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Title: **Women's experience of HIV as a chronic illness in South Africa: hard-earned lives, biographical disruption and moral career**

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Women's experience of HIV as a chronic illness in South Africa: hard-earned lives, biographical disruption and moral career

Abstract (177 words)

This paper presents findings from a longitudinal qualitative study (48 in-depth interviews with 12 women on antiretroviral treatment (ART)) exploring the experience of living with HIV as a chronic illness in South Africa by applying the structural and interactionist perspectives on chronic illness. The *structural perspective* indicates that the illness experience needs to be contextualised within the wider framework of the women's hard-earned lives: throughout the interviews, the women tended to refuse singularising HIV/AIDS and continuously framed the illness within the context of general hardship and adversity. Employing an *interactionist perspective*, the repeated interviews demonstrated the partial applicability of the concept of biographical disruption to the illness experience: most women experienced feelings of denial and disbelief upon diagnosis, but the availability of ART clearly mitigated the impact of HIV on their biographies. In addition, our findings demonstrate that the interaction between structural aspects, (stigmatising) social relations, and the illness (and its treatment) determines the never-ending cycle of identity appraisals, revisions and improvements, rendering the moral career of the HIV-positive women on ART a continuous work in progress.

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Background

Medical sociologists describe the evolution after ART roll-out as the transition of HIV/AIDS from an acute to a chronic disease. Accordingly, HIV/AIDS care is turning into “chronic disease management”, reaching beyond the world of medicine into all aspects of the infected person’s life. Because ART requires high levels of adherence to be effective, a successful ART programme involves far more than patients swallowing pills on a daily basis (Deeks et al., 2013; Etienne et al., 2010; Lange et al., 2004; Selman et al., 2013). Long-term patient retention and ART adherence are prerequisites in ART efforts to ensure success. Without sufficient attention to the social and psychological dimensions of life with HIV/AIDS as a chronic illness, it is highly unlikely that the favourable short- to mid-term results of the South African ART programme can be replicated and sustained in the upcoming decades when the country will probably have to rely on ART as its primary curative weapon for combating the HIV/AIDS epidemic (Wouters, 2012; Wouters et al., 2009).¹

This paradigm shift of HIV/AIDS to a manageable chronic condition is slowly leading to an associated line of research. In this regard, Thorpe (2009) stated that “given the relatively recent development of ART and re-definition of HIV as a chronic illness, the physiological, sociological and psychological effects of long-term treatment are still emerging” (Thorpe, 2009), thus creating great need for appropriate and ongoing research efforts. The few studies on the adjustment to living with HIV on ART and on the role of HIV/AIDS as a chronic illness in precipitating changes in identity have mostly been conducted in Western industrialised settings (Carricaburu & Pierret, 1995; Ciambrone, 2001; Crossley, 1998; Pierret, 2000, 2007; Thorpe, 2009). With the advent of live-saving treatment now a reality in great parts of sub-Saharan Africa, people living with HIV/AIDS (PLWHA) have an opportunity to rebuild or to renegotiate their lives despite this former life-threatening diagnosis (Matovu et al., 2012; Russell & Seeley, 2010; Russell et al., 2007).

Increased research is being done into how this new reality of treatment availability shapes infected people’s lives in this region: improvements in clinical and laboratory outcomes are translated into

¹ In absolute figures, South Africa has the most HIV infected people worldwide (5.6 million) (UNAIDS, 2012) and boasts the largest publicly funded ART programme that officially started in 2003 after the controversial years of “AIDS denialism” epitomised by former president Thabo Mbeki. Since 2003 there has been a steady increase of patients enrolling onto ART. In 2011, 1.8 million or 52% of the people living with HIV/AIDS (PLWHAs) in need of treatment were receiving ART (Mayosi et al., 2012). Median life expectancy has also increased by 13.9 years since ART roll-out (Bor et al., 2012).

improved physical and mental health functioning and socio-economic well-being (quality of life; household well-being; labour productivity) for patients and for those around them (Beard et al., 2009); studies are done on how people on ART self-manage their illness and how ART adherence impacts on their life activities, on social relationships and on rebuilding livelihoods (Martin et al., 2013; Parker et al., 2009; Samuels & Rutenberg, 2011). ART is said to strengthen social relationships and self-identity as it “improves people’s capacity to work, important for social and economic viability and validation, allowing people to play their societal role as breadwinner, parent or adult” (Wekesa & Coast 2013: 5 - 6).

However, it has been found that fundamental characteristics of a person’s identity are not left unscathed by an HIV diagnosis especially in relation to issues of sexuality and reproduction (Wekesa & Coast, 2013) and it is equally critical to understand the experiences of being HIV positive and of being on ART because this inevitably provides a better understanding of the circumstances linked to disclosure, the support networks available and eventually the treatment outcomes of HIV-positive people (Abrahams & Jewkes, 2012; Liamputtong et al., 2015; Wouters et al., 2014). However, an extensive literature review revealed only a very limited number of studies investigating the incorporation of HIV as a long-term chronic condition into the identity and lives of those affected in sub-Saharan Africa (the area worst hit by the pandemic and characterised by prevalent precarity), a problematic issue recently highlighted by Russell and Seeley (2010). This is an important aspect of ART management that needs to be understood and analysed as it has been found that many PLWHA live in between hope and uncertainty “leading to contrasting and ambivalent views about ART, even among those individuals who have developed a positive identity” (Wekesa & Coast, 2013). Incorporating HIV/AIDS and ART into one’s identity also involves “multiple phases of identity transition, including diagnosis, (non-) disclosure, positive living and attempts at repair and normalcy (...)” (Wekesa & Coast, 2013).

This study aims to extend the current literature by investigating the impact of HIV/AIDS and its associated ART on PLWHA biographies and identities in a context where this information is needed most: a high HIV-prevalence, resource-constrained setting – the Free State Province of South Africa.

