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Biographical disruption, HIV/AIDS and chronic poverty

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The concept of biographical disruption speaks about refers to the ontological uncertainty and questioning that accompanies the suffering experienced when one is living with a serious or chronic illness. Most studies on biographical disruption have been conducted among Western individuals. The few qualitative illness studies among individuals living in chronic poverty and/or other debilitating social circumstances indicate that such individuals sometimes experience the phenomenon of biographical disruption differently. This is evident in a Grahamstown biographical study on six women living with and affected by AIDS and generational poverty. This finding echoes other empirical studies on women living with HIV/AIDS and chronic poverty in sub-Saharan Africa, India and the USA.

Biografiese ontwrigting, HIV/VIGS en kroniese armoede

Die begrip biografiese ontwrigting verwys na die ontologiese onsekerheid en bevraagtekening wat met die ervaring van swaarkry saamgaan in die geval van iemand wat met 'n ernstige of chroniese siekte saamleef. Meeste studies oor biografiese ontwrigting is onder individuele Westerlinge gedoen. Die enkele kwalitatiewe studies oor siekwees tussen mense in chroniese armoede en/of met enige ander ontwrigtende sosiale omstandighede, toon aan dat die ervaring van biografiese ontwrigting anders is. Dit kom na vore in 'n biografiese studie van ses Grahamstadse vroue wat deur HIV aangetas is en daarmee saamleef. Hierdie vroue, uit verskillende generasies, bevind hulleself in armoede. Soortgelyke bevindinge kom voor ander empiriese studies oor vroue met HIV/VIGS in 'n toestand van chroniese armoede in sub-Sahara Afrika, Indië en die VSA.

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How does living with a chronic or serious illness disrupt the life of an individual and that of her/his close family members? A review of literature on the concept of biographical disruption (Bury 1982) provides a compelling analytical framework for exploring the profound, mostly negative emotional changes that occur when one is living with a chronic or serious illness. However, empirical studies among Africans and Indians with a predominantly collectivist world view reveal that biographical disruption does not necessarily result from a chronic or serious illness (Chisaka 2007, D'Cruz 2004). Individuals in these societies conceptualise their identities mostly in collective terms. For this reason, they make sense of their biographical disruption due to a grave illness in relation to others, and this lessens the impact of the experience of illness. Similarly, living through several generations of chronic poverty or other debilitating social circumstances cushions the assault of illness on identity.

Following the literature review is a discussion of a life-story study (Chisaka 2007). The study shows how the concept of biographical disruption is permeated with poverty and intergenerational personal narratives. The initial aim of this study was to apply the concept of biographical disruption to women living with HIV/AIDS and experiencing poverty. However, as the study progressed, it became apparent particularly during the interviews that the women's experience of generations of poverty was of greater concern to them than that of HIV/AIDS. Of the six participants, only one woman centred her life story on AIDS. The narrative of her illness exemplifies a biographical disruption caused by a serious illness. The finding that chronic poverty was more threatening than the reality of AIDS echoes other studies on HIV/AIDS among poor women.¹

1 Cf Baylies & Bujra 2000, Ciambone 2001, D'Cruz 2002 & 2004, Feldman *et al* 2002.

1. Biographical disruption

Empirical studies often show that chronic illness is experienced as a “critical situation” not only for the physical suffering, but also for the accompanying ontological uncertainty it inflicts on individuals (Lawton 2003: 25). The latter relates to the sense of disruption by something that is perceived to be beyond the control of the individual, beyond fairness and beyond logic, and of being forced into an awareness of insecurity (Crossley 2000: 78-89, Kleinman 1988: 29, Murray 2000: 339-40). The ontological uncertainty experienced by individuals living with a chronic or serious illness is addressed in terms of their biography and their stock of common knowledge about health and illness (Radley 1993: 109). The disruption affects how one views one’s self-identity, and has led to the formulation of concepts such as “biographical disruption” (Bury 1982: 167-82), and “loss of self” (Charmaz 1983: 167-98). A common thread running through these concepts is that the most basic, underlying existential assumptions that people hold about themselves and the world are thrown into disarray during a serious or chronic illness. Another shared assumption is that the onset of physical illness entails a whole range of challenges regarding the individual’s interconnected conceptions of the body, the self and the world. This includes a basic sense of space, time and language (Crossley 2000: 82-3).

