



Full Length Research Paper

“People don’t know that I’m HIV positive”: self-stigma in the lives of sub-Saharan African migrant women in Belgium

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Antiretroviral treatment has significantly reduced AIDS-related deaths but the increased number of people living with HIV/AIDS and experiencing stigma remains a global health challenge. Self-stigma deeply affects the lives of people with HIV/AIDS and may thwart prevention efforts. This paper explores the drivers of self-stigma, experiences and the coping strategies common to HIV-positive sub-Saharan African (SSA) migrant women in Belgium. Qualitative study of 40 SSA migrant women was conducted between April 2013 and December 2014. Participants were recruited through purposive sampling and snowball techniques from AIDS Reference Centers and AIDS workshops in Belgium; if 18 years and older, French or English speaking, and diagnosed HIV-positive more than 3 months. We conducted semi-structured interviews with patients and did observations during consultations and support groups attendances. Follow-up interviews were conducted four to eight months later. Thematic analysis was used to identify themes, aided by NVivo 8 as they emerged from data. Self-stigma was ubiquitous in the lives of almost all participants, driven by: public endorsed negative feelings, chronic/incurable nature of disease, HIV transmission misconceptions. The most striking implications of HIV self-stigma include: reluctance to seek treatment/care, unwillingness to disclose HIV+ status. Participants reported that disclosure/non-disclosure, treatment adherence, faith in God, empathy and support help them cope HIV/AIDS self-stigma. Our findings highlight the complex and shifting nature of self-stigma experienced by SSA migrant women living with HIV/AIDS in Belgium. There is urgent need for innovative culturally-adapted self-stigma reduction programs that will improve personalized support services and optimize HIV prevention and treatment.

Keywords: HIV/AIDS, Self-stigma, Stigma drivers, African migrant women, Belgium.

INTRODUCTION

People who are ill and the society they live in have a shared responsibility for health promotion (Bhugra and Malhi, 2013) because the interaction between the

individual and society is pivotal in constructing positive feelings about oneself and others. However, the public stigmatizes people they judge negatively. Some studies have elucidated the link between public negativity towards a group of persons and the internalization of negative attitudes by this group (Dinos, 2014; Shefer et al., 2013). Stigmatized disease can either be visible or

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concealed and often contributes to a hidden burden of illness. When a stigmatized disease is visible to others, a person may become discredited (Goffman, 1963). Stigma related to disease is a major social and health challenge because it impedes proper testing, diagnosis and treatment of chronic diseases such as diabetes, asthma, cancer and HIV (Fortenberry et al., 2002); (Earnshaw and Quinn, 2012; Hatzenbuehler et al., 2013).

HIV-related stigma involves public prejudice, maltreatment and negative attitudes directed at people living with HIV/AIDS (Fielden et al., 2010). The stigma of HIV/AIDS is more complex than that of other long-term diseases (mental disorders or disturbances, Diabetes, Asthma, Cancer and Ebola) because it is predominantly contracted through sexual activities. Studies have shown that HIV-related stigma is also highly associated with self-stigma (Mak et al., 2007). Agreeing with public beliefs and replicating these beliefs in daily lives foster self-stigma. Self-stigma of HIV/AIDS occurs when public stigma of HIV/AIDS is endorsed and internalized by the patient (Lee et al., 2002). People passively isolate themselves or deny themselves social interaction or relationships because they feel ashamed, worthless or fear prejudice from others (Corrigan and Rao, 2012).

HIV self-stigma is a process whereby people living with HIV impose feelings of difference, inferiority and unworthiness on themselves, making prevention and treatment of HIV more difficult (Overstreet et al., 2012; Tsai et al., 2013). Although self-stigma emanates from public stigma, other studies denote that the process of self-stigma can be reversed at the individual level with appropriate interventions (Liamputtong et al., 2009). Self-stigma always affects people, notably sub-Saharan African (SSA) migrant women with HIV/AIDS at some stage in their lives (Linda, 2013; Monjok et al., 2009). Therefore it is necessary to understand why self-stigma drives HIV underground and how it may prevent health-seeking behaviour (Vogel et al., 2013). Furthermore, it is important to know what self-stigma means to these women. It is largely known that antiretroviral treatment prevents AIDS-related deaths but new HIV infections increase the number of people living with the disease globally (WHO/UNAIDS/UNICEF, 2013). Treatment as prevention may not be enough to eradicate HIV as previously documented (Auerbach et al., 2011; Dieffenbach and Fauci, 2011).

To date there is little literature that has explored self-stigma among SSA migrant women with HIV/AIDS in Belgium in this era of effective antiretroviral therapy. Sex and sex-related issues are seen as taboo in most SSA cultures, making HIV/AIDS a shameful, mockable and dreadful disease even outside Africa (Bischofberger, 2008; Drummond et al., 2008). Migrant women from SSA with HIV/AIDS experience a decline in 'sense of self and diminished sense of power'. They have to deal more with self-stigma than with public stigma, as most often their HIV status remains unknown to the general public.

Between 2006 and 2012 about 9403 women were diagnosed HIV positive in Belgium (ECDC, 2013). In 2012, an estimated 393 women were diagnosed HIV positive, of whom about 90% were of African origin. The aims of the study are to explore the drivers of self-stigma among SSA migrant women with HIV/AIDS, to describe the experiences of these women and, finally, to investigate how they manage self-stigma.

METHODOLOGY

Study design and Sample

A qualitative study based on semi-structured interviews with SSA migrant women. Follow-up interviews were conducted four months after the first interviews. In addition, observations were made during consultations and support group attendances and information from the hospital records as to the age and year of diagnosis to complement data was obtained (Figure 1). We included women originating from SSA, aged 18 years and older, speaking French or English, diagnosed HIV positive more than three months ago and receiving treatment in Belgium. The main researcher (AEA) explained the objectives of the study to care givers at the AIDS Reference Centre (ARC) and asked them to recruit patients.