Analytical Framework

A rich tradition of sociological research has studied the role and position of the ‘ill individual’ in contemporary society (Bury & Gabe, 2004). Talcott Parsons (1951) instigated this sociological theory – from a structural perspective – with his seminal concept of the sick role, in which he highlighted that illness is not just a physical phenomenon, but also a socio-cultural one, because it influences and defines the role and position of people in society (Parsons, 1951). However, Parsons’ concept did not seem to

capture the nature of many chronic illnesses that bear little prospect of recovery. More recent sociological studies applying a structural perspective to chronic illness research therefore use a life course perspective which researches how social structural factors can influence life chances through their interactions with dramatic life events, economic inequalities and health-related factors. In practice, large-scale cohort studies have examined the complex effects that structural factors such as social class, ethnicity, gender and living circumstances can have on a variety of health outcomes (Bury, 2002; Phillips et al., 2001). In the context of HIV/AIDS, this perspective is usually applied in macro-level studies, discerning the social drivers of the epidemic in high HIV-prevalence, resource-constrained settings (Heunis et al., 2012). While such a structural approach to HIV/AIDS as a chronic illness might be valuable, it remains limited in its capacity to reveal links between HIV/AIDS, ART and the lived experience of the chronic illness and its treatment (Bury, 2002).

A second sociological perspective on chronic illness was instigated by Erving Goffman (1963) and Strauss and Glaser (1975) and specifically approaches health and illness from an interactionist perspective. In the footsteps of these influential writers, the focus of medical sociology has largely shifted towards the illness experience and the ways in which affected people cope with their illnesses in everyday life (Goffman, 1963; Strauss & Glaser, 1975). Methodologically, this perspective employs more in-depth, qualitative studies, rather than large-scale surveys relying on epidemiological data. One of the most influential contributions to this approach and to medical sociology in general, is Michael Bury's classic paper entitled 'Chronic illness as biographical disruption' (Bury, 1982; Lawton, 2009). In this article, Bury states that the onset of a chronic illness constitutes a biographically disruptive event, thereby targeting the impact of chronic illness on the person's self and his/her sense of identity (Bury, 1982). Critics of Bury's theory have highlighted alternative views related to chronic conditions: disability studies emphasise that oppressive social disadvantage determines experiences instead of individual pathology whereas the post-modernist turn focused on deconstructing and de-essentialising embodied experiences to better grasp the lived experiences of those with chronic conditions (Williams, 2000). However, in the same vein as Williams, we firmly support what he calls a "modernist" defence of the "biological reality of pain and suffering, disability and death, including legitimacy of medical diagnosis and therapeutic interventions", chronic illness being one of life's "existential events *par excellence*" (Williams, 2000: 47). Renewed emphasis on the impact of timing (age), gender, class, ethnicity and the social context as well as norms and expectations is sought to fortify the conceptual and empirical meaning of the term "biographical disruption" (Cornwell, 1984; Pound et al., 1998; Williams, 2000) in order to highlight the myriad of factors associated with the "social patterning" of chronic disease

(Williams, 2000: 48). In this way, our theoretical view on the concept of biographical disruption is closely related to the life-course analysis framework as developed by Elder and Rockwell (1979) in which the concepts of timing and (socio-historical) context gravely impact individual life courses and health trajectories (Corna, 2013) and thus also impact the experience of the onset of chronic illness (as a biographical disruption) (Elder & Rockwell, 1979).

With time, those infected with HIV learn the experiences that characterise the plight associated with infection, as this event is normally associated with a host of intricate stigma-related circumstances: both discreditable and discredited forms of stigma, to use the classic distinction drawn by Erving Goffman (1963). Subsequently, those infected with the illness are never totally resistant to the diagnosis and its lifelong treatment and they have to make certain adjustments to their everyday lives, given the fact that they have to reflect on their own sense of self and the implications for their personal and their social identities. Erving Goffman (1963) refers to the “moral career” of the person who has to make these adjustments. The moral career is characterised by two phases: firstly, the infected person (or the “stigmatised” person to adopt Goffman’s lexicon) “learns and incorporates the stand-point of the normal, acquiring thereby the identity beliefs of the wider society and a general idea of what it would be like to possess a particular stigma” (HIV infection, in this case) (Goffman, 1959, 1963). The second phase involves the infected person realising that she possesses this particular form of stigma, and the everyday life “consequences of possessing it” (Goffman 1963: 45). However, the moral career does not follow a linear, simple path towards negotiation and acceptance as there are many ambivalences and oscillations built into the individual’s attachment to her stigmatised condition. By reflecting on her own moral career, the “stigmatised individual may single out and retrospectively elaborate experiences which serve for him [her] to account for his [her] coming to the beliefs and practices that [s]he now has regarding his [her] own kind and normals. A life-event can thus have a double bearing on moral career, first as immediate objective grounds for an actual turning point, and later (and easier to demonstrate) as a means for accounting for a position currently taken” (Goffman, 1963: 52-53). The notions of “biographical disruption” (and the revisions thereof) and the “moral career” of PLWHA serve as heuristic tools to understand issues related to HIV infection, concomitant ART treatment and identity negotiations and surprisingly few studies have attempted to apply these concepts to PLWHA (Baumgartner, 2007; Carricaburu & Pierret, 1995; Ciambone, 2001; Gilbert & Walker, 2010; Wilson, 2007).

The current longitudinal qualitative study, organised in the Free State province of South Africa, will aim to shed new light on (1) the notion of biographical disruption and (2) the moral career of PLWHA. Firstly, and in contrast with the majority of previous studies on the topic which were performed in western settings with low HIV-prevalence (Baumgartner, 2007; Carricaburu & Pierret, 1995; Ciambone, 2001; Crossley, 1998; Pierret, 2000, 2007; Thorpe, 2009; Wong & Ussher, 2008), the current study explores *the experience of a HIV-positive diagnosis as a potentially disruptive event* in a setting where HIV is affecting almost one out of every five people aged 15 to 49 (Day et al., 2011). In addition, the widespread introduction of public-sector ART potentially instigates *a second phase of biographical change* – not captured in previous studies – as PLWHA will have to incorporate not only the illness but also its associated life-long treatment into their identity. Secondly, we aim to assess role of HIV-related stigma in the lives of the women by exploring *the moral career* of these HIV-positive women on ART. This second aim describes how the notion of moral career can be used to understand the continuous processes of transformation of self and identity as the women try to incorporate the illness and its treatment through often stigmatising interactions with the social context. However, we will also aim to *explicitly incorporate the omnipresent structural factors* affecting the HIV/AIDS experience: poverty, social exclusion and vulnerability are conceptualised to impact on both the biographical disruption following an HIV-positive diagnosis and the initiation of ART, as well as the day-to-day management of the “moral career” as a PLWHA on ART.