Biographical disruption due to an illness extends beyond the affected individual, because “the experience of illness is not bounded by the bodies or consciousness of those who are ill, it reaches to encompass a household, a family, or a social network” (Kleinman & Seeman 2000: 231). The suffering is thus located not only in the individual with the illness, but also in those closest to her/him. This negative impact on close family members is evident from the stories of the two sets of three generations of women in the research finding discussed later in this article (Chisaka 2007).

Commentators suggest that during an illness not only one’s body but also one’s identity is threatened and disrupted (Bury 1982, Charmaz 1983, Kleinman 1988). In this sense chronic illness can be understood as disturbing not only one’s embodied self but also “the

trajectory of one's whole life at a number of levels" (Nettleton 1995: 88). For this reason the study cited in this article used the life story data collecting method to explain the women's personal understanding and interpretation of disrupted biographies as a result of their living with HIV/AIDS. This includes the disruptions in their relationships. For example, one woman living with AIDS lamented the reversal of the caregiver role between herself and her mother. As the eldest child, she is expected to care for her aged mother, who also has medical problems. Instead it is the mother who cares for her because she is now suffering from AIDS-related illnesses. When she is not ill, she is too weak to do anything. Other researchers have also pointed out that the experience of illness is "fundamentally inter-subjective" (Crossley 2000: 86). This means that not only the individual living with an illness is affected, but also the lives of family members and others close to the individual. In the case of debilitating illnesses such as rheumatoid arthritis, physical dependency on others becomes a norm and this disrupts "normal rules of reciprocity and mutual support" (Bury 1982: 169). Like Bury, Charmaz (1983: 169-70) highlights how "loss of self" is a multifaceted experience for the participants in her study. She notes that by virtue of their illness, the participants often led restricted lives, experienced social isolation, were discredited by self and others, and experienced the humiliation of being a burden on others.

The inability to reciprocate in social interactions and the progressive physical dependence on others exacerbate the suffering of the ill individual and affect how the illness is experienced. For example, D'Cruz's (2002: 413-34) study shows the negative feelings associated with being dependent because of illhealth. Participants in this study noted that they felt the need to reciprocate the help received, either physically or emotionally. This is their way of affirming their social significance, as well as a way of compensating for their predicament. This feeling was articulated by both AIDS patients and their caregivers. Dependency on others also intensifies the shame and other emotions related to being HIV positive. The above points to the complex and overlapping ways in which different aspects of the illness experience (for example, emotional anguish, pain, strain on relationships, social isolation, and so on) may reinforce and amplify

one another (Lawton 2003: 26). For example, Charmaz (1983) observed how “loss of self” in one area of her participants’ lives often spiralled into a loss of another aspect of their lives, with serious negative consequences. To illustrate, she notes how stigma associated with a chronic illness causes individuals to experience feelings of low self-esteem and withdraw from social activities. The latter, in turn, may exacerbate feelings of “loss of self”, as this “leads to fewer opportunities for constructing a valued self” (Charmaz 1983: 172).

1.1 Does collectivism (*ubuntu*) help?

It must be pointed out that the consequences of illness on self and identity, on the loss of self or of control, and on biographical disruption may not be universal (Pierret 2003: 9-10). Most research on the experiences of chronic illness on self-identity has been carried out among Westerners.² Non-Western philosophies and ways of being in the world may influence how the onset of a serious or chronic illness is experienced and it may influence the meaning of the illness on selfhood. This, in part, is due to the collectivist nature of the social context in non-Western societies (D’Cruz 2004: 421). In these societies interdependency (for example, the Southern African concept of *ubuntu*) is preferred to Western independence and self-autonomy (Ramose 2002: 237). *Ubuntu* is a world view where

... the distinctive collective consciousness of Africans is manifested in their behaviour patterns, expressions, and spiritual self-fulfilment, in which values such as universal brotherhood of Africans sharing and treating other people as humans are concretised (Prinsloo 1998: 41).