The recruitment of patients was done in two phases. Firstly, the HIV experts treating the women at an ARC identified patients according to these inclusion criteria from the consultation list and invited them to participate in the study. The second phase of the recruitment involved self-identified HIV/AIDS women attending AIDS workshops in Belgium recruited through snowball techniques. The workshops were focused on empowering women living with HIV/AIDS and on the different cycles in the life of women in general and particularly those living with HIV/AIDS. During coffee breaks, the researcher met some workshop participants and explained the objectives of the study to them and asked if they would participate in the study. Those who were interested chose the venue and time of interview. Two support groups for African migrants living with HIV/AIDS were contacted and permission was obtained to attend their meetings.

Data collection

All data were collected between April 2013 and July 2014. For the interviews, a sample interview guide for patients was prepared by the interviewer (AEA) and the content was then amended and approved after discussion by the rest of the research team. Patients invited by the ARC healthcare providers to participate in the study were presented to the interviewer and interviews were held at a place and time selected by the

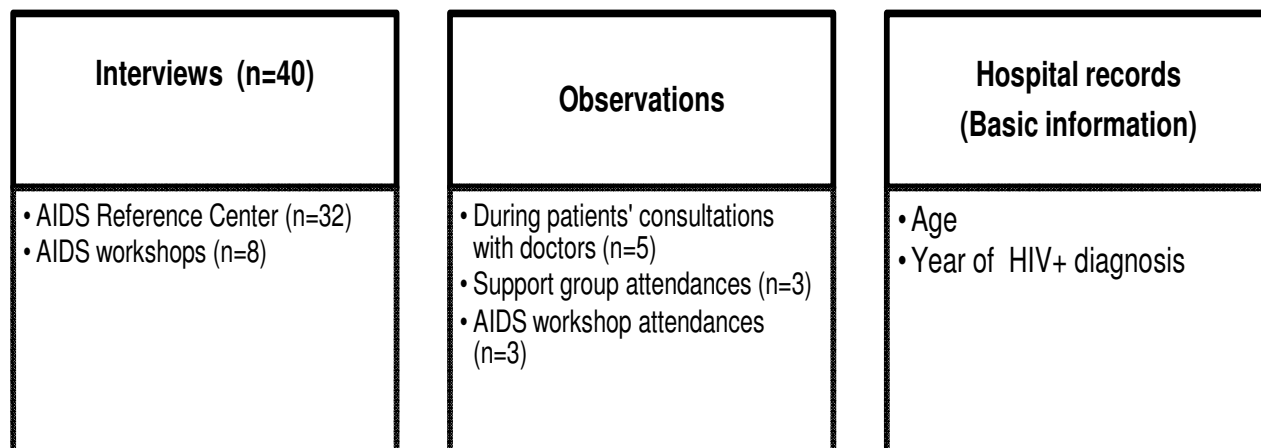


Figure 1. Schema presenting data collection sources

Table 1. Interview questions

How did you feel after being diagnosed HIV positive?
Has your lifestyle changed since the diagnosis? -If yes, in what ways? -If not, why?
Are there instances that you denied having the HIV disease?
Have you ever been ashamed of being HIV positive?
How do people who know of your illness approach or treat you?
Do you feel comfortable whenever there is a discussion about HIV/AIDS?
Are you living with your illness without blaming yourself or how you contracted the disease?
What do you do when you have these negative feelings as a result of living with HIV/AIDS?

patients.

At the beginning of the interviews, the objectives of the study were explained to the participants before they were asked to sign the informed consent form. All participants were asked permission to record interviews digitally. Interviews were conducted in French or English as preferred by the interviewees. During the interviews, participants were asked what it was like to live with HIV/AIDS; how they feel with the disease and what they do to manage their feelings as a result of living with HIV/AIDS (see table 1 for a list of questions asked). At the end of each interview, each participant was asked for permission to conduct a follow-up interview at a time convenient for her in order to better understand her experiences. Participants who accepted follow-up interviews were contacted once between four and eight months after the first interviews.

While in-depth interviews were conducted to explore the self-stigma, observations provided contextual data. Patients were observed during their consultation with their HIV treating physicians. Notes were written as to what was observed and heard during consultations and support group meetings. Treating physicians obtained

consent from participants for the researcher to observe consultations. Observations during consultations and support group meetings were recorded as field notes adding to the contextual data to better understand the interaction between patients and treating physicians on the one hand and between peers on the other hand. In order to protect confidentiality, data was anonymized.

Data analysis

All interviews were transcribed verbatim and NVivo 8 software was used to aid data management and thematic content analysis. Constant comparative techniques were used to analyze data (Corbin and Strauss, 1990) as they emerged by two researchers (AEA and RD) and discussed their findings until there was consensus about the codes and their meanings (Bradley et al., 2011). The analysis began with open coding on a line-by-line basis using participants' words and ideas also known as "bottom-up approach" (Miles and Huberman, 1994). Thematic analysis was important to identify new themes that could eventually produce a bigger picture (Braun and

Clarke, 2006). Preconceived theoretical concepts were avoided in the initial stage. In the next stage relevant ideas were compared and grouped together in more abstract categories. Quotations under each category indicate the drivers, experiences and management of self-stigma. Three experienced researchers also read and discussed the findings to ensure the reliability and validity of the data. Potential identifiers were removed from all quotations

RESULTS

Study demographics

Socio-demographic details of the patients are displayed in (Table 2). We conducted 40 semi-structured interviews that lasted between thirty minutes and two hours. Eight participants agreed to follow-up interviews which were conducted four to eight months from the time of the first interviews with patient participants. Of the 40 patients that were interviewed, 24 were living together with intimate partners and had disclosed their status to their partner. Seven were living separately from partners and had not disclosed their status. Nine were single and living alone or with their children. The age range of patient participants was between 20-69 years. They were all practicing Christians or Muslims. Six of those interviewed were childless. Twenty-two were regularly employed and eleven were unemployed. Eighteen had disclosed their HIV status to some family members; ten had disclosed it to friends and only nine to their children. One had revealed her status only to HIV care professionals.