Methodology

The article draws upon a qualitative longitudinal study of the life transitions of HIV-positive women on ART in the Free State province of South Africa. The research aims to understand the lived realities of an HIV-positive diagnosis, enrolment in a public-sector ART programme and HIV as a chronic condition, as well as to critically assess the applicability of existing sociological theory on the lives of these women. The study was approved by the Ethics Committee of the Faculty of Health Sciences of the UFS and authorised by the Free State Department of Health.

Twelve women were recruited from a previous study entitled the Free State Effective AIDS Treatment Study (FEATS), a prospective cohort study which aimed to assess the impact of peer adherence and nutrition support on clinical outcomes in a sample of 653 HIV-patient enrolled in the Free State province's public-sector ART programme.

For the purpose of the current study, four rounds of in-depth qualitative interviews (August 2011 – November 2012) were executed among our subsample of 12 HIV-positive South African women residing in the Free State province (48 interviews in total). Convenience sampling was used to select the twelve women from the FEATS data set, with the convenience criteria being geographical spread (residing in Manguang municipality) and willingness to participate in the study. Interviews were undertaken with the women only after informing them about of the nature of the research, the possible risks and benefits to their participation, their right to privacy and confidentiality, and the voluntary nature of their participation in the research and consequently receiving full informed consent from all participants.

Most of the participants started treatment in 2007; therefore they had been on treatment for almost seven years. The twelve interviewees were aged between 25 and 58 years and most of them had at least successfully finished secondary school (Table 1). On each visit a loosely-structured interview was conducted with the participant and observations were made. In accordance with Russell & Seeley (2010), a life-history instrument was used to gather data on the changes to the participant's lives since the HIV diagnosis and the initiation of ART. The participants were also asked a set of eight questions developed by Arthur Kleinman (Kleinman, 1980) constituting an explanatory model of illness designed to elicit the participant's perspective of her affliction in a culturally sensitive setting. Overall, the interviews addressed a wide range of subjects surrounding the experience of life with HIV and on ART in a high HIV-prevalence, resource-constrained setting. Visits usually lasted about two hours. The interviews were recorded, while the fieldworkers (Katinka de Wet and Veronica Masenya) took notes and immediately

following the interview wrote a short report. The participants were compensated for their time by giving them a R100 vouchers from a supermarket.

Table 1: Biographical details of the participants (all names are pseudonyms)

| | Age | Children/ Dependents | Partner/ husband | Currently on ART | Diagnosis | Treatment start date and CD4 count (if known) |
|---|-----|---|---|------------------|---|--|
| Elisabeth (self-employed: shop in front of her house that sells food, airtime, etc.) | 46 | 1 daughter of 15 Looks after her niece of 21 | Her estranged/ abusive husband died of HIV in 2007 | Yes | 2007 | 2007 - 172 |
| Elaine (domestic worker) | 41 | 1 son of 21 Looks after her niece of 17 whose mother passed away due to HIV | Long-term partner died of HIV in 2013. She currently has a casual relationship with a married man | Yes | 2006 | 2007 - 79 |
| Susan (mostly unemployed) | 34 | No children She looks after her brother of 16 and her cousin of 22 | None | Yes | 2003 – also diagnosed with non-Hodgkins lymphoma | 2007 (134 when first diagnosed and 16 when going onto ART) |
| Karen (unemployed – gets a social grant) | 38 | 1 son of 14 (involved in a dangerous peer gang) | None (the father of her child died of HIV but they were not together anymore) | Yes | 2005 | 2007 - Unknown |
| Brenda (mostly unemployed) | 48 | 1 daughter of 27 who has a daughter of 5 1 son of 24 who died 1 son of 20 not living with her | Her estranged husband is in jail for the rape of their daughter. Adeline has a casual relationship with a man | Yes | 2008 | 2008 - 10 |
| Lucy (works at a take-away shop) | 30 | None (she lives with her mother) | She had a boyfriend who she hardly ever saw | Yes | 2008 | 2008 - Unknown |
| Vanessa (cleaner) | 37 | 2 daughters of 11 and 23 | Her husband died of HIV in 2008 | Yes | 2003 | 2007 - Unknown |
| Linda (unemployed) | 25 | 1 son of 3 | Frequently changes partner (often in abusive relationships) | No | Raped in the late 1990s. She was not given prophylaxis and became | Only went onto ART for PMTCT - Not known |

| | | | | | infected | |
|---|----|--|---|-----|----------|---|
| Joanne (works as a cashier at a shop) | 34 | 1 son of 6 | Husband is also HIV positive but not on treatment yet | Yes | 2007 | 2007 - 126 |
| Sarah (works as a lay health care worker at a private hospital) | 41 | 1 son of 13 1 daughter of 7 | Estranged husband died of HIV in 2007 | Yes | 2007 | 2007 - Unknown |
| Julia (unemployed – looks after relatives' children) | 58 | Had 1 child in 1971 who died at 3 weeks of age | None | Yes | 2005 | 2007 - 84 |
| Jewel (works as a volunteer at a local NGO) | 41 | 1 son of 15 1 daughter of 3 2 adopted children of 19 and 20 of which one has a baby who also lives with Dimakatso) | Husband is also HIV positive and on treatment | Yes | 2008 | 2008 - High CD4 count – went onto ART for PMTCT |

The analysis followed standard qualitative approaches (Hammersley & Atkinson, 1995). Each interview was transcribed verbatim and added to the interviewer's observation notes. Two members of the research team – the authors of this article – carefully read and coded the interview data. By separately coding the qualitative data, inter-coder reliability was established. Any discrepancies were resolved and consensus among coders was established. Both authors independently analysed the full data set, with data analysis being guided by a combination of hermeneutic and grounded theory (Corbin & Strauss, 2008). A series of qualitative topic codes was developed to facilitate content analysis and interpretive understanding. This involved starting with an initial set of broad concepts, drawn from the literature, that were likely to be of theoretical importance in understanding women's lived experiences with HIV/AIDS and ART. As the data gathering and analysis proceeded, these categories were refined and extended to reflect and incorporate themes that emerged from the data. In addition, – because of the fact that the interviews were biographical in nature and that we performed multiple interviews with each participant – a longitudinal analysis of individuals' life and illness histories was undertaken. In this way, analysis was also sensitive to narrative analysis approaches (Ezzy, 2000), exploring the way participants constructed accounts of themselves in the past and the present to reveal features of their adaptive coping and transition, for example the evolving meaning they attached to the illness and its

treatment (Russell & Seeley, 2010). Longitudinal qualitative data were also used to further test, refine, verify, or reject theoretical conclusions based on common findings that emerged (Foote-Ardah, 2003).