This philosophy is captured in the common saying “I am because we are: I exist because the community exists” (Gbadegesin 1998: 293). Therefore, the individual’s illness and its devastating consequences are shared by the collective, especially the family. For example, D’Cruz (2004) found in another study that familial values underpinned caregiving behaviour towards AIDS patients. The participants expressed “innumerable reasons such as a sense of duty, love, lack of choice, humanitarian concern and social reasons” (D’Cruz 2004: 421) as

2 Cf Bury 1982, Charmaz 1983, Ezzy 1998, Fife & Wright 2000, Williams 1984.

motivation for caregiving. All this may cushion the negative impact of illness on self-identity felt by patients in individualistic societies.

1.2 What about poverty?

Besides the cushioning effects of collectivism, living in poverty and its negative consequences or other “disruptive life situations” (Ciambrone 2001: 517) may also minimise the upsetting impact of a serious or chronic illness on the concept of self. This is illustrated in Ciambrone’s (2001) study, in which the participants were purposely drawn from poor, HIV-positive African-American women with drug and other related problems. Despite the fact that HIV infection posed an immediate threat to their sense of self and had a lasting impact on their future plans and goals, retrospectively 71% of the participants did not consider HIV to be the most disruptive event in their lives (Ciambrone 2001: 532). This is expressed well by a woman who describes her former violent and abusive intimate relationship relative to her HIV-positive status:

I would say the hardest time was the abuse [...] Because when you are in an abusive relationship, your body’s just dead. It’s just like a robot, that’s doing what it has to do. Compared to just living with HIV, I would rather live with having AIDS and HIV any day compared to being abused [...] When you are abused you are nothin’, I had nothing. I had no feelings, I had nothing, I was just one cold person (Ciambrone 2001: 522).

Ciambrone and other researchers conclude that, in poor countries in particular, “HIV may be just another in an ongoing string of disruptive events” (Ciambrone 2001: 532).³ In addition, widespread poverty and political problems in sub-Saharan Africa, South Asia and other developing regions mean that narratives of illness are sidelined in research in favour of macro-problems, such as:

Extreme disempowering and debilitating poverty; economic recessions, foreign debt, the effects of economic structural adjustments programmes, and massive unemployment; underdevelopment and poor infrastructure; weak leadership, poor governance and corruption; political instability, conflict and violence; pervasive patriarchy, with women discriminated against and disadvantaged;

3 Cf Baylies & Bujra 2000, D’Cruz 2002 & 2004, Feldman *et al* 2002.

the effects of droughts, floods and pestilence on agriculture; livelihoods and food security; and rampant disease, including malaria, tuberculosis, waterborne disease and malnutrition — and now HIV/AIDS (Ferreira 2004: 1).

This overrepresentation of macro-issues does not, however, deny the existence of individual suffering among Africans or Asians, as the research in this article attempts to highlight (Chisaka 2007). Other similar studies in sub-Saharan Africa show that concepts of “biographical disruption” or “loss of self” may well be utilised in interpreting the negative effects of chronic illness on selfhood and relationships (Cardo 1999). The onset of a major illness, let alone a chronic one, necessitates a rethinking of one’s established life and the disrupting effects on selfhood and relationships, regardless of one’s social context and world view.

1.3 Chronic poverty and HIV/AIDS

The phenomenon of chronic poverty, according to report of the Chronic Poverty Research Centre (CPRC 2004-5: 3), is a household’s inability or lack of opportunity to improve its circumstances from generation to generation. People remain poor for much or all of their lives and are unable to sustain themselves through difficult times. The following Ugandan saying articulates well the manner in which this type of poverty is easily passed on:

Some poverty passes from one generation to another as if the offspring sucks it from the mother’s breast — Group of disabled Ugandan women (CPRC 2004-05: 3).

This observation is echoed in May’s (1998) study, in which he concludes that being born in a poverty-stricken household, or marrying into such a household, is a key long-term trend for chronic poverty (May 1998: 35). This is also echoed in the accounts of the three generations of women participants in the Grahamstown study discussed later in this article (Chisaka 2007). The octogenarian and septuagenarian grandmothers were born in impoverished households, married equally poverty-stricken husbands and bore children (daughters and granddaughters in the study) who continue the trend.

