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IS IT ALL CHAOS, LOSS AND  
DISRUPTION? THE NARRATIVES  
OF POOR, HIV-INFECTED SOUTH  
AFRICAN WOMEN

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# Is it all chaos, loss and disruption? The narratives of poor, HIV-infected South African women

## Abstract

*The purpose of this article is to employ a qualitative research approach to explore whether the lives of poor HIV-infected South African women are predominated by chaos, loss and disruption. Five women were each interviewed three times over a six-month period. Data was analysed using a narrative lens as well as the theory of illness narratives. The narratives revealed that some disruption was associated with women's initial diagnoses. However, they were typically not preoccupied with HIV unless they were actively ill and not receiving antiretroviral therapy, and even for these women, wellbeing shifted over time. Moreover, women had denial-based coping strategies that kept HIV and chaos marginalised. Competing narratives concerned with poverty were typically dominant and served as a constant through which women's experiences were filtered. The case studies suggest that both mental health services and poverty alleviation are important components of appropriate health care for poor HIV-infected women.*

## Introduction

Three out of every four HIV-infected women live in sub-Saharan Africa, making it the clear epicenter of the pandemic for women, as well as the region with the highest levels of poverty globally (UNAIDS, 2006). Located within this region is also the country with the largest number of people living with HIV, namely South Africa. As in the region as a whole, women outnumber men, with black African women constituting the largest single group of infected individuals in the country (Shisana et al., 2005). Given the legacy of race politics in South Africa, these are mostly women who live in endemic poverty and who make use of public sector health services.

The context in which poor, HIV-infected women, their household members and communities live has been linked in several ways with reduced physical and psychological health, thereby placing them at risk for experiences of loss and disruption (Stillwaggon, 2006; UNAIDS, 2004; Whiteside, 2002). The available

evidence as a whole, most of which is drawn from quantitative studies conducted in developed countries, indicates higher levels of psychiatric morbidity and distress amongst infected women compared with both non-infected women and the community in general (for example Brandt, 2007; Mast et al., 2004; Milan et al., 2005; Morrison et al., 2002; Olley, 2006). This is especially true of levels of self-reported depression amongst black and/or minority group women in developed and developing countries. Still other studies, while finding high levels of distress, have questioned whether HIV-related issues are of greater significance to women than other daily stressors, most notably chronic poverty (Brandt, 2007; Ciambrone, 2001; Gillman & Newman, 1996; Smith et al., 2001).

Relatively few more considered qualitative accounts have addressed these issues and still fewer have employed a narrative approach<sup>1</sup> or the tradition of illness narratives which can potentially complement population-based research that often drives knowledge generation and policymaking largely in isolation. Two South African studies employed a narrative approach together with discursive and psychoanalytic theory to examine the experiences of poor HIV-infected women. Soskolne (2003) found that diagnosis represented a “junction” in women’s lives that compelled them to shift community ties and redefine themselves, often in the context of previous traumas and losses that diagnosis re-evoked. Like the women in Rohleder and Gibson’s (2006) study (living in the same community), they were engaged in the difficult task of constructing a positive identity despite the presence of more vulnerable parts of themselves and the negative implications of living with HIV. Soskolne and colleagues also demonstrated that women vacillated between conflicting notions of illness and health, empowerment and disempowerment, strength and weakness, and death and continuity (Soskolne, Stein, & Gibson, 2004), and that most women reported positive experiences subsequent to diagnosis (Soskolne, 2003). The latter included a re-affirmed sense of identity, hope, and acceptance regarding their status and the limitations it imposed.

Drawing on sociological theory regarding chronic illness, Ciambrone’s (2001; 2003) employed a larger, more diverse sample in the United States to argue that women who viewed HIV as the most disruptive event in their lives were more likely to be white, non-drug users. Thus for poor, predominantly African American women, many of whom (in the US) were previously drug users, HIV was likely to be just one in a series of disruptive life events and not necessarily their most pressing concern (ibid; Weinberg & Simoni, 2004). Further, many expressed the desire for others to view HIV as only one aspect of their identity, just as they viewed HIV as one part of their life trajectories (Ciambrone, 2001). For such women, HIV/AIDS was an additional stressor for individuals, families

and households already at risk due to a range of poverty-related factors, of which drug-use was just one.

The present study aimed to address the gap in qualitative research by exploring the experiences of a particularly large and at-risk group, namely HIV-infected black African women in South Africa who live under conditions of extreme poverty. The purpose of this article is to employ a narrative approach to address the question of whether their lives are predominated by experiences that are chaotic and involve loss and disruption. Further, the role of poverty in women's lives, as highlighted in both quantitative and qualitative research, will also be considered.

## **Methods**

### **Site and sample selection and composition**

The study sample consisted of five women who were participants in a larger quantitative project (n=180) on the mental health consequences of living with HIV for poor South African women. The study was conducted in a large peri-urban area in Cape Town in which nearly one in three people are HIV positive (Shaikh & Abdullah, 2003), one in two are unemployed, and the vast majority (84%) live below the poverty line (City of Cape Town, 2006). The sample size was chosen due to the fact that particularly rich data was able to emerge from a sample of the same size during pilot work. In addition, the focus of the qualitative study was to add depth to the understanding of women living with HIV and a large sample may have detracted from, rather than contributed to, this attempt.