Findings

Contextualisation

The HIV illness experience must be framed within lives of poverty and hardship which is a powerful factor in the lives of all the participants in this study. All participants grew up during apartheid and had consequently experienced (and are still experiencing) structural violence, adversity, inequities and loss. Because of apartheid's devastating economic but also social consequences, several participants had never known their biological fathers and literally all had lost several close relatives to HIV/AIDS and/or to other unnatural causes. Karen had lost the father of her child, her mother and her brother in less than two years. Sarah had lost three of her four siblings and her own mother to the illness. Several participants were raising the children of their deceased relatives or neighbours as their own, as is the case with Jewel:

"I have four children [...] My own children are two and two it's orphans. [...] My neighbour was a friend of mine. When she passed away, her family just left the children on their own so I took them in and assisted them until I took them to the welfare." (Jewel 1 (1st interview))

The lives of several women have also been marked by (sexual) violence. Their life histories include episodes of domestic violence (Elisabeth), rape (Linda), teen pregnancy (Vanessa who was 14 when her daughter was born) and child abuse (Brenda's daughter was raped by her father). Throughout the repeated interviews, it becomes apparent that all these lives have been heavily touched by crises and struggle, as verbalised by Elisabeth:

"He [the husband] used to be abusive so I have to make court order because he was beating me with a hammer [...] Maybe he realised that he got sick and I would find out, I don't know, because what he wanted, he used to say 'I want to kill you, I want to kill you, I want to kill you!' so I have to make court order so they have to take him out of the house." (Elisabeth 3)

Linda's story is just as telling:

"I was infected when I was raped by those boys who were with me at school. We went out to town drinking and everything, and I got raped. My mother was told that I was raped, we went to the clinic to National and got tested and everything. It didn't show I went again - I tested I was positive, she was crying I wasn't crying" (Linda 1)

In general, participants do not cite health-related issues but rather financial problems as their biggest concern. Many of the participants do not have a formal job and are thus dependent on financial support

from other sources such as the extended family and government grants. However, even participants who have (in)formal employment, struggle to make ends meet. Several women state that they want to go back to “school” to become a nurse (or an assistant nurse) but social mobility is limited by the fact that they do not have the money to enrol (or that they do not know the right people to get accepted into the programme). Others indicate that their financial situation is precarious as they have to support the financial and emotional needs of the (extended) family, as indicated by Lucy:

“Yes and next month March we are going to open the tombstone for my father [a ritual to appease ancestors] so we were budgeting for it. [...] We didn’t have money back then [over 20 years ago when the father died] so, now when I work I help my mom” (Lucy 3)

Given their extensive responsibilities – caring for their own and other’s children and elderly family members in difficult circumstances while struggling to generate an income – normal roles cannot be cast away to take on the sick role, as indicated by Elisabeth:

“I have to face life and go on with my life. So that is how I managed, that is how I survived because I never saw myself sleeping in bed even a single day”. [meaning that she does not give in] (Elisabeth 1)

The women find themselves in a dual position: requiring care themselves as PLWHA on ART and secondly, providing care to others in need. Throughout our interviews, it becomes apparent that the latter role gains ascendancy. This is reflected in the fact that several participants either already provide care (as a health care worker or a volunteer) like Jewel:

“I didn’t have a break over the Christmas holidays because I was working at the organisation where I am volunteering. [...] They took me to a centre [which] works with children who are orphans and are on ART. They also take care of children who are neglected by their parents. [...] These children do not have adult supervision so we had to look after them” (Jewel 3)

The in-depth information gathered in the repeated information clearly shows how these women have to negotiate a wide range of roles and responsibilities. This struggle is further complicated by the illness and its treatment.

HIV and ART as a biographical disruption

The first research objective addressed the applicability of the notion of biographical disruption to HIV as a chronic condition in a high HIV-prevalence resource-limited setting. The data of the qualitative

interviews were applied to explore (1) the experience of an HIV-positive diagnosis as a potential biographical disruption and (2) the initiation of public-sector ART as a second potential phase of biographical change.

Diagnosis: a “biographical disruption”?

A range of interviews revealed the *initial denial* with which these women took cognisance of their condition. Most participants remember their CD4-count when they got tested or initiated onto treatment, and it was almost always at a dangerously low level. One participant’s husband told his wife that he was HIV positive, but she did not want to believe him. When she eventually tested positive when she went for a test when she was pregnant, the initial disbelief was replaced with anger and disappointment.

“He eventually told me but I didn’t believe him. We continued using condoms and we stopped because I still wanted a baby. You know when you love a person so much that when he told me I didn’t believe him and took it so simple because I love and trust him. [...] No I didn’t know my status and I didn’t go get tested. When I was a month pregnant, I gave them permission to test me and it was only then that I started to believe that I am HIV positive. [...] I slapped him numerously until he bled.” (Jewel 2)

Two other participants (Brenda and Sarah) also indicated that the unfortunate news of a HIV-positive diagnosis was first met with disbelief. However the initial shock was quickly replaced by acceptance – social support, post-test counselling and especially Drug Readiness Training (preceding ART) helped turning the potential death sentence into a chronic condition.

“It was very painful and I kept asking myself where did I get it from? I started accepting my status once I attended the classes [Drug Readiness Training].” (Brenda 1)

“The first time it was horrible; I wanted to kill myself. But I have the support of my family that is why I am so happy.” (Sarah 1)

A second group of women accepted their status at face value, mostly by stating: “I am still the same person”. Given the prevalence of HIV in the country and their immediate environment and experiences, participants were often *expecting a positive diagnosis*. One respondent (Susan) for example indicated that her lifestyle – including partying and drinking – left her expecting the negative news:

“I just recap on my life so I was like okay so if it’s positive I mean I have lived you know so I was actually expecting it that way...” (Susan 1)

Overall, the classification of the HIV-positive diagnosis as a biographical disruption thus does not fully resonate with the reality - initial denial followed by acceptance or an anticipated diagnosis - experienced by the women interviewed. However, repeat interviews inevitably indicate that both groups did grapple with this new reality on multiple levels – even the women expecting the diagnosis, as the illness had clear *symbolic significance*. HIV diagnosis was thus not necessarily a shock, but it definitely changed the women’s sense of self.