Apart from disclosure to intimate partners, family and friends, fifteen had revealed their status in HIV support groups where confidentiality is expected of members. The researcher (AEA) attended three support group meetings and took notes during the meeting sessions. Of the three meetings, one was with an ARC-based group of male and female participants (n=25); two with an HIV/AIDS activist-run group of male and female participants (n=30) (names withheld for anonymity reasons). Three HIV/AIDS workshops for women only were held and most participants were from sub-Saharan Africa. The meetings lasted between two and six hours and participants felt relaxed during these meetings.

The prevalence of self-stigma

All patient participants described negative personal reactions to HIV-positive status that may result in significant loss of self-esteem, poor management of illness, low health seeking behaviour and treatment adherence that could engender unnecessary suffering to patients. They also acknowledged that knowing the effects of a positive status may provoke depression, self-

Table 2. Demographic details of patients (n=40)

Variables	Frequency
Age	
20-29 years	3
30-39 years	10
40-49 years	15
50-59 years	8
60-69 years	4
Education	
University	13
High school	9
Secondary school	16
Primary school	1
Informal	1
Civil status	
Married	24
Single with partner	7
Single/Widowed/ without partner	9
Have children	
Yes	34
No	6
Mode of transmission	
Heterosexual	38
Homosexual	0
Service-related	1
Perinatal	1
Probable place of infection	
Belgium	5
Country of origin	35
Knowledge of HIV status	
Before leaving Africa	5
In Belgium	35
Employment status	
Employed	22
Unemployed/jobseekers	11
Retired	3
Disability	3
Religion	
Christians	38
Moslem	2
Disclosure status	
HIV treating staff	40
Other health care professionals	30
Intimate partner only	25
Family	18
Friends	10
children	9
Support group adherence	
Members	15
Non-members	25

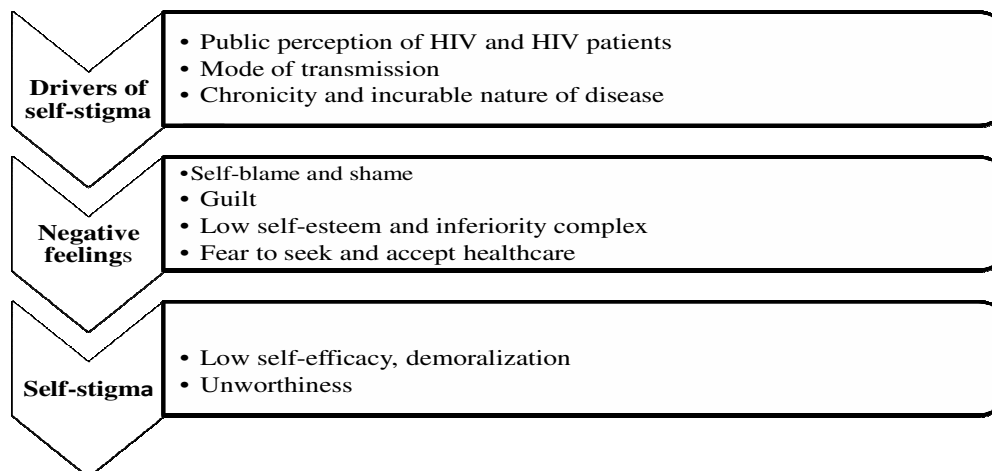


Figure 2. Linkage between self-stigma drivers and negative self-feelings

judgment, fear and denial. All the participants revealed that at a certain time in their lives with HIV, they had felt worthless, believed they had betrayed those who looked upon them as role models or bread winners, or felt they were a burden or not fit for the society. Many participants reported social isolation and distancing.

Drivers of self-stigma: Three main themes that emerged from the discussions with the women as to why they self-stigmatized were: the public perception of HIV patients, mode of transmission myths and the chronic and incurable nature of HIV/AIDS. The women indicated that these mechanisms had led them to have negative feelings about themselves as shown in (Figure 2).

Public perception of HIV patients: Participants reported that public perceptions of HIV and HIV/AIDS patients after more than thirty years drive self-stigmatization. All the participants reported that they had witnessed public stigmatization and discrimination with the public in general and within the African diaspora, as one participant commented:

Africans have their way of looking at illnesses. Some don't understand people who are ill [HIV positive]. I think it's an African way of thinking. When you are ill and pale, they say 'that one is sick' -meaning having HIV/AIDS. For example in my country, a woman who is HIV positive is taken to be a prostitute or promiscuous. But you can have HIV without being a prostitute. I was married with children and thought HIV was for others. I did not go out to look for HIV. (Interviewee 18, mother of 2 children)

Mode of transmission myths: Participants described how contracting HIV through sexual activities contributes to self-stigma. All but two participants reported contracting HIV through sexual activities. On the mode of transmission one woman reported:

Until now HIV/AIDS has remained a taboo among Africans. I do believe that it is a taboo even here in Belgium because it is predominantly contracted through sexual activities. Nobody wants to be branded with HIV. You can tell anyone that you have hypertension, diabetes, or anything like that but not HIV. HIV/AIDS is a shameful disease that you don't want people to know about' (Interviewee 6, mother of 3 children)

The chronic and incurable nature of HIV/AIDS: All participants reported fear of living with a chronic and incurable disease, medication side-effects and the eventual AIDS-related diseases. When asked why a participant can't make plans for the future, she responded:

'I don't have projects because the illness remains incurable. I don't see myself as someone who is not ill. All incurable diseases scare me. There are always doubts—"how long do I have to live?" There is always fear, panic and doubts about life with HIV/AIDS'. (Interviewee 16, with a partner and 4 children)