Women were selected from the larger study sample on the basis of preliminary data analysis which indicated that their cases were extreme or unique in one of two ways: they were well adjusted despite particularly adverse circumstances (for example, multiple HIV-infected significant others or extreme poverty) or poorly adjusted despite the presence of apparent protective factors (for example, a sound support system). Psychological adjustment, in the context of the larger study, referred to the levels of depressive and anxiety symptoms reported by women. Later analysis confirmed that these women represented the outliers or extremes in the sample on at least one variable (for example, the highest depression score, the highest CD4 count, and the lowest rating of physical wellbeing). While this selection might undermine the generalisability of

findings, that was neither the primary objective of the research nor a strength of the chosen methodology. Rather ‘outliers’ represent those women whose experiences are not well captured by statistical models and to which a qualitative approach could make a useful contribution. Brief case vignettes of each of the women are provided below<sup>2</sup> (see Box 1).

## **Box 1. Case details**

### **Case 1: Lindiwe**

Lindiwe is 31 years old, unemployed and receives a disability grant. She has a grade 8 education. She lives with her mother, two brothers, an adult niece, and an eight-year-old nephew and ten-year-old niece for whom she helps provide care. She has no children of her own and is not in a relationship. Lindiwe’s mother receives a pension, her brother has a part-time job, and one of the children receives a child support grant. There is no other source of material support to the household and they often go without food.

Lindiwe tested HIV positive six years previously and had a CD4 count of 263. She rated her physical wellbeing as very poor (2/10), and had been sickly with TB for a long time as well as being hospitalised for nearly two of the previous six months. Her mother, two brothers and an aunt were her sources of support, and she did not attend an HIV-related support group. Lindiwe attended church on a daily basis.

### **Case 2: Pumza**

Pumza is 40 years old and lives in a one-room shack with her nine-year-old daughter, her thirteen-year-old nephew, and her eleven- and twenty-two-year-old nieces. Pumza has a grade 8 education and receives a disability grant. Neither she nor her adult niece is employed, and the household does not receive either formal or informal support in the form of food or other goods on a regular basis. However, the household is rarely without food. The eleven- and thirteen-year-olds are partly sustained through child support grants that their mother, Pumza’s sister, receives for each of them.

Pumza rated her physical wellbeing as fairly good (7/10) and had not been hospitalised recently although she had been ill with TB in the previous year. She tested HIV positive five years previously and had a CD4 count of 206. Pumza had been receiving ARVs for six months and after numerous initial side-effects, reported an improvement in her physical wellbeing. She was not attending a formal HIV-related support group, and considered a friend to whom she had disclosed her HIV status one year after diagnosis and who was also on ARVs as her main source of support.

### **Case 3: Zoleka**

Zoleka is 47 years old, has no formal education and lives with her two adolescent daughters (14 and 17 years), their infant children (3 and 12 months respectively), and a clan cousin and his girlfriend. While her cousin is employed, neither Zoleka nor the children receive a regular source of income and they are not supported through the cousin's income. The family receives food parcels from friends or neighbours at times, but mainly relies on waiting for food distributed at the clinics or occasionally begging in nearby, wealthier townships. They often go hungry.

Zoleka rated her physical wellbeing as below average (4/10), and had recently been treated for TB as well as spending time in hospital. She was diagnosed HIV positive one year previously after her boyfriend died of AIDS, and had just commenced antiretroviral treatment. She was not attending an HIV-related support group and had only disclosed her HIV status to her fourteen-year-old daughter who she also considered her sole source of support.

### **Case 4: Nomsa**

Nomsa is a 28-year-old part-time domestic worker with a grade 11 education. She lives with her husband, her six-year-old daughter (from a previous partner) and her adult niece. The household does not receive any material support; and are sometimes without food. Nomsa's husband is employed at a chemical factory.

Nomsa tested HIV positive three years previously, shortly after marrying her husband who also tested positive. She rated her physical wellbeing as good (7/10) and her CD4 count was 1 215 although she had been in hospital for two weeks in previous months. Her husband was receiving antiretroviral therapy and had applied for a disability grant due to periods of illness that prevented him from working. Nomsa was not yet attending a support group and described her husband as her main source of support.

### **Case 5: Buyiswa**

Buyiswa is a farmworker with a grade 9 education and lives in a one-room brick house with her mother, brother and six-year-old daughter. Buyiswa is 28 years old and has a partner who lives in her neighbourhood. Her brother is studying engineering, her daughter attends crèche, and her mother earns some income as a vendor. The household is rarely without food and receives no regular material support aside from Buyiswa's partner who contributes to their daughter's expenses.

Buyiswa tested HIV positive five years previously and had a CD4 count of 250. She felt physically well (7/10) and had not required hospitalisation recently. Her daughter, partner and mother were also HIV-positive and none were receiving antiretroviral therapy. As a result of her work hours, Buyiswa only attended a support group occasionally.

## **Data collection**

For the qualitative study on which this article draws, each woman was interviewed in her home language (with the assistance of an interpreter) on three separate occasions over a six-month period. Except for one home visit that was necessitated by the woman's poor health, interviews were conducted in a private room at the local HIV clinic and tape recorded with women's permission. Women were also provided with transport money and food stamps to compensate for their time and costs.

The interviews were largely unstructured and were underpinned by the aim of exploring each woman's personal story of living with HIV in a low resource setting. Further, given the larger study's concern with mental health, the interviews probed, where appropriate, the role and relevance of psychological experience for these women. The second and third interviews were additionally concerned with questioning women about changes in their lives since the previous interview in order to bring a dynamic perspective to the research.

