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Citation for published version (APA):

Stutterheim, S. E., Bos, A. E. R., Shiripinda, I., de Bruin, M., Pryor, J. B., & Schaalma, H. P. (2012). HIV-related stigma in African and Afro-Caribbean communities in the Netherlands: Manifestations, consequences and coping. *Psychology & Health, 27*(4), 395-411.
<https://doi.org/10.1080/08870446.2011.585426>

Document status and date:

Published: 01/01/2012

DOI:

[10.1080/08870446.2011.585426](https://doi.org/10.1080/08870446.2011.585426)

Document Version:

Publisher's PDF, also known as Version of record

Document license:

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To cite this article: Sarah E. Stutterheim , Arjan E.R. Bos , Iris Shiripinda , Marijn de Bruin , John B. Pryor & Herman P. Schaalma (2012) HIV-related stigma in African and Afro-Caribbean communities in the Netherlands: Manifestations, consequences and coping, *Psychology & Health*, 27:4, 395-411, DOI: [10.1080/08870446.2011.585426](https://doi.org/10.1080/08870446.2011.585426)

To link to this article: <https://doi.org/10.1080/08870446.2011.585426>



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HIV-related stigma in African and Afro-Caribbean communities in the Netherlands: Manifestations, consequences and coping

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(Received 17 September 2010; final version received 28 April 2011)

HIV-related stigma in African and Afro-Caribbean diaspora communities in the Netherlands was investigated. Interviews with HIV-positive and HIV-negative community members demonstrated that HIV-related stigma manifests as social distance, physical distance, words and silence. The psychological consequences of HIV-related stigma among those diagnosed with HIV reported were emotional pain, sadness, loneliness, anger, frustration and internalised stigma. The social consequences included decreased social network size, limited social support and social isolation, and resulted from not only enacted stigma but also self-imposed social withdrawal. Also, poor treatment adherence was a health-related consequence. People living with HIV employed both problem-focused and emotion-focused coping strategies to mitigate the negative consequences of stigma. Problem-focused coping strategies included selective disclosure, disengagement, affiliating with similar others, seeking social support and, to a lesser extent, activism. Emotion-focused strategies included distraction, positive reappraisal, religious coping, external attributions, disidentification and acceptance. HIV-related stigma clearly permeates African and Afro-Caribbean communities in the Netherlands, and should be targeted for intervention.

Keywords: HIV/AIDS; stigma; consequences; mental health; coping

Introduction

HIV is not merely a condition that impacts the physical health of those infected. It is a condition that has major social and psychological implications that are rooted in perceptions about what it means to have HIV. HIV is, in fact, a highly stigmatised condition because it is often thought to be highly contagious, very severe, and the result of irresponsible volitional behaviour considered by many to be norm-violating such as commercial sex work, homosexuality and promiscuity (Bos, Dijker, & Koomen, 2007; Dijker & Koomen, 2003; Herek, 1999). Stigmatisation is, in essence,

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a systematic and complex process of devaluation whereby a person is considered to possess a discrediting attribute and subsequently deemed tainted or flawed by others (Crocker, Major, & Steele, 1998; Goffman, 1963; Jones et al., 1984; Parker & Aggleton, 2003). Stigma arises in social interactions (Alonzo & Reynolds, 1995; Crocker et al., 1998; Herek, Capitano, & Widaman, 2002; Jones et al., 1984; Major & O'Brien, 2005) and is impacted by structural factors (Link & Phelan, 2001; Parker & Aggleton, 2003). In fact, stigma reproduces existing social inequalities and is perpetuated by hegemony and the exercise of social, economic and political power (Campbell & Deacon, 2006; Rankin, Brennan, Schell, Laviwa, & Rankin, 2005; Scambler & Paoli, 2008).