Having a sense that no cure is available for HIV was supported by another participant:

'The fact of feeling or knowing that I am ill [HIV positive] destroys me. What I feel inside destabilizes me' (Interviewee 37, mother of 3 children)

Experiences of negative feelings

Several women in the study described that they 'isolated themselves', 'felt sad' and had many 'negative feelings' about themselves. Participants varied in terms of the

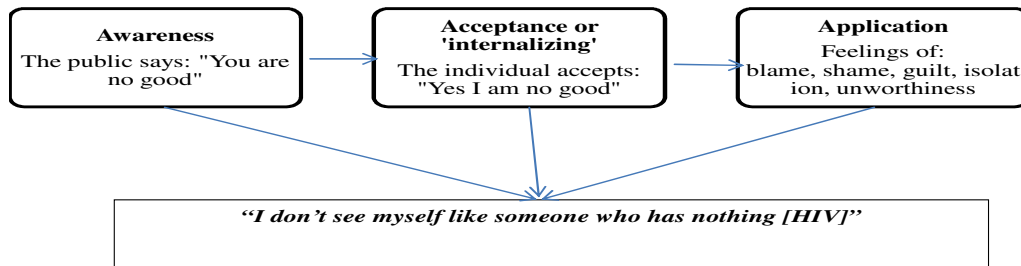


Figure 3. Negative feeling mechanisms

awareness, acceptance and application of the negativity of being HIV positive. The main themes related to the negative feelings that emerged from the women's discourses were: guilt, shame, blame, loneliness, unworthiness and inferiority complex as shown in (Figure 3). Being *aware* of the stigma related to HIV, these women *accept* (*internalize*) and *apply* the self-stigma mechanisms to their lives with HIV.

Feeling of self-blame and shame: All but one participant blamed themselves for not preventing HIV despite their awareness of HIV as a serious disease as commented by a participant:

"I blamed myself for having this disease because I did not take precautions despite my awareness of the seriousness of the disease" (Interviewee 9, mother of 2 children)

In referring to the feelings of shame, one woman confided:

Our children were informed about our illness very late because we were ashamed. I did not attempt to tell anyone. I tried telling a friend but I could not because in my country when you say you are HIV positive, you are really marginalized. That is why I could not tell anyone. Maybe they knew later on when my husband became very ill, lost a lot of weight and was always hospitalized. They concluded 'if he is sick, then his wife is also sick'. Maybe my husband told his family but me, I never told anyone except my children when they became adults. (Interviewee 19, mother of 4 children)

Feelings of guilt: The feeling of guilt was expressed by all participants if their HIV/AIDS status was to become public as expressed in these words:

'People are afraid of being judged especially as you don't know in what circumstances you contracted the disease. People will take you for a prostitute or something like that despite the fact that there are several ways of contracting the disease. It is normal that you feel guilty and will

not like to disclose your [HIV] positive status to anyone'. (Interviewee 13, mother of 1 child)

Another participant commented:

'One feels humiliated. If you say you are ill, you have HIV, everyone looks at you as if you have sinned. People think it was no accident. We prefer to talk to our treating doctors'. (Interviewee 2, mother of 1 child)

Feelings of low self-esteem and inferiority complex:

Some participants reported that they were unable to give positive meanings to their lives and envision a positive future, as one patient explained:

I have a project to become a nurse, but in my head, I say 'knowing my health situation, nobody will accept me as a nurse. I can't find my place in society'. Whatever I do, I always say 'you complete your studies, you can succeed, and I have to succeed. I will do my best to succeed but I don't see my place in society. I will finish school and will not have a job because I have HIV. I will not be employed'. I am always having these thoughts. (Interviewee 1, childless)

Another participant went on to describe her feelings:

'I don't have much self-esteem since I was diagnosed HIV positive. You really feel diminished in all that you do and you lose all confidence in yourself. In my choice of job, I try not to venture much to look for work with probable stress. I have never tried to look for a job equivalent to my university education...Is it going to make me more stressed and ill?' (Interviewee 9, mother of 2 children)

A striking example came from a woman who described her inability to envision a positive future as follows:

I have never felt stigmatized or discriminated against, but personally I am unable to have any intimate relationships because I have a problem.

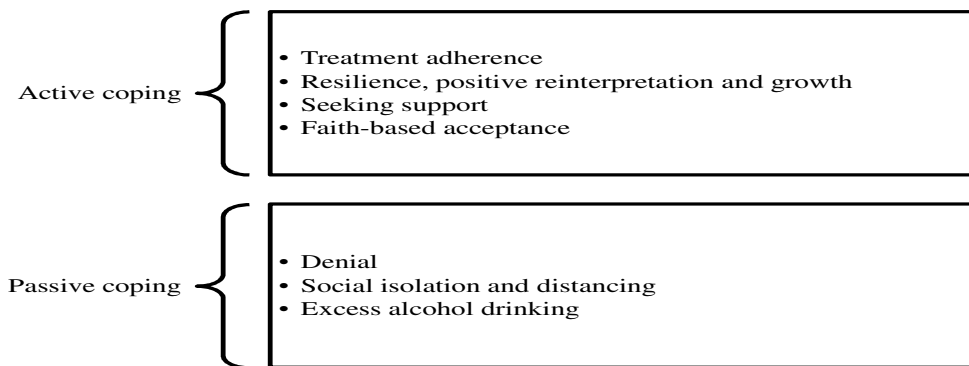


Figure 4. A schema to understand HIV-self-stigma coping strategies employed by study participants

HIV limits my freedom. I may have to tell a man who wants a relationship, which I don't want to do, or I may contract another STI. I have been alone since my diagnosis 18 years ago. I can never let a man in. Men who are interested in me don't know my status because it is never discussed. (Interviewee 11, mother of 2 children)

Fear of seeking or accepting health care: Some participants reported that they were afraid to go to the clinic because someone might recognize them and associate them with HIV/AIDS. A participant explained why she refused HIV-positive diagnosis in these words:

I refused the diagnosis and refused to go to the hospital for treatment for more than six years because to me going to the hospital meant I was HIV positive and would meet someone at the clinic who would identify me as HIV positive and spread the news. I had to run away from people and did not want to be treated. I continued having unprotected sex with my partner who is HIV negative and had two healthy children. I decided to start treatment when the doctor insisted that my life and that of my third baby was at stake if I continued refusing treatment. (Interviewee 32, mother of 4 children)

Coping strategies

Coping mechanisms for most participants included personal activities deemed active or passive. Fifteen reported participating in support groups. All HIV-positive SSA migrant women in the study used one or more of these strategies to help them cope with self-stigma as illustrated in Figure 4.