Firstly, the illness is often associated with *immoral behaviour*. One woman (Elisabeth) got ill, suspected that it was TB, but was not surprised when she tested positive for HIV, given that her estranged husband was seriously ill with all the symptoms normally ascribed to HIV. However, it is especially difficult for her to reconcile with the fact that HIV was supposed to be happening to others, mostly “immoral people”, given her strong religious convictions:

“Before, I knew what people used to say, so I have to say, now, is my time. I was one of those who was talking bad.” (Elisabeth 1) *“We think that maybe this sickness is for those who are doing it outside in the shebeen [informal and often illegal drinking place], in the taverns, whereas it is for everyone...”* (Elisabeth 4)

Secondly, HIV has an impact on the *women’s sexual, reproductive and personal life*. The majority of the women interviewed do not have a partner and indicated that the prospect of disclosure and negotiating safe sex is the most important barrier to finding a new partner. A related issue is the desire to have children: HIV has changed these women’s lives as they – despite the availability of drugs for prevention-of-mother-to-child-transmission (PMTCT) – feel forced to forget the idea of having children because of their status. The practical consequences of HIV thus have important symbolic significance on the lives and resulting identity of these women.

“I wish every day that I, [...] I cannot be able to have an affair. I was thinking just like now, I just keep myself alone because I think of that because I cannot. I don’t know men because the others said when you can tell him, he is going to act like this, like this, so I said, hey, you know that’s why I said it took even my freedom because I am not free like I used to be” (Elisabeth 2)

“It has changed. [...] Yes, it’s like I was supposed to make children before I got HIV. Now I’ve got HIV, I don’t know how to. It’s like a different thing.” (Lucy 2)

ART initiation: biographical disruption or reconstruction?

Five of the twelve participants' HIV diagnosis was directly followed by initiating their ART, which left little space for a separation between a possible "double disruption", or double shock: firstly after being diagnosed, and secondly, going onto treatment.

Prior to ART initiation, PLWHAs need to complete Drug Readiness Training, a specific education programme (three times weekly training session) to provide the knowledge to enable them to take ownership of their health. Topics that are tackled include positive living (dealing with stigma and discrimination, legal issues, disclosure, and healthy lifestyle including good nutrition), basics on HIV and AIDS, opportunistic infections, care and treatment for HIV (including ART), ART adherence, and ART side-effects. As indicated above, several participants indicated that this training was crucial in overcoming the initial shock of being HIV positive and reconstructing their lives.

"I had to attend classes where they taught us about the treatment and they told us that HIV is better than other chronic diseases such as diabetes. They told us not to worry and stress, just accept our conditions so I decided to accept it ..." (Brenda 3)

At the time of the interviews, only one participant – who had initiated ART to prevent mother to child transmission – had defaulted treatment. Almost all participants viewed the life-long treatment as a second chance at life and were thus very motivated to consciously comply with treatment guidelines. ART was thus cited as a crucial component of the biographical reconstruction after the HIV-positive diagnosis. When answering the question of the applicability of the concept of biographical disruption to the reality of HIV-positive women on ART in South Africa, the interviews seem to suggest that, in times when ART is readily available, HIV cannot really be qualified as the 'major kind of disruptive experience' originally described by Michael Bury (1982). When responding to Kleinman's question "How severe is your sickness?", participants indicated that they do not consider HIV to be such a serious condition as they indicate that they expect to live a long life with the illness. ART has thus significantly altered the anticipated biographies of these women. Some participants consider themselves to be healthy individuals as HIV does not physically limit their daily functioning.

"I said it's a second chance and I have to use it... You have to use it the right way." (Elisabeth 2)

"Now I can see that or is it because I have accepted my status. There is nothing wrong; it's almost as if I'm not even ill. I feel just fine." (Brenda 4)

However, the repeated interviews do seem at times to expose the vulnerabilities that HIV/AIDS and ART have created, now stressing *the symbolic significance of the treatment*. The women especially cite two important practical consequences of ART which have important symbolic ramifications. Firstly, the practical consequences of treatment – the required level of compliance and the difficulties in adhering to treatment when in the company of people whom the participant does not want to disclose to – have a clear symbolic significance as they remind them every day of their positive status.

“I told myself that I don’t mind, there is nothing wrong, but what I realise is that I know that there is a boundary between me and my life, because these tablets are the ones that keep me going. Yes, so I have to think about that, not being worried so much, but I said sometimes I told myself that it’s fine, but I know deep down it’s not fine. There is something in between. There is a boundary [...]”

(Elisabeth 2)

Secondly, the interviews underline the importance of *the bodily aspects* of ART and thus urge the researchers to ‘bring the body back into analyses’. Several participants complained about ART-related nausea, rash and swollen and painful feet. However, by far the most disrupting side-effect of treatment is lipodystrophy – a metabolic condition characterised by fat redistribution, insulin resistance and hyperlipidemia. This side-effect is often associated with one tablet (Stavudine or d4T) contained in initial first-line ART regimens available in South Africa. The women interviewed all started treatment in the period when Stavudine was still included in the first-line regimen – rendering them part of a specific cohort in the history of HIV/AIDS and ART (Elder & Rockwell, 1979). This drug is associated with the highest relative risk for lipodystrophy and is now being phased out given the adverse effect of – in some instances – drastic bodily alterations. Several women complained about fat loss in the legs and buttocks, as well as fat build-up in the abdomen and breasts. These changes in physiology and appearance could possibly fracture biographies into a life before and a life after ART initiation. The bodily changes could also have clear social ramifications as the community knows the association between HIV treatment and the physical transformation.

“The biggest worry is not that I am sick, but the shape of my body [...] I decided to accept my condition very early, because I am not the only one who has the virus. My attitude started to change again when my body started to change as I did not like it. I didn’t have a problem with accepting my status, but the body change was just too much for me to handle” (Vanessa 2)

“Now I have to wear towels under my clothes so that my body could have a bit of a shape. [...] My biggest worry is not that I am sick but the shape of my body even more now that its summer”
(Vanessa 1)

However, none of the women alluded to the possibility of ceasing their treatment despite this side-effect. Not even Vanessa considers stopping her treatment, as she values the fact that she is still alive, and also because they have all internalised the prominent message received at the Drug Readiness Training that resistance to ART will be every HIV positive person’s worst enemy.