Although the impact of women being interviewed previously about their HIV status (during the quantitative study) cannot be ignored, interviews were grounded in the assumption that HIV would not necessarily be a salient part of women's identities. Particularly during the first interview, the approach was therefore sensitive to allowing women to incorporate HIV into their narrative when and how they deemed it appropriate. The starting point for the interview was to have women talk about their life experience in general and to allow HIV related issues and/or psychologically-relevant experiences to unfold for further exploration.

## **Data analysis**

Narrative analysis was chosen as an appropriate approach to analyse the transcripts of multiple interviews conducted with each of the five women. A narrative approach draws on the principle that telling stories<sup>3</sup> is a defining aspect of human experience since it is through this process that individuals construct, interpret and make meaning of experience (Bruner, 1991; Sarbin, 1986; Widdershoven, 1993). While this means that narratives cannot be assumed simplistically to have correspondence with their narrators' emotional wellbeing, they have the advantage of reflecting psychological perceptions and interpretations of 'objective' events (Parker, 2005; Squire, 2005). This is important for the present study given the aim to employ case studies to



complement population-based approaches which de-emphasise the perspective of the individual.

## **A theoretical framework: illness narratives and biographical disruption**

In addition to the broader narrative lens, three key concepts taken from the work of Arthur Frank (1995), Michele Crossley (2000) and Michael Bury (1982) served to frame the analysis, namely, chaos, loss and biographical disruption. For Frank, the chaos narrative is characterised by the absence of order and purpose. The narrator cannot imagine life getting better, feels out of control and subjected to “emotional battering”, and experiences “vulnerability, futility and impotence” (Frank, 1995, p. 97). Similarly, Crossley’s story of loss is a narrative in which the person with HIV lives in an empty present, unable to project into the future or to live with hopes and aspirations. While the term “chaos” (Frank) has quite different connotations to “loss” (Crossley), there is a sense of stuckness consequent on illness in both the chaos narrative and the story of loss. In addition, there is a notion of disruption in these narratives that is explicitly part of Crossley’s discourse but not Frank’s, and that suggests a potential correspondence with Bury’s (1982) notion of biographical disruption.

According to Bury (1982), biographical disruption occurs as a result of the challenge chronic illness poses to the individual’s everyday life and fundamental belief systems. Taken-for-granted assumptions and behaviors, one’s self-concept, and the mobilisation of resources are all potentially disrupted. Further, like chaos and loss, disruption is about disturbance – psychical, philosophical or behavioural. In all three concepts, the ill person succumbs in some way to disease with the resultant undermining of sense of wellbeing, emotionally if not physically. Used in relation to HIV, this idea provides a useful parallel to the one often implicit within a traditional psychiatric paradigm on which much of the quantitative research draws, namely that HIV is a source of morbidity or mental illness. It is these constructions of living with HIV that the study aimed to explore using a case study approach.

## **Surface narratives: Disruptive experiences, chaos and loss in relation to HIV**

Examining the case studies as a series, the experiences of the five women reflect something different and more subtle than chaos, loss and disruption in relation to HIV. For one, the term biographical disruption (as used by Bury (1982)) while not irrelevant, appeared too broad and encompassing, suggesting a fairly radical shift that was not clearly evident for any of the women. Degrees of disruption and disturbance and chaotic moments were, however, narrated and lend themselves to the term ‘disruptive experiences’ rather than ‘biographical disruption’. Moreover, these experiences tended to be linked to infection and diagnosis, as in Ciambrone’s (2003) work with women in the US.

Two women had particularly difficult experiences related to diagnosis. Pumza lost both the partner who had infected her and several friends following disclosure, while Zoleka lost her house and community after her common law partner died of AIDS (before she herself tested positive): “Oh, when the man that I was staying with died, his family wanted to take everything that was in the house and it was this whole fight, they wanted to stab me... They actually wanted me to leave with nothing, but I took everything overnight without them seeing”. Subsequently, Zoleka experienced a marked loss of quality of life as she was forced to set up home in a new community without the resources and (relative) financial security that she had been accustomed to. It was during this time that Zoleka confirmed her positive status when she tested several months after her partner’s death.

For one of the other women, disruption was also associated with infection by her partner, although in a different set of circumstances. Nomsa was diagnosed shortly after her marriage and subsequent to her husband testing positive, and described feeling “shocked and upset” as well as confused as to how this could have happened (in what she experienced as a highly significant and trusting relationship). Initially, she “wouldn’t even go to the shops. I would say that I don’t need too many clothes after all I will die very soon”. She therefore confronted an issue that Frank (1995, p. 38) believes virtually every person facing a serious disease must negotiate, that is, ““Why buy shoes? Why have dental work done?”” This moment in Nomsa’s narrative, in addition to reflecting disruption, conveys the idea of lost desire for life and difficulty engaging with the future that Crossley defines as the story of loss. Nomsa’s chaos is difficulty thinking about something other than being positive at the time, leaving her stuck and emotionally challenged or depressed. One of the other women, Buyiswa, also spoke of concerns regarding death at the time of diagnosis, reporting that

“all she was thinking about was death and that HIV kills”. Buyiswa was also the only woman to test positive during pregnancy or to have an HIV-infected child, and the youngest at age of diagnosis (23 years).