Active coping

Participants described that adhering to their treatment, resilience, positive reinterpretation and growth, faith-based acceptance and seeking support underlined their

ability to cope with self-stigma.

Treatment adherence: All participants reported adhering to treatment which helps to keep them healthy (looking good) and strengthens efforts in the self-management of their lives with HIV/AIDS. The participants confided that complying with treatment and care guidelines mirrors a positive outward appearance and helps reduce negative feelings about themselves. On treatment adherence one had this to say:

'The doctor told me that with treatment I had a high chance of living longer. Now I don't think of HIV as a killer disease because of the availability and accessibility of good treatment in Belgium. To me, it [HIV] is just like any chronic disease. I take my medications regularly. I have no problems. The HIV in me is now undetectable and the viral load is very low'. (Interviewee 17, mother of 3 children)

Resilience, Positive reinterpretation and growth: Despite experiencing some negative feelings, most of the women reported looking at HIV-positive diagnosis not as the end of the world but as a push to improve on their lives through achieving their motherhood desires, education and employment. Reflecting on resilience and positive change a participant said:

After our fourth child was born, my husband started blackmailing me. He did whatever he wanted. I could not say anything. I decided to disclose to my family because I could no longer endure this alone. Since I disclosed, I have been liberated. I ended the relationship and decided that I would live like any other person who could die from any accident or other illnesses. I started asking my treating physicians lots of questions about living with HIV/AIDS. I have four healthy children and lived with a man without him contracting HIV. So why should I not live normally, I asked myself? I learnt to drive. I have

a job and I am now relaxed, unlike to when I felt useless and ashamed. (Interviewee 32, mother of 4 children)

Faith-based acceptance: A majority of the participants experiencing self-stigma reported having accepted the fact that they have to live with HIV all their lives. Devotion to prayers and fasting helped them manage unavoidable negative feelings as one said:

'As a devout Christian I have accepted my HIV status and there is nothing I can do about it. I take my medications as instructed by the treating physician and pray to God. HIV is like cancer, diabetes, hepatitis and I am living with HIV like anyone living with these chronic diseases. There is nothing I can do except accept and live with the disease'. (Interviewee 6, mother of children)

Seeking support: Fifteen participants who were members of support groups revealed that peer support offered an outlet for inevitable negative feelings, permitting them to talk to someone who could understand their plight and provide peer-to-peer solace. This point was highlighted by one woman:

'I can pick up my phone and call one of my peers when I am on the down side. A few minutes into our conversation, I realize that I am not alone. There are people out there I can turn to. I often feel a lot much better after talking with a peer'. (Interviewee 22, mother of 3 children)

Similarly, participants who were not members of any support group reported that in addition to clinical care, the emotional support they got from their HIV treating personnel whenever they were "down" was very good. These participants prioritized their relationships with their treating personnel in these words:

'I can call to see a doctor when I am not feeling "fine", not necessarily having physical pains. I always ask the doctor if I can do anything, what to do and what not to do whenever I come for consultation'. (Interviewee 2, mother of 1 child)

Passive coping

When describing how they manage self-stigma, some participants said that they remained in denial, isolated and distanced themselves from their communities and used excessive alcohol to mediate living with HIV/AIDS.

Denial: HIV-positive diagnosis denial was strong among three patients who have been living with HIV for more than 10 years and were unable to rework the

intrusive thoughts of having HIV/AIDS. They reported denying their HIV positive status despite receiving antiretroviral therapy (ART) and respecting scheduled consultations at the clinic. One participant said the following about living in denial:

'It is all in my head. I refuse to accept my HIV-positive diagnosis. Hospital visits remind me that I have this thing [HIV] in me'. (Interviewee 14, mother of 2 children)

Social isolation and distancing: A majority of the participants reported social isolation and distancing as a strategy to cope with self-stigma. They made rules to limit interaction with friends and family members for fear of humiliation, being treated different or being associated with pain as one participant commented:

'Generally, I avoid meeting people especially people with HIV/AIDS because I hate seeing people live in pain'. (Interviewee 27, mother of 1 child)

Another example is from a participant who reported having only her children as friends:

'I have no friends. My children are my friends and my motivation to continue fighting'. (Interviewee 38, mother of 3 children)

A participant also commented on avoiding people:

'Because of my illness, I distance myself from people. It is not people who distance themselves from me, but I who distance myself from them. Nobody knows that I am ill, I don't accept-, I distance myself, I don't know how to explain this to you.... I don't allow myself to associate with people because there is 'something in me'. I don't feel like a normal person. I feel it can be read on my face and that is why I have withdrawn from almost all of my friends. (Interviewee 1, childless)

Excessive alcohol: Excessive intake of alcohol as a strategy to manage dejection was reported by four women as one commented:

'I started drinking alcohol heavily when I was diagnosed HIV positive. Presently, I still drink when I am depressed. I have destroyed my liver because of too much alcohol. I had even tried to kill myself several times but thinking of my children helped me to be resilient. But whenever I have any emotional problem, I start drinking again'. (Interviewee 35, mother of 4 children)

DISCUSSION

We identified the salient domains of the feelings of worthlessness, blame, guilt, shame, low self-esteem, dejection and inferiority complex among all HIV positive SSA women in our study. Our findings also indicated that the perceived public stigma, the incurable nature of HIV and its mode of transmission perpetrate self-stigma. On the other hand, adherence to ART, resilience and growth and faith-based acceptance are active coping strategies employed by the women to reduce self-stigmatization. Conversely, denial, social avoidance and distancing and excess alcohol use were some of the passive coping strategies employed by certain participants to manage their self-stigmatization.