Stigmatisation towards people living with HIV (PLWH) affects the treatment of PLWH in a number of ways and across a broad range of settings. Manifestations include avoidance, exclusion, rejection, social ostracism, blaming, violence, physical distance, indifference and awkward social interaction. Relevant settings are families, communities, friends, sexual relationships, health care, housing, the financial services sector, religious institutions, work and educational settings (Malcolm et al., 1998; Shamos, Hartwig, & Zindela, 2009; Stutterheim et al., 2009; Varas-Diaz, Serrano-Garcia, & Toro-Alfonso, 2005). The consequences of HIV-related stigma are severe and include hampered HIV prevention efforts, testing delays, problematic treatment adherence, psychological distress and disrupted social interactions (Bos, Schaalma, & Pryor, 2008; Moskowitz & Wrubel, 2005; Stutterheim et al., 2009, 2011; Vermeer, Bos, Mbwapo, Kaaya, & Schaalma, 2009). In an effort to mitigate the negative psychological and social impact of HIV-related stigma, PLWH can employ a number of coping strategies that are geared to either altering the relationship between the person and the environment (problem-focused coping) or to regulating negative emotions (emotion-focused coping). Problem-focused coping strategies can target the self, the situation or others, and include selective disclosure, compensating for the stigma during social interactions, avoiding situations where stigmatisation is likely (disengagement), affiliating oneself with similar others, seeking social support and activism. Emotion-focused strategies documented include downward social comparison, external attributions, denial or prejudice minimisation, distraction, positive reappraisal, and disidentification with the stigmatised identity (Crocker et al., 1998; Major & O'Brien, 2005; Miller & Kaiser, 2001; Moskowitz & Wrubel, 2005).

HIV/AIDS prevalence is high in Sub-Saharan Africa and the Caribbean. As a logical consequence, African or Afro-Caribbean diaspora communities also have high prevalence rates for HIV. For example, in the Netherlands, non-Western migrants comprise one-tenth of the total population but one-third of all HIV cases. Of that third, more than half originate from Sub-Saharan Africa and almost a third from the Caribbean (Shiripinda & van Eerdewijk, 2008). Not only are prevalence rates for HIV higher in these diaspora communities than in the general population, so too is HIV-related stigma. In fact, high levels of stigmatisation have been reported not only in Sub-Saharan Africa (Greeff et al., 2008; Kalichman & Simbayi, 2004; Nyblade, Pande, Mathur, MacQuarrie, & Kidd, 2003) and the Caribbean (Carr, 2004; Varas-Diaz et al., 2005) but also in these regions' diaspora communities (Anderson et al., 2008, 2009; Bond, Chase, & Aggleton, 2002; Carr, 2004; Dodds, 2006; Doyal & Anderson, 2005; Gardezi et al., 2008; Nyblade et al., 2003), although documentation in these diaspora communities has been less extensive. Nonetheless, the fear of stigmatisation and the degree to which stigmatisation is experienced have been reported to be substantially greater among black PLWH living in the developed

world than among white PLWH (Dodds, 2006; Erwin, Morgan, Britten, Gray, & Peters, 2002). This may, at least in part, be because African and Afro-Caribbean diaspora are already socially marginalised and disadvantaged by racism, immigration processes and anti-asylum discourses, and experience barriers in accessing health and social services as well as employment (Dodds, 2006; Dodds et al., 2004; Shiripinda & van Eerdewijk, 2008). Clearly, HIV and HIV-related stigma are relevant issues in African and Afro-Caribbean diaspora communities. However, there remains a paucity of literature on HIV-related stigma in African and, to an even greater extent, Afro-Caribbean diaspora communities. To our knowledge, the literature is limited to a few studies on African immigrants in the UK (Burns, Imrie, Nazroo, Johnson, & Fenton, 2007; Dodds et al., 2004; Doyal & Anderson, 2005; Kinniburgh, Scott, Gottlieb, & Power, 2001; Ndirangu & Evans, 2009; Papparini, Doyal, & Anderson, 2008), one study on predominantly Sub-Saharan African PLWH in the Netherlands (Shiripinda & van Eerdewijk, 2008), one study on Caribbean communities in the UK (Anderson et al., 2008), and one study on African and Caribbean communities in Canada (Gardezi et al., 2008; Lawson et al., 2006). These studies have documented a fear of stigmatisation among African and Afro-Caribbean diaspora PLWH and some of the manifestations and consequences of HIV-related stigma in their communities but comprehensive knowledge of the manifestations and consequences of HIV-related stigma in African and Afro-Caribbean diaspora communities is still lacking and almost nonexistent in the Netherlands. Also, comprehensive and detailed information on how these PLWH cope with stigma remains limited. More research in terms of not only volume but also comprehensiveness and rigour is necessary to, first, support PLWH subjected to HIV-related stigmatisation and, second, develop culturally appropriate community-based stigma reduction interventions. To help meet these needs, this study endeavoured to: (1) document manifestations of HIV-related stigma in African and Afro-Caribbean communities in the Netherlands from the perspectives of both PLWH and their fellow community members; (2) delineate the psychological, social and health-related consequences of HIV-related stigma for these PLWH and (3) explore the strategies these PLWH employ to cope with stigmatising experiences.