Thus while four of the five women included varying difficult experiences associated with diagnosis in their narratives, these experiences were clearly time-limited (forced removal, being left by a partner) and occurred in the context of a range of other life events that did not merit the term disruption and will be discussed in more detail later. It is for this reason that the term “disruptive experiences” is preferred to “biographical disruption” that connotes a deep and substantive change in the individual with chronic illness.

Further, while the theoretical fit between Bury’s concept and Frank’s and Crossley’s narratives of chaos and loss was suggested, the experiences of these five women lend only limited empirical support to the relevance of the latter two concepts. While Nomsa talked about a degree of chaos, but more particularly the kind of difficulty engaging with the future that Crossley refers to in her story of loss, the chaos narrative and story of loss were not reflected in the other women’s HIV-related experiences. As later analysis will indicate, these were not women that were emotionally overwhelmed (Frank) or that were living in an empty present (Crossley) as a result of their HIV status. The kind of biographical disruption that Ciambone (2003) reported in her sample of North-American women is therefore not evident, nor the juncture to which Soskolne (2003) referred in her sample of South African women. At least where HIV was concerned, these women were therefore not “narrative wreck[s]”, particularly beyond the time surrounding diagnosis.

The remainder of the analysis will consider another way in which chaos can be read in the narratives of women living with HIV, as well as the kinds of narratives that compete with chaos, loss and HIV.

## **Narrating untellable chaos: HIV in the case of Lindiwe**

Staying first with chaos and HIV, it is possible that what may not initially appear to be chaos is in fact what Frank (1995) terms “untellable chaos”. In the remaining case not discussed above, it initially appeared that disruption was largely experienced in relation to events other than the diagnosis of HIV and thus the relevance of HIV-related disruption was less clear. Following her early and middle childhood during which “[e]verything was nice, I was growing like

an egg, I was getting everything ... I needed”, Lindiwe’s mother and father separated and things began to change for her. She described having lots of boyfriends, smoking, drinking and being very “silly”. However, “[a]t the age of twenty-two I accepted God and become very strong, but I was getting very sick”. She was later diagnosed with TB and eventually HIV. Therefore when Lindiwe “heard about this disease, I had already accepted God into my life” and was “not afraid for this disease” and nothing changed. For Lindiwe it therefore appeared that her parent’s separation and her later acceptance of God following a rebellious period, and not her HIV diagnosis, represented significant shifts or disruptions in her life.

On one level, this reading of Lindiwe’s narrative draws attention to the way in which her account differed from other women’s as well as the fact that disruption can emerge in the narratives of women living with HIV in ways unrelated to HIV diagnosis, an issue that will be explored in more detail in the next section. However, it is also possible to provide a counterpoint to this reading which minimises the role of HIV. Such a reading draws only on Lindiwe’s interpretation of events, an understanding that was either in her conscious awareness or that she was willing to share at that moment in the interview process. However, a closer analysis of Lindiwe’s transcripts through the lens’ of Craib (2000) and Hollway and Jefferson (2000) suggests that reliance on conscious communications and expressed emotional talk alone can sometimes lead to a superficial analysis.

The latter psychoanalytic approach acknowledges that people’s verbal communications are both consciously and unconsciously motivated and conflictual (Hollway & Jefferson, 2000). People’s talk is not necessarily transparent because the “psycho-social subject” cannot be assumed to “know[s] its own mind and... communicate this in a largely autonomous fashion” (Hollway, 2001, p. 13). Similarly Craib’s (2000) narratives of “bad faith” (Sartre’s term) involve various manifestations of the denial of psychological processes. Bad faith can manifest as the displacement of emotions into ‘unemotional talk’ as well as the denial of the complexity, contradictoriness or disruptive strength of these feelings at times. The listener/interpreter must therefore “look in two opposite directions at the same time - at the imaginary creativity with which people tell the story of their lives and at the reality of those lives - and also at the meaning of the difference” (Craib, 2000, p. 69). Similarly, Bury (2001) draws attention to the fact that illness narratives are neither fact nor fiction thus a contextual and evaluative approach is required.

Two examples taken from Lindiwe’s case illustrate an unconscious or bad faith process at work. More specifically, Lindiwe used language defensively at

moments when particular interview questions challenged coping strategies in which she was strongly invested at the time. First, Lindiwe responded with a version of one of three refrains repeatedly during the initial interview when questioned about childhood experiences or times in her life when she felt unable to cope. These variations were: “I didn’t have problems [while growing up]”, “Everything was fine”, and “Everything was very nice”; “I was not afraid for this disease”, “I’m going to live like the other people”, and “I don’t describe myself like someone who is HIV, I describe myself like the other people”; and “God accepts you no matter who you are”, I have “faith in God”. Second, having communicated effectively in English for most of the interview, Lindiwe chose to use the interpreter when asked to describe herself, when asked about difficult times in her life, and when asked to rank HIV in terms of its overall salience and importance in her life. At the very least, this response set reflects the lack of complexity which Craib (2000) refers to as one of the manifestations of emotional denial.

Seen in isolation, it might be inappropriate to assume that these statements were used defensively particularly since a research interview cannot be equated with a clinical assessment that provides the detailed history needed to interpret communications in this manner. However, not only is there objective evidence that Lindiwe’s communications were expressed repeatedly and at particular moments in the interview, they evoked a sense of their importance in the interviewer and interpreter, as well as creating confusion, frustration and uncertainty. Moreover, there was additional evidence to challenge the likelihood that “everything was fine” during Lindiwe’s childhood and that living with HIV was not disruptive. For one, Lindiwe reported that her mother used to drink too much and shout at her when she was a child, suggesting that statements that “everything was fine” are probably at least a partial idealisation of her childhood. With regard to Lindiwe’s position on her HIV status, her verbal protestations stood in marked contrast to her repeated coughing throughout the interview, a symptom of her chronic TB and her HIV. The idea that coughing symbolised the disruptive insertion of HIV into her narrative despite statements to the contrary was confirmed later by the sudden deterioration of Lindiwe’s health and subsequent hospitalisation and diagnosis with full-blown AIDS.

