Toward a new psychology of gender*, pp.203-221. London: Routledge.

The Centre for Social Science Research

Working Paper Series

RECENT TITLES

- 16/02 *Popular Attitudes towards the South African Electoral System* By R. Southall & R. Mattes
- 17/02 *Are Urban Black Families Nuclear? A Comparative Study of Black and White South African Family Norms* By M. Russell
- 18/02 *AIDS and Human Security in Southern Africa* By N. Nattrass
- 19/02 *Public Works as a Response to Labour Market Failure in South Africa* By A. McCord
- 20/02 *Race, Inequality and Urbanisation in the Johannesburg Region, 1946-1996* By O. Crankshaw & S. Parnell
- 21/02 *The "Status" of Giving in South Africa: An Empirical Investigation into the Behaviour and Attitudes of South Africans towards Redistribution* By C. Pengelly
- 22/02 *How Important is Education for Getting Ahead in South Africa?* By M. Keswell & L. Poswell
- 23/02 *Missing Links? An Examination of the Contribution made by Social Surveys to our Understanding of Child Well-Being in South Africa* By R. Bray
- 24/02 *Unemployment and Distributive Justice in South Africa: Some Inconclusive Evidence from Cape Town* By J. Seekings
- 25/02 *Comparing Alternative Measures of Household Income: Evidence from the Khayelitsha/Mitchell's Plain Survey* By J. Skordis & M. Welch
- 26/02 *The Employment of Domestic Workers by Black Urban Households* By M. Russell
- 27/02 *Poverty, Survival and Democracy in Southern Africa* By R. Mattes, M. Bratton & Y.D Davids
- 28/02 *The Cost Of HIV Prevention And Treatment Interventions In South Africa* By N. Geffen, N. Nattrass & C. Raubenheimer

The Centre for Social Science Research

The CSSR is an umbrella organisation comprising five units:

The Aids and Society Research Unit (ASRU) supports quantitative and qualitative research into the social and economic impact of the HIV pandemic in Southern Africa. Focus areas include: the economics of reducing mother to child transmission of HIV, the impact of HIV on firms and households; and psychological aspects of HIV infection and prevention. ASRU operates an outreach programme in Khayelitsha (the Memory Box Project) which provides training and counselling for HIV positive people

The Data First Resource Unit ('Data First') provides training and resources for research. Its main functions are: 1) to provide access to digital data resources and specialised published material; 2) to facilitate the collection, exchange and use of data sets on a collaborative basis; 3) to provide basic and advanced training in data analysis; 4) the ongoing development of a web site to disseminate data and research output.

The Democracy In Africa Research Unit (DARU) supports students and scholars who conduct systematic research in the following three areas: 1) public opinion and political culture in Africa and its role in democratisation and consolidation; 2) elections and voting in Africa; and 3) the impact of the HIV/AIDS pandemic on democratisation in Southern Africa. DARU has developed close working relationships with projects such as the Afrobarometer (a cross national survey of public opinion in fifteen African countries), the Comparative National Elections Project, and the Health Economics and AIDS Research Unit at the University of Natal.

The Social Surveys Unit (SSU) promotes critical analysis of the methodology, ethics and results of South African social science research. One core activity is the Cape Area Panel Study of young adults in Cape Town. This study follows 4800 young people as they move from school into the labour market and adulthood. The SSU is also planning a survey for 2004 on aspects of social capital, crime, and attitudes toward inequality.

The Southern Africa Labour and Development Research Unit (SALDRU) was established in 1975 as part of the School of Economics and joined the CSSR in 2002. SALDRU conducted the first national household survey in 1993 (the Project for Statistics on Living Standards and Development). More recently, SALDRU ran the Langeberg Integrated Family survey (1999) and the Khayelitsha/Mitchell's Plain Survey (2000). Current projects include research on public works programmes, poverty and inequality.