This paper is one of the first papers on self-stigma among SSA migrant women with HIV in Belgium. Similar studies among minorities in Hong Kong (Mak and Cheung, 2010) and men and women living with HIV/AIDS in South Africa (Simbayi et al., 2007) support our findings that stigma and self-stigma exist in different environments. Thus there is still an urgent need for sustainable stigma and self-stigma reduction interventions.

The qualitative nature of our study limits generalizability because of the small sample size but the findings provide insights into self-stigma mechanisms among SSA migrant women. However, the findings may be limited by the context. The relatively small number of participants who experienced overt stigma strengthened the assumption that most of the stigma was self-imposed by the women living with HIV. Consistently with previous research (Cuca et al., 2012), our findings reiterate that a majority of women with HIV/AIDS have preconceived negative feelings that fuel self-stigmatization.

This study sheds further light on illness stigmatization in the cultures of some African communities that are hard on members deemed bad or deviant. For example, personal responsibilities are linked to HIV/AIDS in these environments and the infected or affected person self-stigmatizes through self-blame, guilt, shame, denial and fear. Vulnerable individuals in these communities endorse self-stigma by accepting the negative beliefs developed and defined by the society power and domination (Parker, 2012; Kalichman et al., 2009; Link and Phelan, 2014). The public including the media, communities, health care settings, families, friends, employers and work colleagues demonize HIV which diminishes participation in prevention, treatment and care (Airhihenbuwa and Webster, 2004; Sofolahan and Airhihenbuwa, 2013; Browne et al., 2013).

Self-stigma diminishes self-esteem and self-efficacy, and may lead to a sense of loss and disempowerment as our study depicts. The feelings of worthlessness, shame, blame, guilt, avoidance and the sense of hopelessness experienced by participants in our study are similar to previous research on HIV positive women (and men) in

other parts of the world (Anderson et al., 2010; Petros et al., 2006; Duffy, 2005). However, treatment adherence was found to be a strong booster to the feelings of self-worth and independent living as has been evidenced in other studies (Tsang et al., 2010). Treatment adherence diminishes HIV/AIDS-related disfigurement and death, fosters positive living and enables self-stigma reduction.

Our data also demonstrates that resilience; internalization, positive reinterpretation and growth in the course of stressors like HIV/AIDS are prevalent, suggesting that adjusting to any stressful event can be less distressing. For example, though the women in the study self-stigmatized, they could still pursue their personal growth (education, employment, motherhood), improve their quality of life and rethink their life priorities. They believed that they are stronger than before the HIV-positive diagnosis and have benefited from a stressful and traumatic life event. Apart from the women who use alcohol to cope with self-stigma, most of the participants have adopted healthy behaviour and positive lifestyles.

We found that fear was a common feeling among the women, which stays in them for a long time. Sometimes disclosure could not help dissipate the fear of dying from an HIV-related illness. The fears of staying single, of not having a job that corresponds to their educational level, of rejection and abandonment by HIV-negative partners remain pertinent in personal empowerment. Furthermore, fear of medication side-effects, self-image changes and the fear of leaving their children motherless preoccupied participants' thoughts as found in a previous study (Hackl et al., 1997). We also noted that fear of loss of reproductive capacities and the fear of 'what people will say' if their status is revealed are devastating to many of our study participants. Our study shows that living with a dangerous disease like HIV/AIDS enhances the feeling of 'fear of everything and everybody'. With regard to our study, education as prevention alongside treatment as prevention can help reduce HIV-related stigma/self-stigma among SSA migrant women and other individuals living with HIV/AIDS, as acknowledged by other studies (Cohen et al., 2012; Smith et al., 2011).

Stigma is a social error but self-stigma is personal and internalized, summarized in these words: 'people don't know that I'm HIV positive but I distance myself from them'. Silence, secrecy, social distancing and avoidance, faith and prayers, ART (Campbell et al., 2011), support and compassion helped shield women with HIV/AIDS from external stigma and enable them, *in their own way, to live well with HIV/AIDS*. Self-stigma may not only affect women who are HIV positive but also those who have not yet been diagnosed. Even the possibility of being HIV positive is a reason for self-stigmatization for many people. Self-stigma can have a negative impact on HIV testing, treatment adherence and prevention by decreasing health seeking behaviour, increasing high-risk sexual conduct, increasing substance abuse, increasing depression and reducing wellbeing. Given the link

between public-stigma and self-stigma, it is imperative that both be addressed in a holistic way. HIV self-stigma is a phenomenon that needs individual, family, community and global efforts to make people living with HIV/AIDS less stigmatized and discriminated.

CONCLUSION

The link between public stigma and self-stigma is undeniable, as the former directly or indirectly affects the latter. Our study suggests the urgent need to confront self-stigma that may undermine HIV prevention, treatment and efficacy. HIV/AIDS negative feelings among SSA migrant women remains a social and public health challenge. Sustainable health-seeking behaviour that will maximize HIV prevention and treatment investments for women from sub-Saharan Africa living in Belgium should be encouraged. Interventions to help change negative self-beliefs before HIV diagnosis should be focused on vulnerable groups, especially SSA migrant women. People should be helped to *externalize* when they become ill with HIV/AIDS or other life-threatening and chronic illnesses. HIV/AIDS self-stigma impacts the lives of SSA women in diverse ways, pointing to the need develop self-stigma reduction strategies targeted toward women, men and the broader community. We recommend rethinking interventions that will reduce HIV/AIDS stigma/self-stigma, sustain treatment and prevent new infections in order to obtain a decline in the number of people living with HIV/AIDS.