Taken together, this evidence indicated Lindiwe’s (conscious or unconscious) need to present herself as coping, either through denial that HIV was a source of disruption or through the use of language (not spoken by the interviewer) to distance herself from personal questions that she felt too threatened to answer directly or honestly. The gap created between herself and the interviewer/question by her confusion understanding English and the need to have the question translated into isiXhosa therefore aided Lindiwe in protecting

the coping self that she needed to preserve from the potentially bad feelings that the questions might evoke. It is possible that the idealisation of her childhood functioned in the same manner, splitting off bad associations, memories and experiences from her view of ‘everything as fine’ that she needed to preserve. The effect of this denial and idealisation is that Lindiwe’s early narrative leaves HIV the unspoken wound at the centre while the narrative circles continuously at the edge of her distress, an image on which Frank (1995) draws in his concept of chaos. Chaos stories contain an “untellable silence [which] alternates with the insistent ‘and then’ repetitions”, just as the unspoken influence of HIV is the subtext to the refrains and patterns identified above in Lindiwe’s narrative (pp. 99-100).

## **Narratives that compete with chaos, loss, disruption and HIV**

The final issue that this article will consider is what characterises women’s narratives in the absence of chaos, loss and disruption in relation to HIV. While other possibilities may also apply to the experiences of a different group of women, three key issues emerged in the present study and will each be discussed in turn.

## **Being sick versus having an illness: HIV, AIDS and HAART**

First, not all HIV-infected women are necessarily actively sick and it was the experience of being sick rather than having an illness per se that proved a key contributor to HIV as a source of chaos and disruption in women’s lives. While Lindiwe was symptomatic throughout the interview process, the other four women were in relatively good health despite their positive HIV status. For two of the women (Nomsa and Buyiswa) this was due to the early stage of their disease, while the other two had responded well to antiretroviral treatment (Pumza and Zoleka). Particularly during the home visit and final interview (at the clinic) conducted after her hospitalisation, illness and the disruptive nature of HIV occupied a very substantial part of Lindiwe’s narrative, something that was never apparent in those of the other women. Moreover, it was during Lindiwe’s earlier interview when her illness was, at least comparatively, less advanced, that she was most invested in downplaying the relevance of HIV. It was therefore the status of her health rather than her HIV status per se that drew illness and untellable chaos into Lindiwe’s narrative just as it kept such

disruption and chaos relatively absent from the stories of Nomsa, Buyiswa, Pumza and Zoleka.

While HIV/AIDS is often used as one term, it does not refer to one thing. Rather AIDS is an advanced stage of HIV infection associated with more serious illness for longer periods of time. During earlier stages of infection, periods of illness are intermittent and less acute and debilitating, and it is thus understandable that most of the women were unlikely to view themselves as ill and hence to include narratives of HIV as disruptive in their stories. Further, for women on HAART, particularly those on treatment for a substantial period of time, their experience of the disease may once again begin to approximate the earlier, asymptomatic stages with similar implications for the role of HIV in their narratives. Both disease severity and access to and duration of treatment were therefore important factors moderating the salience of illness narratives and the likelihood of disruption in women's stories. This is consistent with the results of several quantitative studies conducted both in Africa and elsewhere which report a decrease in depression and/or an improvement in quality of life over a period of between one and two years after commencing antiretroviral therapy (Jelsma, Maclean, Hughes, Tinise, & Darder, 2005; Judd et al., 2000; Mannheimer et al., 2005; Rabkin, Ferrando, Lin, Sewell, & McElhiney, 2000; Stangl, Wamai, Mermin, Awor, & Bunnell, 2007).

## **Coping with HIV: The role of self-distraction and other denial-like processes**

Second, the strategies that women used to cope with their HIV status were associated with the extent of chaos that they experienced. In particular, the narratives shed light on the role of self-distraction and other similar, denial-like processes (to use Lazarus and Folkman's (1984) term) in distracting women from the reality of their lives and thereby reducing, or at least managing, anxiety and distress. If focusing on HIV is a source of distress and a factor contributing to perceived chaos, then diverting one's attention may have the effect of reducing distress and disruption. As Pumza stated, "I ... miss the [support] group because when I'm there I forget about all these problems. But the minute I come home I'll start thinking about the fact that I have all these problems and I need to solve them. They won't just disappear." This is consistent with the findings of several quantitative studies from the US (Catz, Gore-Felton, & McClure, 2002; Commerford, Gular, Orr, Reznikoff, & O'Dowd, 1994; Sherbourne, Forge, Kung, Orlando, & Tucker, 2003; Simoni & Cooperman, 2000; Simoni & Ng, 2000) as well as four qualitative studies from Africa that have confirmed the salience of avoidant coping as a predictor of psychological

adjustment (Austin, 2003; Dageld & Duckert, 2008; Keogh, Allen, Almedal, & Temahagili, 1994; Van Woudenberg, 1998). The most recent qualitative study, conducted with rural South African women, reported that coping strategies involving avoidance of, escaping from, or minimising HIV were predominant (Dageld et al., 2008). While the present study highlighted the utility of these strategies in coping with emotional distress, Dageld and Duckert argue that these strategies may be adaptive in a society with scarce resources. Both are reasonable explanations that further highlight the role of both HIV and poverty (scarce resources) in the lives of poor, HIV-infected women in South Africa.