In addition, people living in these conditions often suffer and even die from preventable diseases, and are extremely vulnerable to epidemics (CPRC 2004-05: 3). This type of poverty exacerbates the impact of episodic calamities, such as the HIV/AIDS pandemic (Kleinman *et al* 1997: xx). Furthermore, people in chronic poverty face layers of social discrimination. For example, in South Africa, as is the case in most developing countries, a common scenario

... involves a coincidence of poor health, meagre education, and fractured families, on the one side, with skewed resource distribution, inadequate infrastructure, and scarce employment opportunities, on the other side. The combination is more than sufficient to trap many people in poverty, i.e. to make them chronically poor (Aliber 2001: 2).

As noted earlier, women are hard hit by chronic poverty and its consequences. For example, Steinberg *et al* (2002) found that three-quarters of the 771 households surveyed on the impact of AIDS were female-headed and mostly elderly. These researchers noted the devastating impact of HIV on already impoverished households. According to the authors, as bleak as the findings of this survey are, the households are relatively better off than other poor families who do not receive any help from NGOs. All participating households in this survey had contact with NGOs who provided support to HIV-affected families. A major concern highlighted by Steinberg *et al* (2002) is that in chronically poor households, HIV/AIDS is the tipping point from poverty to destitution. As noted above, poverty is an all-encompassing intergenerational phenomenon, which is usually passed on from one generation to the next. For this reason the majority of chronically poor women in Sub-Sahara Africa regard poverty as their prime concern above all others, including the risk or reality of HIV (UNAIDS 2004: 15-6).

Most researchers on AIDS note the above concern, and have found that those who are already economically and politically marginalised and oppressed suffer the most. An elderly traditional healer in Mozambique states: "when you have somebody sick in the house, poverty has already entered" (Breslin 2003: 12). This impact on the poor demonstrates the capacity of HIV to exploit the fault lines of an already economically divided society such as South Africa (Aliber

2001). The apartheid/colonial historical contexts continue to have a negative impact on most blacks in South Africa, especially peri-urban and rural women. The stories of the women in the Grahamstown study in the following section demonstrate this point.

2. Generational (chronic) poverty, AIDS and biographical disruption: a Grahamstown study

This section draws on an account/biographical study carried out in a Grahamstown township in the Eastern Cape province of South Africa. The interviews were conducted in 2005/6 as part of a five-year NRF-funded project entitled *Social suffering: a narrative study of the lives of people finding themselves on society's margin* (NRF focus area of Sustainable Livelihoods) and for a masters degree thesis (Chisaka 2007). The in-depth interviews were conducted in English by Chisaka (2007) with the help of a Xhosa translator, a manager of a Grahamstown community care project. Transcribing was done with the help of two Rhodes University Xhosa students, who checked for inconsistencies in the translations of the interviews.

The study examines the life of two sets of three generations of women infected and affected by HIV/AIDS, and living in chronic poverty. The rationale behind the research design is that the majority of poor Africans live in multigenerational family units, which are predominantly headed by women (Ferreira 2004: 6). This particular family set-up is currently more prevalent, because of the AIDS pandemic. In addition, statistics in sub-Saharan Africa show that women are increasingly more infected and affected by AIDS than men (UNAIDS/UNFPA/UNIFEM 2004: 2). In addition, according to the UNAIDS/WHO (2005: 20) report on the prevalence of HIV infections, Southern Africa remains the epicentre of the global epidemic. While the statistics are useful indicators of the gravity of the situation, they offer limited insight into the experiences of individuals living with HIV/AIDS, and little or no insight into the effects of the illness on those directly caring for AIDS patients. As one HIV-positive woman so aptly states, "statistics don't mean anything. Behind every figure there's a person with feelings that hurt, that cries. But we are so wrapped up in the statistics" (Cardo 1999: 165).