Methods

Following study approval by Maastricht University's Ethics Committee, HIV-positive and HIV-negative members of African, Dutch Antillean and Surinamese communities were recruited for face-to-face, semi-structured interviews of approximately an hour by a researcher (Sarah Stutterheim, Iris Shiripinda and Marijn de Bruin) or by 1 of 12 peer interviewers employed and trained by the researchers. The large number of peer interviewers was deemed necessary as recruitment for participation in similar research has previously proven to be difficult. Recruitment of all participants was purposeful and occurred directly through interviewers or through announcements distributed by the Dutch HIV Association, Humanitas Foundation or HIV nurses working in Dutch hospitals. Interviews were held in either English or Dutch in accordance with the participant's preference. Both HIV-positive and HIV-negative African, Antillean and Surinamese community members were included in the study as this allowed for triangulation across data sources. Our sample comprised 42 HIV-positive participants, of which 16 were

African, 9 Antillean, 16 Surinamese, and 1 both Antillean and Surinamese and 52 HIV-negative participants, of which 16 were African, 19 Antillean and 17 Surinamese. Once recruited, participants were given information regarding the study's purpose and procedure. Informed consent was obtained and a monetary reward of €30 was provided after interview completion. The interviews were held between January 2005 and May 2008 and were guided by a structured protocol of open-ended questions with follow-up probes. The protocol for HIV-positive participants explored the following topics: how others have reacted to their HIV status (stigma experiences), the consequences of negative reactions and how one has dealt with negative reactions (coping). The protocol for HIV-negative participants explored how PLWH are treated in African and Afro-Caribbean diaspora communities in the Netherlands (settings and manifestations of stigma).

To enhance rigour, all interviews were recorded with a digital voice recorder and transcribed verbatim. Data were processed with QSR NVivo 2.0 and analysed using a general inductive approach by a bilingual researcher trained in cross-cultural translation (Sarah Stutterheim). Each transcript was read thoroughly while listening to the corresponding recording to identify emerging themes and establish categories to which text fragments were assigned. As coding occurred, categories and subcategories were linked to one another. A decision trail was maintained. All emergent categories were documented, as were changes made to the categories and the rationale for those changes. Coding continued until saturation was evident. Findings were subsequently checked with relevant stakeholders in the African, Antillean and Surinamese communities in the Netherlands.

Results

Manifestations of HIV-related stigma

Stigmatisation through social distance

PLWH extensively reported manifestations of HIV-related stigma that reflect an increase in social distance (e.g. avoidance, rejection, abandonment and social exclusion). Many reported experiencing greater social distance in specific settings. One such setting was the family: 'I used to go to [my family's] home. They would invite me, you know. I don't get invited anymore. It's like I've been forgotten' (HIV-positive Surinamese man). Another was with friends: '[I have] friends who did not want to cooperate with me because I was HIV-positive, who did not want to really see me anymore' (HIV-positive Kenyan man). Yet another very relevant and important setting for many PLWH was romantic partners. Some participants reported abandonment by the partner they were with at the time of diagnosis: 'The relationship was good. When he heard I had HIV/AIDS, he stayed for a bit but, after a while, he was [snaps her fingers to imply "gone"]' (HIV-positive Antillean woman). Participants also reported rejection by new or potential partners: 'When I told a guy that I am HIV-positive, he said, "I'll call you", but he never did' (HIV-positive Surinamese woman).