The moral career of HIV-positive women on ART

Goffman’s framework provides a “two-sidedness” which links internal matters (the image of self and self-identity as HIV-positive and on ART) with broader social structures. The concept *moral career* incorporates the important process of developing an identity interacting with the social context. In other words, the women may develop self-identity as ‘HIV-positive women on ART’ as they interact with the people surrounding them. The moral career of (potentially) stigmatised people is determined by the point of view of “normal” people (Goffman, 1963): do they know the person is HIV-positive and on ART? Key aspects of the moral career of these women thus are (1) the continuous process of HIV-disclosure and (2) the everyday negotiation of treatment in various social situations.

Non-disclosure/living in two worlds

According to Wekesa & Coast (2013:4) “managing the flow of information about HIV status, including (non-)disclosure of HIV status is central to how people manage their identity post-diagnosis. Decisions to disclose evolve over time, encompassing a process beginning with non-disclosure and sometimes ending in forced disclosure.” The issue of disclosure is still problematic to most of the ladies, especially to their children and at their workplace. Not disclosing could lead to a more fractured sense of self, as one constantly has to be on guard not to accidentally reveal something.

In Karen’s case, she tries her best not to speak about her illness too often.

“I hardly ever speak about it. I only remember at occasions, like now where we have to speak about it. I don’t want to dwell on the thought that I am infected” (Karen 4)

She has a teenage son who has become her biggest source of anxiety, given that she suspects his involvement in a notorious gang, and him failing at school and not attending his classes. Karen lives at the back of a house that used to belong to her deceased grandparents. Her aunt occupies the main,

front piece of the house, and at times gets verbally abusive towards Karen. In fact, in a state of drunkenness, she has revealed Karen's status to her son, in front of Karen. Karen then wanted to undo the damage by convincing him that she is not positive, because she thinks that her son will then worry that she is going to die. Karen has few people she trusts in the world. Her mother and siblings died, she never knew her father, and the father of her child also died because of HIV, although he was not part of their lives. Concerning the illness, her greatest fear is:

"reaching the last stage of the illness and I won't be able to do things for myself. I don't want to be a burden, especially to my son, T., because I don't even have a mother. It would have been much better if I did have a mother..." (Karen 4)

Two participants also indicated that they did not disclose their status to the children living with them as they were not their own, but adopted – and they feared that these children would spread the information in the community.

"I can't tell these children what is going on in me. You see these children are so silly so I don't want them to go outside to do their own thing you see." (Elaine 4)

"You know why I don't tell the 19 year old boy? Because he can't keep secrets and he tells other people our family business. We are not his biological parents so when we make him angry then he retaliates by revealing our secrets." (Jewel 1)

Susan was also diagnosed with non-Hodgkins lymphoma as a side-effect of HIV, and spent the better part of 2007 undergoing chemotherapy. She is very selective about disclosing her HIV status to anyone, given the fact that she can explain her past illness and her lifelong treatment on the fact that she was also diagnosed with cancer (she is in remission now). Her friends remind her to take her daily treatment, but she makes them believe that it is for cancer, thereby not having to disclose her HIV status to anyone. She was diagnosed with HIV in 2003, but did not want to take ART because she was scared of side-effects. She looked after herself at first, but as she grew stronger, she started neglecting herself again (she started "partying" again), and got very ill because of HIV, but also because of the cancer. During this trying time of chemotherapy and relapses, she became a new person by adopting a new church and by changing her friends from *"quantity friends to quality friends"* (Susan 3) However, she is still very selective of disclosing to anyone, explicitly unfolding a strategy of first gauging a person's attitudes towards HIV, and secondly what information to share:

“And if they are still ignorant I choose not to [...] I kind of assess people first and check their views on HIV” (Susan 1)

Those few participants who have formal employment (see Table 1) indicate that there is a fear that they will be stigmatised for disclosing at work, mostly because they know what people tend to say about HIV and those infected. Lucy, Joanne, Vanessa and Sarah make mention of this, in Lucy’s words:

“At work, I don’t speak about my status. I don’t tell them because I think they will judge me. So, I just keep quiet, it’s only me, my mom and other families that know (...) like all of them, when they talk as if HIV people, they are bad, so it’s hard to come out, I think they will judge me...” (Lucy 2)

Those afflicted with less stigmatised chronic conditions or even an illness such as cancer, are normally more forthcoming with the fact that they have another illness that is not HIV. This frankness is not always the case with HIV, which in some ways leads to a level of identity negotiation that did not exist before the diagnosis with HIV.

Negotiating everyday ART

Most participants mentioned that taking treatment, mostly twice a day, did not result in any concrete difficulty. Most of these women had initial side-effects, lasting for a couple of days to a couple of weeks. According to their accounts, they adhere strictly to the regime, respecting the specific time the treatment has to be taken, and making plans to obtain their treatment if they cannot do so themselves. Although we cannot check these statements in an objective manner, the quantitative data (CD4 count) of the preceding FEATS study seem to confirm these statements as the vast majority of respondents (87.1%) display a CD4 cell count above 200 after a mean treatment duration of 2.2 years.

According to Sarah, taking ART for the rest of her life is fine, because *“it’s my life”* (Sarah 2).

Joanne states:

“it’s going well with my treatment, I have no problems. Just drinking it every day, eight in the morning, at night at eight o’clock” (Joanne 2)

Jewel mentioned that she doesn’t think about the virus, to a point whereby she sometimes even forgets about it:

“The virus doesn’t control me, I control the virus [...] I told myself that this treatment will give me life to live form my children” (Jewel 4)

Susan’s version of her daily ART is:

“Ag, I don’t have problems with it right now. I mean, it’s like second nature, it’s like eating, so even before my alarm rings, I know when the time is right [...] it’s part of me now” (Susan 2)

Susan reiterates this:

“HIV is my friend, it is part of me [...] I tell it, you need to chill today, I am going out, so I will see you” (Susan 3)

Brenda, who accepts her status and her treatment without question or apprehension, stated that:

“In the past, it was stigmatised, because people will tell you that you are going to die. The virus was associated with negative talk. Today, if you take your medication then you will be fine and healthy to live for 50 more years. People shouldn’t commit suicide over it anymore” (A2)

Elisabeth revealed a level of suspicion with regards to the treatment:

“The other thing that I ask myself is that when time goes on, is this tablet going to get tired to work in our bodies?” (Elisabeth 2)

Whereas Vanessa completely accepts her diagnosis and the fact that she has to be on lifelong treatment, of the 12 women, she is the only one who complains about a range of side-effects. She has difficulty with hearing in one ear, she feels as though *“her blood isn’t flowing”* (Vanessa 3). In the mornings when she wakes up, one side of her body is stiff, as if she had a stroke, she is in a lot of pain, she sometimes gets a rash, she is constantly tired, she complains about a change in her complexion, and during all our visits to her, she laments the fact that she does not get proper medical attention and care from the personnel at the clinic she attends. As discussed before, the most serious side-effect, according to Vanessa herself, is the fact that her body changed because of the treatment – she suffers from severe lipodystrophy and mentions this as her biggest adaptation during each visit. Although this is a complaint that many of our participants mentioned, but for Vanessa, this was unacceptable (*“...but the body change was just too much for me to handle”*). It causes her tremendous anxiety, especially the fact that the changes might be permanent.