Two other coping strategies that had the same outcome as self-distraction (whether intended or not) were women's acceptance of their HIV status and their characterisation of HIV. With regard to the latter, Zoleka stated,

‘When I heard that I’ve got it, I did not worry myself at all, I just told myself that everybody has got it, the person who does not have it is the one who has not tested. Even here [the clinic] you see that it’s full; everyone has got this.’

Further, with regard to acceptance, all women referred to acceptance of their status in some manner during the interviews, either directly or indirectly. For example, Zoleka stated that she had accepted her HIV status because she could not change the situation and must therefore learn to live with it, while Buyiswa “believes that she wouldn’t be bothered [about this thing of people calling other’s names in the street]... because she is opened about HIV”. Just as acceptance allowed women to “live with it [HIV]”, characterising HIV as a common illness that “everybody has” served to distract women from the fear and depression associated with other characterisations of HIV, for example, that “HIV kills”. Both strategies, like self-distraction, therefore moderated the potential distress and disruption that women faced as a result of their HIV status.

However, other elements of women's stories clearly demonstrate that such strategies were not equally effective at all times and across all situations. Thus HIV-infected women who function best (as with other stressors) are likely to be those that are able to adapt their coping strategies flexibly to the demands of different contexts and circumstances (Lazarus & Folkman, 1984). As Lindiwe's experience demonstrates, for example, denial and self-distraction were sustainable during periods of comparatively good health (early in the interview process), but it was acceptance of the possibility of death when her illness later reached full-blown AIDS that was associated with healthy functioning. This manifested in the shift from Lindiwe's construction of herself and her family as



“fine” to the more differentiated view that her household’s situation was “a little bit good”.

The transition away from denial-like processes in the advanced stage of disease is an important one that the other women had not yet been confronted with, given their comparatively good health. However, the relevance of shifting positions on the salience and disruptive nature of HIV was also apparent in the fact that while most women reported that HIV was “low on the list” of important life events, they characterised HIV as salient in other ways. For example, Buyiswa reported that “we have completely different needs as HIV positive people” while Pumza expressed the view that “HIV is a blood disability. It is forever, you are going to be buried with it”. However, Lindiwe’s comment regarding the visibility of HIV perhaps best expresses its salience at certain stages of the disease, and thus the extent to which women’s attempts at self-distraction and denial-based coping are challenged:

‘... it’s easy to see a person with HIV... once you become thin, people will think that it’s HIV. Once your face turns dark, people will think it’s HIV. If you just sick with something else, people will just think you are HIV. Even when you are coughing...’

## **The relative salience of competing narratives**

The third and final point regarding the absence of chaos, loss and disruption in relation to HIV is that this may oftentimes be a function of competing narratives that assume greater salience in women’s lives, either at a given point in time or more generally. This manifested in two ways that are important for the present argument. First, as has already been suggested, there were issues other than HIV that emerged as salient in women’s narratives. Second, in terms of the structure of the narratives, women usually took time to get to the issue of HIV. With regard to the latter, given the opportunity to insert HIV into their narratives when and how they saw fit, four of the five women spoke first, and at some length, about other aspects of their life experiences including their early childhood and family circumstances. In these cases, while HIV was part of women’s narratives, it was not sufficiently important to be mentioned first. The exception was, once again, the case of Lindiwe whose acute illness forced HIV to the beginning of her narrative (although she denied its salience). And as argued earlier, this salience was sustained through most of the narrative due to her poor health relative to the other four women.

Turning to the content of the narratives, issues related to mothering (rather than HIV) were important for three of the women. In the case of Zoleka, the number of dependants for whom she was caring increased from four to five during the course of the research, when a niece arrived unexpectedly in Cape Town. At the time, Zoleka was already living with and caring for her two teenage daughters and their two infant children. Given her limited resources – she had no regular income at the first meeting – this was a potentially difficult situation. Nonetheless, Zoleka’s response to her niece’s arrival was to say that “it is exciting because I never had like a lot of children. I only managed to have two and now that the house is full, I must work hard to feed them”. Although she was clearly aware of the likely difficulties involved in having “to feed them”, taking on an added care role was a salient and valued aspect of her life. In this respect, Zoleka’s experience was consistent with the results of a metasynthesis of qualitative studies focusing on mothering in HIV-infected women which reported that being a mother (or carer) was central to these women’s lives (Sandelowski & Barroso, 2003).

However, while mothering was an important narrative for Zoleka and two of the other women (Nomsa and Pumza), the most dominant competing narrative across the five cases concerned women and their household’s socio-economic situation. In fact, financial pressures emerged as a narrative for each of the five women at some point during the interview process and two of the three above narratives, while most explicitly concerned with mothering, were also linked to socio-economic issues. Zoleka’s comments are particularly apt in this regard:

‘HIV has never been a problem to me. My major problem has always been finances. There were times when I couldn’t even afford bath soap; I didn’t even have clothes to wear. Things have gotten better now because I have a [disability] grant; the only thing I would like to have now is a job.’