HIV-negative community members also acknowledged the avoidance, rejection, abandonment and exclusion of PLWH. One Antillean woman said, 'As soon as people know that someone has the virus, that person is no longer part of the group. They would rather not spend time with that kind of person'. In fact, a number of community members indicated that PLWH are seen as 'pariahs' or

‘untouchables’: ‘That person essentially gets a label. For people who don’t know him well, he is, in a matter of speaking, really a pariah’ (HIV-negative Antillean woman).

It is almost as though they are the ‘untouchables’. There is this sympathy but a displaced sympathy. There is sympathy as long as they are at a distance from you. You know, you sympathise at a distance but it is not that you welcome them in your home and take care of them. There is sympathy for as long as it is not your business. (HIV-negative Kenyan woman)

Increased social distance might result from perceptions that HIV is very severe. It might also occur because of moral judgements, as exemplified by the following citation from a Surinamese community member: ‘If you hear that someone has HIV, you always think, “Distance!” because people associate HIV with bad behaviour, and people think, “He’s going to die anyway. He’s going to die and I want nothing to do with him.”’ (HIV-negative Surinamese man).

Stigmatisation through physical distance

In addition to experiencing social distance, PLWH and particularly African PLWH, reported increased physical distance in social interactions. One participant said, ‘If he [a friend] greets me, if we were kissing before, now he would give the hand from one meter or two meters’ (HIV-positive Burundian woman). HIV-negative participants confirmed that people do maintain increased physical distance from PLWH. Some reported that, if they were to encounter a PLWH, they would indeed maintain physical distance: ‘I’d prefer to have as little contact – physical contact with that person as possible’ (HIV-negative Antillean woman). PLWH furthermore reported that some people not only maintain physical distance but also avoid actual physical contact with them. Numerous PLWH reported incidents whereby people were unwilling to sit next to them, touch them or shake their hand.

Participant: There are some people whom you tell and they do not have much knowledge and therefore they still think they get AIDS maybe by handshaking or maybe by -

Interviewer: So don’t they shake your hand? They shake hands with the other ones?

Participant: Yeah, they “Hi”. You know, that “Hi” and waving at you. They just wave and say, “Hi, how are you?”, and then that’s it. That is how it ends.

Interviewer: Were they hugging you before?

Participant: Yeah, before we had like really a very good relationship, not hugging as such, but we would shake hands.

(HIV-positive Zimbabwean woman)

PLWH reported that increased physical distance even occurs within romantic relationships: ‘[My ex-husband] didn’t want to eat or drink with me. Sometimes, he didn’t want to sleep next to me . . . He found it difficult to touch me. He wore gloves’ (HIV-positive African woman). This fear of physical contact appears to extend also to objects PLWH touch, such as food, dishes, toilets and chairs. One participant said, ‘[My relatives] don’t feel very comfortable for me to handle food, especially food that you eat without cooking like apples or whatever’ (HIV-positive Zimbabwean woman). Another told the interviewer, ‘[I heard my brother] saying to the wife, “Whatever he uses, keep it somewhere different. Don’t mix it: the cups, the glasses, the spoons”’ (HIV-positive Kenyan man). HIV-negative community members confirmed this. One participant said, ‘I wouldn’t drink out of the same glass’ (HIV-negative Surinamese woman). Another stated, ‘If I see a person with

AIDS and that person has sat on a chair, if he gets up, I won't go sit on that chair' (HIV-negative Antillean man).