Our oldest participant, Julia, tells us that her body has changed substantially since she has been on treatment:

“You must see me when I am naked! I look like a pregnant woman.... it was not like that before, and now it’s worse...” (Julia 4)

Despite the fact that several women were suffering from various degrees of lipodystrophy, it was only Vanessa who reported that this had an adverse effect on her daily interactions: for example, because of her bodily alterations she mentioned that she did not want to go to a funeral of a distant relative as the people there might have noticed this transformation. These changes in physiology and appearance thus not only potentially fracture the biography into a life before and a life after ART initiation, but also partly determine Vanessa's presentation of the self by impacting the interactions with the social environment.

HIV as non-illness

Our participants do not necessarily consider themselves ill just because they are HIV-positive. In fact, they are only really ill when they are physically feeling ill or when there is a manifestation of an opportunistic infection that render them ineffectual and aware of their status. As discussed earlier, it was physical illness that caused most of these women to find out (or rather, to accept) that they were HIV-positive. However, despite the fact that they do not consider themselves to be ill, they mention that they still wanted to be healed from HIV. There is thus a blurred distinction between illness and well-being; an ostensible acceptance combined with a more subdued rejection, as indicated by Lucy:

"[HIV] is serious, but I don't think it is that serious. It is serious when you are not taking your treatment, but if you take your treatment, it's like you are not going to die". (Lucy 4)

Lucy claims that she is "still the same person" after her infection, but that she wants to be cured, she wants to be "normal" again. She is scared of dying because of the rumours that *"when you are feeling strong and healthy, it is actually when you are going to die"* (Lucy 4)

Brenda does not reflect on her diagnosis or her treatment, because to her, *"It's like I am not sick"* (Brenda 2)

Julia also mentioned that she is *"still the same person"* (Julia 4). She mentions that she thinks that she is going to live a long life, but soon thereafter, she ponders: *"I don't want to think that tomorrow I can die..."* (Julia 4)

She doesn't consider her illness to be too serious, but her illness stopped her from continuing with her work as a domestic worker, which makes her very dependent on other family members, as she has no children or partner. Once she voiced a looming concern: *"I wonder what is going to happen to me..."* (Julia 4)

Susan and Elisabeth have also mentioned that they wanted to be completely healed from HIV. Susan often asks us when they are going to discover a cure for *“this illness of mine”*, while Elisabeth believes that one day she is actually going to get cured through prayer, as other people in her church have apparently been cured of HIV:

Elisabeth: *“I know that one day, the same God who healed them, He or She can heal me”*

Interviewer: *“So you want to be HIV free, actually?”*

Elisabeth: *“Yes, but spiritually, I am HIV free!”* (Elisabeth 1)

All of the participants reflected on their status (indirectly or more directly) as being part of their daily lives. These reflections were not necessarily health related, but their status seemingly adds an additional dimension to their everyday life experiences. In fact, HIV infection and the concomitant treatment indirectly or directly exacerbate existential fears despite the professed return to normality given their successful ART treatment up until now. These existential doubts play out with regards to their level of acceptance and disclosure, their treatment adherence, as well as within their families around responsibilities, past experiences and future outlooks. Despite the fact the women have greatly incorporated the illness and its treatment into their life trajectories, the continuous negotiation between different roles and identities renders the chronic illness experience – and the associated moral career – a struggle with no end. ART may successfully restore the immune system and minimise the physical impact of HIV; it can still not wipe away the social and psychological challenges of living with HIV in a context of poverty, stigmatisation and hardship.

“Yes for my body I can see that I manage, I cope, because I treat myself, I take medication. I take care of myself, I didn’t do this, this so that I can infect others so but the thing is my happiness, sometimes you know what many people they don’t even know, because when I go I am looking, I try to be nice, to look nice, but I know, sometimes, I thought that ‘hey, she is looking at me’, you know - it seems as if you know what’s happening whereas they don’t even know” (Elisabeth 4)

Discussion

The purpose of the current longitudinal qualitative study was to explore – by applying the theoretical concepts of biographical disruption and moral career – the experience of living with HIV as a chronic illness in a high HIV-prevalence, resource-constrained setting.

The applicability of Bury's concept of illness as a biographical disruption to HIV as a chronic condition in a high HIV-prevalence, resource-limited setting was investigated. The repeated interviews demonstrated that upon diagnosis, most women had experienced feelings of denial and disbelief. The availability of ART however, played a crucial role in how HIV impacted the biographies of these women. The mandatory Drug Readiness Training displaying the prospect of a long and healthy life facilitated the acceptance of their status. In accordance with the Ciambone (2001) in the United States, the women in our study did not experience HIV/AIDS as the most disruptive event in their lives thus far (Ciambone, 2001). This might seem somewhat surprising, given the destructive impact the HIV epidemic has exerted on South Africa's society.

The explanation is provided by a more structural and contextualised perspective on the epidemic. HIV/AIDS cannot be studied detached from the socio-economic reality of South Africa with its long history of poverty, discrimination and inequity. The information emerging from the repeated interviews demonstrates how the biographies of these women are marked by general adversity and hardship. In this way, the experience of HIV/AIDS should be contextualised within life trajectories which are characterised by a continuous stream of different crises including violence, poverty and (AIDS-related) death. This conclusion is in line with previous research in Western industrialised settings. Pound et al. (1998) noted, in their study among older adults who suffered a stroke, that Bury's theory may be less applicable to people who have undergone prior disruptive experiences that have altered their biographies (Pound et al., 1998). Cornwell (1984) demonstrated that chronic illness, particularly in the context of a life history characterised by hardship, may be a biographically anticipated, rather than a disruptive event (Cornwell, 1984). These findings clearly indicate that biographical disruption holds an implicit assumption that illness enters lives which have been relatively untouched by crises. The theory carries class-related connotations, which are thus far under-researched, especially in resource-constrained settings, where this information is most relevant.