2.1 Why life-story research?

In order to adequately capture the disruptive effects of AIDS, it was necessary to understand how the women construct their life stories in relation to their HIV/AIDS experience. Their biographical trajectories include other disrupting circumstances or situations that have a direct bearing on how they view themselves in relation to their experiences of AIDS. The life story or biographical interview is a “method of gathering information on the subjective essence of one person’s entire life” (Atkinson 1998: 3). An important point is that biographical recounting is not simply a collection of past and present life experiences. Instead, it crucially involves the relations between different narratives within specific social contexts (Bertaux 2003: 40, Linde 1993: 25). This is indeed the case with the accounts of the two sets of three generations of women in this study. Another important fact is that “its methodology transcends the barriers of self/society as well as those of the past/present/future” (Jones 2003: 60). Bertaux (2003: 41) sums up the sociological approach behind a life-story study as follows:

Although life stories are undoubtedly subjective reproductions, they can be used as stepping stones to the construction of sociological descriptions and interpretations that come as close to objective sociological knowledge as is humanly possible. Moreover, life stories allow us to reintroduce into social research the dimension of time and the multiple temporalities of activities.

2.2 A profile of the six women

The age range of the women in this study is between 21 and 83 years. As stated earlier, both households live in abject poverty and have more than one family member living with AIDS (or are HIV positive). In essence, their dire economic situation epitomises the earlier cited Uganda adage which views generational poverty as one that “... passes from one generation to another as if the offspring sucks it from the mother’s breast” (CPRC 2004-5: 3). The generational “breastfeeding of poverty” starts with the grandmothers. They both spoke about their mothers’ meagre subsistence, and their poverty-stricken childhood. Sadly, the trend extends to the granddaughters. One of the negative

effects of such a life is the ill-health vulnerabilities, in this case AIDS for 46-year-old Lulama (middle generation in one household) and an HIV-positive status for 21-year-old Palisa (granddaughter in the other household). As mentioned earlier, other family members living with AIDS in both households did not take part in the study.

The first generation, the grandmothers, started off as labourers on white-owned farms and later moved to informal housing in Grahams-town in the Eastern Cape province, South Africa. They had worked as seasonal farm labourers. Their work experience on the farm was typical of apartheid South Africa — unfair and discriminatory working conditions, in particular for women. As stated above, both grandmothers spoke about childhood and marital poverty experiences.

The second generation continued the trend of farm and domestic work, mainly because of their social position and rudimentary education. As black women, and like their mothers before them, they experienced dual domination. They were controlled by patriarchal norms and practices, both in their natal and marital homes. At work they had to endure the apartheid labour environment, which was even more discriminatory for black women than it was for black men. It is thus inevitable that this second generation continued the mother-to-daughter poverty transmission. As uneducated black women, they were the least likely to access the limited labour market in the democratic South Africa. For them, living with AIDS further limits their chances of getting employed.

The granddaughters have inherited the poverty and will likely pass it on to the next generation. Even though one of them has completed and passed Grade 12, the burden of poverty is too great for her to break without external support. She wishes to study towards a qualification in social work, but this dream is unlikely to be realised. Shortly before the fieldwork was concluded, she had got married and was pregnant. Her husband is a casual worker in a laundromat. The contemporary participant in the other set of interviewees left school because her grandmother, the sole provider for the household, could not afford school fees and other needs.

2.3 The life stories

The following discussion explores the women's accounts in relation to their own and each other's HIV/AIDS and poverty narratives. This includes their patriarchal experiences, and how their identities are affected/disrupted by these phenomena. Seeing that this is a life-story study, some of the women's lengthy personal accounts of their experiences must be cited. This not only enriches one's understanding and appreciation of the women's life stories, but also sensitises one to the enormous challenge of overcoming generational poverty.

2.3.1 Generational poverty, identity, and biographical disruption due to HIV/AIDS

In narrating their past experiences, the women gave insight into how their life is subjectively and intersubjectively constituted. This includes how they conceptualise and construct their identities in relation to each other and non-participating family members. One of the grandmothers (Nonceba, aged 77, Grahamstown) narrated her life tribulations and spoke about the direct link between her experiences and her identity. This was particularly in relation to her family. When asked to describe herself, she said:

I can say that I am a very difficult and sometimes aggressive person. At times I fight, because I find talking through issues to be a waste of time. I don't know how to argue. For example, if I get into a fight or quarrel with somebody, I don't forgive or forget easily. I hold a grudge against that person for a long time. I can go as far as saying that I am a cruel person. I can give you another example. Once my stepson accused me of being a witch, just because I was demanding my money back that he had squandered. I took great offence at being accused of practicing witchcraft and I demanded that he come up with proof of sorcery. I truly put him through hell for this. I was not at all prepared to let this matter go. He was really scared and he moved out of the house. I still have not forgiven him for he has not given me my money and has not apologised for calling me a witch. I think I am very cruel. I don't like the way I beat up my children or grandchildren when they annoy me. I beat them up so bad that if you saw how badly I beat them you would never believe that this is my flesh and blood. I don't know how to express my anger in any other way when dealing with others. I only respond in a very aggressive manner – shout or beat. I literally get sick if I don't vent my anger on whoever has crossed my path. I can not simply speak in a calm voice about what is bothering me.

Her granddaughter (Zintle, aged 23, Grahamstown) also locates aspects of her identity within the family. She explains her introvert tendencies in light of her family's alcoholism:

Sometimes, I like being alone. Even when I am not feeling anything, I enjoy being alone by myself ... There is a lot of tension and fighting among family members. I hate this, I love peace and I think I am a peacemaker in this house. I do not like bad relationships and I always try to broker peace between the family members who are quarrelling or fighting. When my grandfather was ill, he only wanted me or allowed only me to nurse or give him food, even though I was young. This was so because he noticed that I was the only one who was not fighting or arguing with others and that I loved peace. I get very stressed when I have to get involved in these fights. I usually go to my aunt's place next door to try and talk to them. I never involve myself physically. I just plead with them to stop. I always tell my aunt that her behaviour is unacceptable and that it stresses my grandmother a lot. Even when I try to ignore these fights, they still stress me as the noise levels are usually unbearable and it disturbs everyone in our house.

Contrary to the grandmother and granddaughter's perceptions of the self, Zintle's mother (Lulama, aged 48, Grahamstown) views her identity in the light of her AIDS experience. In most of her responses in the interview sessions, she referred to her illness, even when this was not specifically asked. When asked to describe herself, she said:

I like to take care of sick people. For example, I have a friend who is also HIV positive and I usually go over to her house to help her when she is sick. Her mother always wonders how I manage to do this, seeing that I am equally unwell. I told her that I just love helping others and I know that one day somebody will help me as well.

Helping others, especially her friend with AIDS, may well be Lulama's way of making sense of her changing self-identity due to her illness. This suggestion is confirmed by her claim that "I know that one day somebody will help me as well" (Lulama). In this statement she views her identity as a caregiver and a potential care-receiver when suffering from AIDS-related illnesses. She locates her subjectivity in relationships with others in terms of her HIV-positive status and not in the troubled relationships with her family, as her mother and daughter do. Lulama's view of herself is similar to a common observation experienced by chronically ill individuals, namely a "bio-

graphical disruption” (Bury 1982). This, as discussed above, refers to a chronic illness that disrupts an individual’s basic assumptions about her/his identity and her/his relationship with others. As is evident in Lulama’s story, a biographical disruption due to AIDS necessitates a rethinking of her pre-ill self. For her, this implies drawing on a childhood dream in the construction of her identity as a caregiver:

I wanted to be a nurse when I was growing up. When we were still going to school, my friends and I would ask each other about what we wanted to be and one would say I want to be a teacher and the other would say she wants to be a nurse. I used to say I don’t want to be a teacher because these children are not disciplined and they will give you problems, but when you are a nurse, you are able to see that this person I can be able to help and he is not going to mistreat me after that.

In addition to living out her childhood dream, albeit not as a professional nurse, Lulama gives us insight into how she desires to make her “spoiled identity” meaningful (Kleinman 1988: 159). The concept of “spoiled identity” refers to the internalisation of stigma attached to publicly visible or concealed illnesses or conditions. For example, the social stigma attached to AIDS invokes themes and feelings of humiliation, inferiority, boundary violation, personal anguish and self-devaluation (Pattison 2000: 57). Thus for Lulama, being socially relevant as a caregiver reverses some of these negative associations and adds value to her AIDS identity. Like the Indian participants in D’Cruz’s (2002) study who felt the need to reciprocate the help received from others, Lulama is affirming her social significance in her role as caregiver: “when you are a nurse, you are able to see that this person I can be able to help [...] I know that one day somebody will help me as well”. Helping others and being helped are ideally dependent social phenomena, and underpin the earlier discussed philosophy of ubuntu. For Lulama, caregiving and receiving cushion the disruption of AIDS on her self-identity as experienced by some patients in individualistic societies. Her emotional self is protected from the isolation that is inherent in the experience of a chronic illness, especially AIDS.