Stigmatisation through words

Participants frequently reported stigmatising words. HIV-positive and HIV-negative participants indicated that particularly gossip but also blaming, negative remarks and disdain occur within their communities. Gossip was the most frequently cited manifestation among Antillean and Surinamese participants. Many PLWH described having been the subject of gossip. One participant said, 'I told some friends, my closest friends actually, and later people came up to me and said, "So and so told me that you have it"' (HIV-positive Antillean man). Another said, 'I chose to tell my cousin and another aunt and I know for sure that they didn't keep it to themselves. They told other people' (HIV-positive Antillean woman). Ex-partners were also a source of gossip: 'I went to the doctor with my boyfriend at the time and he told all his friends. I wasn't happy about that because I think it is something private – my private matter' (HIV-positive Antillean man).

In similar vein, a number of African PLWH reported violations of confidentiality by religious leaders, community and social organisations, and the health care sector. One participant indicated that her pastor failed to keep her secret: 'He is telling people he is trying to break [stigma and taboo], that people don't have to be laughing at [PLWH] but he is the one who is not keeping secrets for people having HIV' (HIV-positive Zambian woman). Another participant said that a member of an organisation that had his status on file approached him and asked if he was the PLWH on file: 'I thought my information was confidential. My information is not very confidential' (HIV-positive Ugandan man). Yet another participant spoke of a social worker who had informed others of her status: 'She went and told someone else and one day they came to my caravan to see what an HIV-positive person looks like' (HIV-positive Burundian woman). Other participants claimed that health professionals had violated their confidentiality: 'After the test, the doctor invited [my cousin] and even told him about the test before telling me. . . . The doctor let the news out to my cousin before I saw him' (HIV-positive Nigerian man).

HIV-negative participants confirmed the prominent role of gossip: 'Rumours will spread and, before you know it, the whole community will know' (HIV-negative Surinamese man). Many Antillean and Surinamese participants claimed that gossip and rumours are, in fact, part of their culture because 'everyone knows everyone. We all know each other, and we have, in this small community, practically grown up together as brothers and sisters' (HIV-negative Surinamese man). Participants also reported that the Surinamese and Antillean communities use online forums to spread gossip: 'There is a site and if someone knows that someone else has AIDS, they can put it on the site with a picture' (HIV-negative Antillean woman).

In these communities, gossip often occurs under the guise of a warning. People frequently inform others about community members' status so they can, in turn, avoid potential infection. One participant said, 'If I was just standing there having a conversation with a guy, they go to him after the fact and say, "You need to be careful because that girl has AIDS"' (HIV-positive Surinamese woman). Another PLWH who was discrete about his status dated a woman who was less discrete and was warned by others that he should be careful: 'They came to me and said,

“Do you know that this girl has AIDS – that this girl is sick and you must check yourself?” (HIV-positive Nigerian man).

Participants also reported stigmatisation in the form of blaming, negative remarks and disdain, although less frequently than gossip. One participant said that others have commented that she ‘has slept with all sorts of men and that is why I’m now sick’ (HIV-positive Surinamese woman). Another indicated that her husband and his relatives blamed her for apparently bringing HIV home: ‘They were saying that I contaminated him’ (HIV-positive Burundian woman). Yet another participant reported blaming by a health professional: ‘I went to have my uterus examined and I was admitted. The gynaecologist was a woman and she, of course, had read my status and she was really rude . . . and [she said] stuff like “You shouldn’t have gotten that”’ (HIV-positive Surinamese woman).

Other participants, who had chosen to conceal their status, reported having heard others make comments about PLWH that reflect blaming or are negative: ‘I have talked to people, intelligent people, who say, “Cancer is something that happens to you but HIV is something you’ve done yourself. You’re in essence responsible for it happening”’ (HIV-positive Antillean man).

A number of PLWH in our study also claimed that, even when people do not explicitly blame them or subject them to negative remarks, they nonetheless look down on them and treat them with disdain. One participant said, ‘Nobody will dare respect you or talk nicely to you if you are infected’ (HIV-positive Cameroonian woman). HIV-negative community members acknowledged this. One participant claimed that, ‘in no time, people no longer look up to you but rather down at you’ (HIV-negative Surinamese man). Another said that PLWH are ‘second rate citizens’ (HIV-negative Antillean woman).