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REFERENCES

- Airhihenbuwa CO, Webster JD (2004). Culture and African contexts of HIV/AIDS prevention, care and support. *SAHARA.J.* 1(1): 4-13. doi:10.1080/17290376.2004.9724822 [doi]. Retrieved from PM:17600995
- Anderson M, Elam G, Gerver S, Solarin I, Fenton K, Easterbrook P (2010). "It took a piece of me": initial responses to a positive HIV diagnosis by Caribbean people in the UK. *AIDS Care*, 22(12): 1493-1498. doi:926625114 [pii];10.1080/09540121.2010.482125 [doi]. Retrieved from PM:20824553
- Bhugra D, Malhi GS (2013). Disease, illness, sickness and the contract with patients. *Aust.N.Z.J.Psychiatry*, 47(9): 795-797. doi:47/9/795 [pii];10.1177/0004867413502407 [doi]. Retrieved from PM:23985791
- Bischofberger I (2008). HIV-infected sub-Saharan migrants in Switzerland: advancing cross-cultural health assessment. *J. Assoc. Nurses AIDS Care*, 19(5): 357-367. doi:S1055-3290(08)00137-4 [pii];10.1016/j.jana.2008.04.010 [doi]. Retrieved from PM:18762143
- Bradley EH, Fennell ML, Pallas SW, Berman P, Shortell SM, Curry L (2011). Health services research and global health. *Health Serv. Res.*, 46(6pt2): 2019-2028. doi:10.1111/j.1475-6773.2011.01349.x [doi]. Retrieved from PM:22092225
- Braun V, Clarke V (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. doi:doi:10.1191/1478088706qp063oa. Retrieved from <http://www.tandfonline.com/doi/abs/10.1191/1478088706qp063oa>. Retrieved from Routledge.
- Browne JL, Ventura A, Mosely K, Speight J (2013). 'I call it the blame and shame disease': a qualitative study about perceptions of social stigma surrounding type 2 diabetes. *BMJ Open.*, 3(11), e003384. doi:bmjopen-2013-003384 [pii];10.1136/bmjopen-2013-003384 [doi]. Retrieved from PM:24247325
- Campbell C, Skovdal M, Madanhire C, Mugurungi O, Gregson S, Nyamukapa C (2011). "We, the AIDS people. . .": how antiretroviral therapy enables Zimbabweans living with HIV/AIDS to cope with stigma. *Am. J. Public Health*. 101(6): 1004-1010. doi:AJPH.2010.202838 [pii];10.2105/AJPH.2010.202838 [doi]. Retrieved from PM:21164081
- Cohen MS, Muessig KE, Smith MK, Powers KA, Kashuba AD (2012). Antiviral agents and HIV prevention: controversies, conflicts, and consensus. *AIDS*, 26(13): 1585-1598. doi:10.1097/QAD.0b013e3283543e83 [doi]. Retrieved from PM:22507927
- Corbin JM, Strauss A (1990). Grounded theory research: Procedures, canons, and evaluative criteria. *Qualitative Sociology*, 13(1): 3-21. Retrieved from <http://dx.doi.org/10.1007/BF00988593>. Retrieved from Springer Netherlands.
- Corrigan PW, Rao D (2012). On the self-stigma of mental illness: stages, disclosure, and strategies for change. *Can. J. Psychiatr.* 57(8): 464-469. Retrieved from PM:22854028
- Cuca YP, Onono M, Bukusi E, Turan JM (2012). Factors associated with pregnant women's anticipations and experiences of HIV-related stigma in rural Kenya. *AIDS Care*, 24(9): 1173-1180. doi:10.1080/09540121.2012.699669 [doi]. Retrieved from PM:22799618
- Dinos S (2014). Stigma creating stigma: a vicious circle. *Psychiatr. Bull.* (2014.), 38(4): 145-147. doi:10.1192/pb.bp.114.048124 [doi]. Retrieved from PM:25237533
- Drummond PD, Mizan A, Wright B (2008). HIV/AIDS knowledge and attitudes among West African immigrant women in Western Australia. *Sex Health*, 5(3): 251-259. doi:SH07077 [pii]. Retrieved from PM:18771640
- Duffy L (2005). Suffering, shame, and silence: the stigma of HIV/AIDS. *J.Assoc.Nurses AIDS Care*, 16(1): 13-20. Retrieved from PM:15903274
- Earnshaw VA, Quinn DM (2012). The impact of stigma in healthcare on people living with chronic illnesses. *J. Health Psychol.* 17(2): 157-168. doi:1359105311414952 [pii];10.1177/1359105311414952 [doi]. Retrieved from PM:21799078
- ECDC (2013). European Centre for Disease Control. Responses to HIV and migration in western industrialized countries: current challenges, promising practices, future directions. Stockholm: ECDC. Retrieved from: <http://www.ecdc.europa.eu/en/publications/publications/hiv-migration-meeting-report.pdf>
- Fielden SJ, Chapman GE, Cadell S (2010). Managing stigma in adolescent HIV: silence, secrets and sanctioned spaces. *Culture, Health and Sexuality*, 13(3): 267-281. doi:doi:10.1080/13691058.2010.525665. Retrieved from <http://dx.doi.org/10.1080/13691058.2010.525665>. Retrieved from Routledge.