While being diagnosed HIV positive might result in a transitory preoccupation with death and even the loss of relationships, poverty and the “suffering”, “stress”, “headaches” and “pain” it can cause are more long-standing problems. And it was poverty through which these women’s experience of life, including an HIV diagnosis, seemed to be continually filtered. The “problems” to which women referred most often as causing “difficulties” for them, their families and household members were financial ones. As Zoleka said, “I have no worries now. The only time I struggled was before I could get this money; when I lived on handouts from other people or come to the clinic for food parcels”. These were not women whose stories were preoccupied with health and illness. Rather,

given the freedom to choose when and how to enter HIV or AIDS into their narratives, many women spoke of other issues first.

Shifts and changes certainly occurred. For example, Zoleka's daughter started and ended a piecework job, and recommenced school; and Zoleka and Nomsa's husband began receiving disability grants. However, these shifts were experienced as interwoven in women and their households and families' daily lives, as part of the typical ebb and flow. As much as things changed, they also stayed the same, and perhaps this was most profoundly about the level of poverty in which these women had spent their lives. Zoleka, for one, had grown up on a farm in one of the poorest regions in South Africa (the Eastern Cape), while as an adult she experienced times when she "couldn't even afford bath soap". This is perhaps what Miliband meant when he referred to poverty as "an atmosphere in which large numbers of people live their lives and which threatens at any time to assume a more concrete presence" (Miliband, 1974 in Levetan, 1984 in Wilson & Ramphela, 1989, p. 185). Living in poverty and dealing with its associated stressors was 'normal' for these women and it is within this context that the reduced salience of HIV and its limited disruptive role must be understood, even for a woman such as Lindiwe who experienced periods of acute illness.

Consistent with evidence from other international studies, women who have experienced greater hardship in their lives than a positive HIV diagnosis, including living in long-term poverty such as in the present study, are more likely to experience HIV as one of a range of stressors and therefore not completely novel and overwhelming (Bungener, Marchand-Gonod, & Jouvent, 2000; Semple et al., 1993; Weinberg et al., 2004). As Ciambone (2003) reported in her study of US women, those that considered HIV as the most stressful event in their lives tended to come from better backgrounds while for poor, predominantly African American women, many of whom were previously drug users, HIV was likely to be just one in a series of disruptive life events. Of course, the ready availability of antiretroviral therapy is likely to be a further mediator in this context. Kalichman and Simbayi's (2003) study in Cape Town, South Africa, also demonstrated that residents identified HIV as part of a cluster of stressors related to their social context – less serious than crime but not different from violence and unemployment. This may further explain the role afforded to poverty in the present set of findings as well as other studies conducted in poor communities across both the US (Gillman et al., 1996; Marcenko & Samost, 1999; Semple et al., 1993; Smith et al., 2001) and Africa (Keogh et al., 1994; Olley, 2006; Van Woudenberg, 1998).

The intention of the above argument is not to suggest that poverty did not sometimes introduce the level of chaos and disruption into women's lives discussed earlier in relation to HIV. In fact the most powerful chaos narrative told amongst the women points to the salience of poverty and not HIV. Pumza's narrative acquired an almost frantic quality as she attempted to communicate obvious distress at her inability to meet her financial obligations, with "I can't manage" and "everything depends on me" as intermittent refrains. Further, she cried quietly while referring to several pages of letters and accounts that she had brought with her in a shopping bag, which indicated that she was "still owing a lot" despite having paid money towards settling her debts. While some details of her experience were therefore communicated, as was the emotion it evoked, the narrative lacked a coherent sequence, perpetually interrupting itself and conveying a clear sense of Pumza's feeling of being out of control, vulnerable and impotent in the face of circumstances. The refrains "I can't manage" and "everything depends on me" were both the substance of her narrative and that which interrupted its attempt at coherence, and clearly represent the possibility of chaos associated with poverty.

## **The relationship between poverty and HIV**

One final point that bears mentioning is the fact that women's stories constantly confront one with the difficulty of separating poverty and HIV/AIDS. While the preceding discussion has largely highlighted narrative moments in which either HIV or poverty were associated with chaos, loss and disruption, such distinctions are inevitably false. This is particularly true of an attempt to view women's narratives in a broader and more continuous nature that best approximates lived experience.

There are several instances of this interaction in women's narratives. For one, women spoke of inadequate food and poor housing conditions threatening the ability of HIV-infected women to take proper care of themselves. Both Pumza and Zoleka stated that "dirty shacks" are "not suitable for sick people". Second, women referred to the fact that HIV status might threaten job security or limit job opportunities. Nomsa reported that "there are jobs where they demand that you do an HIV test before, so that limits chances of HIV positive people. ... It does worry me, because it might happen to me too". Third, in addition to contributing to poverty, being HIV-infected can moderate poverty and wellbeing where it provides an opportunity to access social assistance in the form of a disability grant (received by many PLWHA). The reason why both Pumza and Zoleka had 'fewer worries' is that they were receiving disability grants, and in Zoleka's case this was the catalyst for her beginning to work and save money

and thus improve her family's situation. The nature of the social security system, and particularly the criteria for the disability grant, threatens the stability of the grant as a moderator for women on HAART<sup>4</sup>. However, the possibility of obtaining such a grant in the context of poverty and fairly limited forms of state social assistance nonetheless points to another interrelationship between the socio-economic and HIV statuses of women living in resource poor communities. Such an interrelationship between poverty and HIV/AIDS more generally, while complex, has been convincingly demonstrated by prominent scholars (Stillwaggon, 2006; Whiteside, 2002).