2.3.2 'I don't want a child': when chronic poverty is more threatening than HIV/AIDS

In contrast to the above three women, the other set of women did not centre their accounts on the granddaughter's HIV-positive status. Their main concern is chronic poverty. For the granddaughter (Palisa, aged 21, Grahamstown), testing HIV positive renewed the anger she harbours towards her family for a "horrible life". Even though she, like the other participants, holds rare fond childhood memories, especially of her grandmother's care and love, she resents her mother and father's lack of parental concern. When asked to talk about her feelings regarding her HIV status, she simply said: "I don't feel well. I am angry. I am angry at my family" [she burst into tears after this statement].

Other than this visible display of emotion, she did not seem overly concerned about her HIV status. Describing her feelings when she tested for HIV, she said:

I was worried. I don't think about it now. It's because I went through counselling and the counsellors made me to be strong. They told me to live like other people and not tell myself that I am sick. My mother also told me that I must not always be thinking about it.

Palisa was much more articulate about the general dire circumstances of her life than she was when talking about her HIV status. She even attributes her lack of desire to have children to poverty and not to her HIV-positive status:

I don't want a child. I did not want to have children even before I knew my status. This is because I have struggled all my life. I can not afford to look after a child. Nobody can help me do this. I can say my life is a mess because I can't afford anything since I don't have money. My grandmother is the only person looking after me because she is getting pension money. Nobody cares for me.

Despite the above sentiments, Palisa did indicate a desire to have a child if her circumstances were to improve. Her desire was made known when she responded to a hypothetical question: "If someone could support you, do you think that you would want to have a child?" She answered in the affirmative. Being concerned about poverty and not an HIV-positive status, Palisa joins other women in similar circumstances who view poverty and its consequences as more threatening

than HIV/AIDS. As discussed earlier, chronic poverty minimises the disruptive impact of illnesses such as HIV/AIDS on the women's life. Thus Palisa's HIV-positive diagnosis "may be just another in an ongoing string of disruptive events" in her life (Ciambrone 2001: 532). This interpretation is not suggesting that Palisa felt no emotional trauma or did not experience a biographical disruption at being diagnosed HIV positive. It simply highlights the interconnectedness of her lived poverty and HIV experiences. The suffering experienced in the former inevitably adds to the emotional pain experienced in the latter and *vice versa*.

2.3.3 The ultimate biographical disruption: suicide

For the one woman (Lulama, aged 48, Grahamstown) living with AIDS, the stigma attached to this illness was compounded by the devastating experience of testing HIV positive following her youngest daughter's HIV-positive result. She took an HIV test after her youngest daughter, who had been sickly since birth, was found to be HIV positive:

So, it means that the child got it from me. So, immediately when I heard that, I went and told my husband and he didn't accept it. Then I came here and I told my family about the results. My family was very upset. But I started getting insults in the community, and even my sisters used to swear at me about it.

Before she even experienced stigma from others, she was blaming herself for passing this disease onto her child. As it has been empirically observed, AIDS is an illness that is often socially viewed as self-inflicted through immoral sexual behaviour. This perception causes the individual living with AIDS to internalise into her/his personality the notion of "... a 'spoilt identity', a feeling of being inferior, degraded, deviant, and shamefully different" (Kleinman 1988: 159). It is evident from Lulama's story that the AIDS stigma may cause an individual to consider suicide as a way out. When the burden of the "insults from the community and her own sisters" as well as her own internalisation of a "spoilt identity" was too much, Lulama attempted to commit suicide:

I decided to take my own life by drinking car petrol that I got from next door. Before drinking it, I realised that I could not stand it

smell. So I decided to take the pills my disabled sister was taking, and I drank all of them. I just wanted to sleep and never wake up. But before I got to my bed, I fell at the door and they saw me and called an ambulance. I told them that I was not going to get inside that ambulance and when the ambulance arrived, I told them that I was not going to get in because they say I am HIV positive so I don't see the point of being taken to the hospital.