Despite the oscillations in the *moral career* of these participants, it seems that they have rather successfully incorporated HIV and its treatment into their life trajectories. Given the time that they have all been on treatment (with the exception of Linda), the women have seemingly transformed – to a large

degree – to a life as a PLWHA on treatment. The majority of their narratives show evidence that they feel in control of their lives in relation to their infection and its treatment. However, these results do not warrant complacency, as the repeated interviews show that despite women regaining their challenged life trajectories, the illness and its treatment cause additional disruptions to their everyday life experiences. There is thus a continuous negotiation between different roles and identities, depending on the specific context as well as the timing of infection and lifelong treatment. ART may successfully restore the immune system and minimise the physical impact of HIV but it can still not completely eradicate the social and psychological challenges of living with HIV in a context of poverty, stigmatisation and hardship. In this way, we concur with Wilson (2007) that an HIV infection *can be as disruptive in a resource-constrained setting* (negating the theory of the “normal crisis”) given the manifold roles and responsibilities that these women occupy in their everyday life (motherhood has been explored in Wilson’s article). Similarly, our results support the recent findings of a Ugandan study by Martin et al. (2013) demonstrating that living with stigma, continuously managing disclosure and adjusting to different roles are key features of life with HIV and on ART (Martin et al., 2013).

Our research has similarly uncovered two practical consequences of HIV and ART with important symbolic ramifications. HIV severely disrupts some of the women’s sexual, reproductive and personal lives as the prospect of disclosure and negotiating safe sex renders them vulnerable to stigmatisation and rejection. While these women have successfully incorporated HIV into their biography, sharing this new biography with potential partners seems to be a more difficult step. Related, the perceived possibility of transmitting HIV to an unborn child or dying because of a complicated pregnancy or birth disrupted the idea of future motherhood for some participants in their reproductive years, which is an important aspect of female identity. These practical barriers have important symbolic significance for the lives and resulting identity of these women.

Our findings also clearly demonstrate that one cannot neglect embodied experiences of women who are HIV positive and on ART. ART seemingly normalises these women’s lives but the bodily changes associated with the initial first-line regimen deeply disturbed the lives of those affected and strongly influenced their embodied experiences thereof. Again, this side-effect is felt much more acutely in the case of women, given the objectification of the female body in contemporary society that cuts across social standing and economic classification. In addition, the impact of lipodystrophy on the illness experience stresses the importance of timing and cohort membership (historical time) in the illness experience (Elder & Rockwell, 1979).

The findings clearly indicate that the women are forced to negotiate a constant process of identity management as different social contexts require different aspects of the self to be presented. The women refrained from disclosing their status at work, as they feared gossiping and stigmatisation. There is little research available on the determinants and consequences of workplace disclosure in South Africa, but the results are in line with a study by Page-Shipp et al. (2007) who reported that the vast majority of respondents (79%) had not disclosed their status to their co-workers (Page-Shipp et al., 2007). In addition, the study findings also demonstrate that several participants did not disclose their status to one or more fellow household members or that they actively reversed the disclosure process (as in Karen's case). This is in line with Goffman's (1963: 84) analysis that assumes that "the possession of a discreditable secret failing takes on a deeper meaning when the persons to whom the individual has not revealed himself [herself] are not strangers to him [her]". Goffman continues by stating that a "discovery prejudices not only the current social situation, but established relationships as well; not only the current image others present have of him, but also the one they will have in the future; not only appearances, but also reputation. The stigma and the effort to conceal it or remedy it becomes 'fixed' as part of personal identity" (Goffman 1963: 84) in a variety of social interactions. Our findings support the results of Gilbert & Walker (2010) demonstrating that stigmatisation remains a core feature of the patient experience of HIV and AIDS in South Africa, even in a time when the availability of ART has transformed it into a chronic condition (Gilbert & Walker, 2010).

The strengths of this study include its theoretical foundation in medical sociology and its longitudinal, in-depth design. In particular, the integration of different important sociological perspectives on health enables us to draw a comprehensive picture of the illness experience: from HIV diagnosis, over ART initiation, to the continuous treatment and moral career within the relevant socio-economic context. The longitudinal and in-depth aspects reflect the intense engagement of the researchers with the participants which enabled us to build trust and to avoid – as much as possible – responses based on social desirability. To the best of our knowledge, this is thus the first study to assess, in a longitudinal manner, the applicability of different theoretical frameworks to the illness experience of HIV positive women in a high-HIV-prevalence, resource-limited setting. However, there are some limitations to our study. First of all, the study only collected the perspectives of those HIV-positive women who had enrolled in the South African ART programme and who were willing to participate in the current study. Besides one exception, all women had successfully been on treatment for several years. It is thus possible that patient groups which do not enrol, which are not retained or which refuse to participate in a research study display different illness experiences (Ware et al., 2013). Secondly, we retrospectively

collected information on women's transition to life with HIV and taking ART. Ideally, future research studies would walk this journey alongside the participants and interview them repeatedly before and after the first HIV diagnosis and ART initiation. Lastly, this article only reflects on women's experiences despite the burgeoning evidence that men face more challenges adhering to ART.

Several important insights have emerged from this study, resulting in both theoretical and practical implications. From a theoretical point of view, we agree with Wilson that the notion of biographical disruption can be used with greater effect if there is a stronger "focus on the relationship *between* identity and illness, rather than only on the effects of illness *on* identity" (Wilson 2007: 623). The intersection of certain aspects – in our study issues such as class, race, gender, age, motherhood status intersecting with infection and treatment – lends itself more fruitfully to understand the continued identity negotiation that takes place among these women infected with HIV and on ART. The interaction between structural aspects, (stigmatising) relations with family members, neighbours and co-workers, and the illness (and its treatment) determines the never-ending cycle of identity appraisals, revisions and improvements, health related or otherwise. The study findings also have important implications for public health policy and practice. The evidence-based knowledge, grounded in sociological theory, expands our understanding of the lives of women dealing with HIV in a resource-constrained setting and explicitly draws attention to the social context in which this challenging illness experience takes place. Future research efforts aimed at creating a health-enabling environment for these vulnerable groups should thus be a research and policy priority.

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