## **Conclusions, limitations and recommendations**

In conclusion, this article has attempted to respond to the question of whether the lives of a group of poor, HIV-infected women in South Africa were all about chaos, loss and disruption. There certainly was disruption of some form associated with HIV for all of the women, most notably at the time of initial diagnosis. However, what was clearer was that women were typically not preoccupied with HIV unless they were actively ill and not receiving antiretroviral therapy, and even for these women, wellbeing shifted over time. Moreover, women had denial-based coping strategies that kept HIV and chaos marginalised. Such moments were experienced at times, but were largely positioned alongside other competing narratives, in particular poverty, which was typically dominant and served as constant through which women's experiences were filtered. For at least one of the women, a story of poverty as chaos emerged. However, for most it was part of their broader life experience and it was often this reality that edged HIV toward the margin of their lives and that provided a significant counterpoint to the possibility of loss and disruption.

Three limitations of the research must also be acknowledged. First, the need to employ a translator presented a challenge for an analytic approach in which language and meaning are central. This was especially true given that the research focused on mental health issues. Not only was difference in language literally a barrier to understanding, language is an expression of culture and culture a mediator of the expression and form that mental health takes (Patel, 2001; Swartz, 1998). Thus it is possible that some of the emotional content central to evaluating the extent of chaos and disruption in women's narratives was missed by the interviewer during the interview or by the transcriber during transcription, or that it was simply lost in translation due to the gap between an utterance and its translation. In order to address this, every attempt was made to draw on a verbatim translation of the women's responses and the same person

was used to translate and transcribe in order to enhance the validity of the transcripts.

Second, it may be that the “sense of need for a personal voice depends on the availability of the means – the rhetorical tools and cultural legitimacy – for expressing this voice” (Frank, 1995, p. 7). Women required a voice for their emotional experiences and vulnerability, and perhaps this was a kind of talk that was unfamiliar and that did not fit their expectations about what was permitted in a clinic setting (where the interviews were conducted). Women may also fail to rehearse such stories in a setting where they lack cultural legitimacy. Nurses, who constitute the frontline of public HIV services in South Africa and much of the developed world, are mostly accustomed to hearing stories about physical symptoms, CD4 counts, medication side-effects, appointment times, disclosure and support group attendance - the tropes of public HIV discourse. Thus complaints about difficulties that fall outside of these tropes are likely to be either silenced or unheard by staff.

Third, the findings of the study are not necessarily representative of the experiences of all women in the research community or generalisable to all poor, HIV-infected women living in South Africa or in the sub-Saharan region. This is particularly true since the five selected women represented outliers in the broader study sample. Having said that, comparison of the socio-demographics of the broader sample and census data for the community in which most of the participants lived revealed a high degree of concordance, thereby suggesting good representivity (City of Cape Town, 2006). Further, despite being outliers in one or another respect, the women selected for the qualitative study all lived in deep poverty in an area with high HIV prevalence, something which they have in common with most other infected women in South Africa. Consequently the findings provide a substantive point of departure for understanding the experiences of other women living in such communities elsewhere in South Africa, with due attention to matters of particular salience in local areas.

While acknowledging its limitations, the study’s findings suggest that appropriate public sector health services for poor HIV-infected women should address women’s mental health needs, poverty alleviation, and should view women’s lives more holistically. HIV-infected women who experience disruption (whether related to HIV status or not) would benefit from mental health services, particularly at potentially vulnerable periods in the illness trajectory, such as when they are most acutely ill and without access to antiretroviral therapy. The call for mental health services for PLWHA in developing countries where HIV prevalence is highest is a recent, but important, contribution to policy discourse (Freeman, Patel, Collins, & Bertolote, 2005).

However, since HIV and vulnerability constituted only part of women's narratives in the present study, appropriate care must also acknowledge, if not directly address, women's broader life experiences as opposed to focusing on disease management alone.

Finally, on a related point, given the salience of poverty for all of the women in the study, their voices contribute to other research which advocates poverty alleviation as part of comprehensive HIV services (Dageld et al., 2008). The case studies suggest that interventions should focus not only on the individual/psychological level, but also on the structural level in order to improve the lives of poor infected women. An approach that integrates the psychological and social needs of HIV-infected women with current medical approaches would also be consistent with the recent recommendations of the World Health Organization (2005; see also Baingana, Thomas, & Comblain, 2005; Freeman et al., 2005). Moreover, it would build on the South African government's policy to provide comprehensive, community-based mental health services that articulate with other health services (Department of Health, 1997).

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#### Notes

<sup>1</sup> The work of Michele Crossley (1997; 1998) and the recent contribution of Corinne Squire (2007) are particularly good examples of the use of narrative analysis to explore the lives of people living with HIV/AIDS. However, they do not focus on women specifically and have therefore not been reviewed in detail.

<sup>2</sup> Pseudonyms have been used in order to protect the anonymity of the women interviewed.

<sup>3</sup> The debate regarding the differentiation of the terms 'narrative' and 'story' is not important for the present analysis, thus the terms will be used interchangeably.

<sup>4</sup> Due to South Africa's social security policy at the time of writing, those on HAART are likely to lose their disability grant once their health improves sufficiently, with no substantial alternatives for state support and in the context of high rates of unemployment. For recent contributions on the debate surrounding this issue see Natrass (2005) and LeClerc-Madala (2006).

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