We can only attempt to understand the emotional pain Lulama must have experienced. Her previously held notions of an unspoilt identity were devastatingly shattered by the experience of the social stigma attached to her being HIV positive. The devastation was such that she refused to acknowledge her family's help in calling an ambulance. In her anguished state she effectively denied to see her family's care and concern. Her focus was only on the insults. As she reasoned, "I was not going to get in because they say I am HIV positive so I don't see the point of being taken to the hospital". For Lulama, it was not only pointless to be taken to the hospital, but significantly, it was pointless to continue living with a "spoilt identity" (Kleinman 1988: 159). In light of her family's poverty, one can assume that an HIV-positive result caused Lulama to simply want to "sleep and never wake up". This assumption is supported by her mother's eloquently expressed dire circumstances of the family's tribulations grounded in generational poverty. As noted earlier, Lulama understandably centred her life story on her AIDS experiences. She said little about her other lived experiences.

3. Conclusion

This article aimed to show the disruptive effects of chronic illness on concepts of the self and social relationships. Using the concepts "biographical disruption" (Bury 1982) and "loss of self" (Charmaz 1983), which were originally applied to the relatively well-to-do individuals in Western communities, this article attempted to show that such concepts may be useful in understanding the lived experience of chronic illness among non-Westerners, in particular those living in poverty. The studies cited in this article demonstrate that the deplorable living conditions exacerbate the suffering for the chronically ill and poor, but at the same time cushion the existential or ontological assault on

selfhood brought on by a chronic illness. For this reason many individuals on the margins of society, especially in rural sub-Saharan Africa, define poverty as their primary concern above all others, including the risk or reality of HIV.

How, then, does one tease out a “biographical disruption” that results from chronic illness among the chronically poor? The answer to this question is multifaceted as it involves a complex interplay of illness and poverty narratives, as the Grahamstown study shows. Both living with HIV/AIDS and in poverty have a disruptive effect on the two HIV-positive women. For the woman with full-blown AIDS, illness narratives are more pronounced than for 21-year-old Palisa, who views poverty as more debilitating than being HIV positive. As indicated earlier, Palisa is the third generation to be “breast-fed” with poverty. This is why she rationally pins her lack of desire to have children on poverty and not on her HIV-positive status. The woman living with full-blown AIDS proximates chronic illness narratives found among wealthier individuals. However, even for her, the underlying theme is poverty, because both her mother and daughter spoke more about their poverty-related life experiences than their AIDS care-giving experiences. As the Grahamstown study shows, using concepts of “biographical disruption” and “loss of self” can be powerful interpretational tools for understanding individuals, specifically women, infected and affected by AIDS, whose voices are often drowned in poverty and whose illness narratives are sidelined in social research.

An unintended consequence of focusing on “biographical disruption” due to illness among the poor, instead of the disruptive effects of chronic poverty, is that it offers a critique of the Western understanding of the experience of chronic illness. Among the poor, studies show that chronic poverty and chronic illness are intricately linked (Baylies & Bujra 2000, Chisaka 2007, Ciambrone 2001). By contrast, wealth and chronic illness are not necessarily experienced or interrogated in a similar manner. For the wealthy, making sense of their chronic illness experiences, unlike the women in the Grahamstown study and other similar studies, is centred on issues of illhealth and not on other living conditions. For them, the previously

held notions of an ontologically secure self-identity is reconstructed or reconceptualised mainly in light of the illness (Bury 1982: 169, Charmaz 1983: 168, Radley 1993: 109). Although studies show that “narrative reconstruction” (William 1984: 175-200) or “narrative reconfiguration” (Kleinman 1988: 144-5) also involves an interrogation of the wealthy individual’s broader life, the focus is centred on self-concepts/identity. Thus loss of control and independence or “loss of self” (Charmaz 1983) due to a chronic illness compounds the suffering inherent in the illness experiences. Significantly, an individual’s wealth and a Western world view do not cushion the devastating impact of a chronic illness on selfhood in a similar way that poverty and an African or Indian world view do.

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