- Fortenberry JD, McFarlane M, Bleakley A, Bull S, Fishbein M, Grimley DM, et al (2002). Relationships of stigma and shame to gonorrhoea and HIV screening. *Am. J. Public Health.* (3). Retrieved from PM:11867314
- Goffman E (1963). *Stigma: Notes on the Management of Spoiled Identity.* New York: Simon and Schuster Inc.
- Hackl KL, Somlai AM, Kelly JA, Kalichman SC (1997). Women living with HIV/AIDS: the dual challenge of being a patient and caregiver. *Health Soc.Work,* 22(1): 53-62. Retrieved from PM:9021418
- Hatzenbuehler ML, Phelan JC, Link BG (2013). Stigma as a fundamental cause of population health inequalities. *Am.J.Public Health,* 103(5): 813-821. doi:10.2105/AJPH.2012.301069 [doi]. Retrieved from PM:23488505
- Kalichman SC, Simbayi LC, Cloete A, Mthembu PP, Mkhonta RN, Ginindza T (2009). Measuring AIDS stigmas in people living with HIV/AIDS: the Internalized AIDS-Related Stigma Scale. *AIDS Care,* 21(1): 87-93. doi:906575058 [pii];10.1080/09540120802032627 [doi]. Retrieved from PM:19085224
- Lee RS, Kochman A, Sikkeman KJ (2002). Internalized stigma among people living with HIV/AIDS. *AIDS and Behavior.* 6(4): 309-319.
- Link BG, Phelan J (2014). Stigma power. *Soc. Sci. Med.* 103: 24-32. doi:S0277-9536(13)00444-9 [pii];10.1016/j.socscimed.2013.07.035 [doi]. Retrieved from PM:24507908
- Mak WW, Cheung RY (2010). Self-stigma among concealable minorities in Hong Kong: conceptualization and unified measurement. *Am. J. Orthopsychiatry.* 80(2): 267-281. doi:AJOP1030 [pii];10.1111/j.1939-0025.2010.01030.x [doi]. Retrieved from PM:20553520
- Mak WW, Cheung RY, Law RW, Woo J, Li PC, Chung RW (2007). Examining attribution model of self-stigma on social support and psychological well-being among people with HIV+/AIDS. *Soc. Sci. Med.* 64(8): 1549-1559. doi:S0277-9536(06)00622-8 [pii];10.1016/j.socscimed.2006.12.003 [doi]. Retrieved from PM:17223239
- Miles MJ, Huberman AM (1994). *Qualitative data analysis:an expanded source book* (2nd ed ed.). California: SAGE Publications.
- Overstreet NM, Earnshaw VA, Kalichman SC, Quinn DM (2012). Internalized stigma and HIV status disclosure among HIV-positive black men who have sex with men. *AIDS Care.* doi:10.1080/09540121.2012.720362 [doi]. Retrieved from PM:23006008
- Parker R (2012). Stigma, prejudice and discrimination in global public health. *Cad. Saude Publica.* 28(1): 164-169. doi:S0102-311X2012000100017 [pii]. Retrieved from PM:22267076
- Petros G, Airhihenbuwa CO, Simbayi L, Ramlagan S, Brown B (2006). HIV/AIDS and 'othering' in South Africa: the blame goes on. *Cult. Health Sex,* 8(1): 67-77. doi:J1T0481H1L757141 [pii];10.1080/13691050500391489 [doi]. Retrieved from PM:16500826
- Shefer G, Rose D, Nellums L, Thornicroft G, Henderson C, Evans-Lacko S (2013). 'Our community is the worst': the influence of cultural beliefs on stigma, relationships with family and help-seeking in three ethnic communities in London. *Int. J. Soc. Psychiat.* 59(6): 535-544. doi:0020764012443759 [pii];10.1177/0020764012443759 [doi]. Retrieved from PM:22588248
- Simbayi LC, Kalichman S, Strebel A, Cloete A, Henda N, Mqeketo A (2007). Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa. *Soc.Sci.Med.,* 64(9): 1823-1831. doi:S0277-9536(07)00018-4 [pii];10.1016/j.socscimed.2007.01.006 [doi]. Retrieved from PM:17337318
- Smith K, Powers KA, Kashuba AD, Cohen MS (2011). HIV-1 treatment as prevention: the good, the bad, and the challenges. *Curr. Opin. HIV AIDS,* 6(4): 315-325. doi:10.1097/COH.0b013e32834788e7 [doi];01222929-201107000-00015 [pii]. Retrieved from PM:21646878
- Sofolahan YA, Airhihenbuwa CO (2013). Cultural expectations and reproductive desires: experiences of South African women living with HIV/AIDS (WLHA). *Health Care Women Int.,* 34(3-4): 263-280. doi:10.1080/07399332.2012.721415 [doi]. Retrieved from PM:23394325
- Tsai AC, Bangsberg DR, Kegeles SM, Katz IT, Haberer JE, Muzoora C, et al (2013). Internalized stigma, social distance, and disclosure of HIV seropositivity in rural Uganda. *Ann. Behav. Med.* 46(3): 285-294. doi:10.1007/s12160-013-9514-6 [doi]. Retrieved from PM:23690283
- Tsang HW, Fung KM, Chung RC (2010). Self-stigma and stages of change as predictors of treatment adherence of individuals with schizophrenia. *Psychiatry Res.* 180(1): 10-15. doi:S0165-1781(09)00342-4 [pii];10.1016/j.psychres.2009.09.001 [doi]. Retrieved from PM:20493552
- Vogel DL, Armstrong PI, Tsai PC, Wade NG, Hammer JH, Efstathiou G, et al. (2013). Cross-cultural validity of the Self-Stigma of Seeking Help (SSOSH) scale: examination across six nations. *J. Couns. Psychol.* 60(2): 303-310. doi:2013-07505-001 [pii];10.1037/a0032055 [doi]. Retrieved from PM:23458605
- WHO/UNAIDS/UNICEF (2013). *Global Update on HIV Treatment 2013:Results, Impact and Opportunities.* Retrieved from http://www.who.int/hiv/data/global_treatment_report_presentation_2013.pdf