Stigmatisation through silence

According to the participants, both HIV-positive and HIV-negative, HIV-related stigma manifests not only through distance and words but also through silence. Numerous PLWH reported that particularly their family never mention or discuss their HIV infection. For these people, it is as if they never disclosed their status: ‘They know but they act like they don’t’ (HIV-positive Surinamese woman). Another participant said, ‘Some of them just ignore it if I tell them. They don’t ask again ever. They just pretend as if I didn’t say anything’ (HIV-positive South African woman). Yet another conveyed, ‘It’s never talked about. They don’t ask about it. They don’t say anything’ (HIV-positive Antillean man).

In some cases, silence and denial ensues even after PLWH communicate a desire to talk about HIV: ‘When I want to talk about it, especially with family, they don’t want to hear about it’ (HIV-positive Antillean woman). Another said that, when she talks to her family about HIV, ‘their reaction is “What? What are you talking about? No.” It’s total denial. It’s like there is nothing going on. They never talk about. They never ask and when I bring it up, they change the subject’ (HIV-positive Surinamese woman).

Silence and denial within families might be rooted in familial shame or fear of being stigmatised by association (Neuberg, Smith, Hoffman, & Russell, 1994). It might also reflect taboos surrounding HIV in African, Antillean and Surinamese communities. Some participants claimed that their communities in the Netherlands

and back home do not want to acknowledge that members of their community indeed have HIV.

Participant: My mother recently said in passing that [a family member] had AIDS, and then she moved on to talking about something else, and that is typical for Surinamese people.

Interviewer: That people would rather not say it?

Participant: Exactly! You know, like, most people that die of HIV/AIDS had ‘cancer’. You know, those kinds of things are said.

(HIV-positive Surinamese woman)

Consequences of HIV-related stigma

Psychological consequences

With respect to the psychological impact of stigmatisation, PLWH conveyed that stigmatising reactions and particularly those related to social distance (avoidance, rejection, abandonment and social exclusion) had brought them emotional pain, sadness and loneliness. One participant said, ‘It hurts like hell. You just want to crawl in a hole and stay there forever’ (HIV-positive Rwandan woman). Another said, ‘You really feel lost. You really feel like you have been thrown away; you are being neglected now because of your status’ (HIV-positive Zimbabwean woman). Yet another said, ‘At that moment, when those things happen, you feel really small’ (HIV-positive Antillean man). PLWH reported that rejection from a (potential) romantic partner and exclusion from dating is particularly painful: ‘Every time you hear that, “Nah,” or “I’ll call you”, it’s painful. It’s a disappointment’ (HIV-positive Antillean woman).

In addition to pain, sadness and loneliness, a number of PLWH conveyed anger and frustration. One participant said that a stigmatising experience ‘made me feel different from other people and it made me feel very uncomfortable. In fact, it annoyed me. It made me very angry’ (HIV-positive South African woman). Another said, ‘It makes me depressed and frustrated because I think that at this point in time, people with HIV should be accepted’ (HIV-positive Surinamese woman).

Social and sexual consequences

The negative social implications of HIV-related stigma include a reduced social network, lack of social support and social isolation. These are the result of not only enacted social exclusion but also self-imposed social isolation. One participant indicated that she no longer kisses her nieces and nephews because she wants to protect them from infection: ‘There is, in you, this feeling that says, “I shouldn’t be doing that. I shouldn’t be kissing”’ (HIV-positive Zimbabwean woman). Further, many PLWH reported having voluntarily withdrawn from their social circles in an effort to avoid situations in which they would be compelled to disclose their status and/or be subjected to stigmatisation. One participant said, ‘I don’t call because I don’t know how to tell them that I am HIV-positive and I don’t know how they will react’ (HIV-positive Surinamese man). Another said that he avoids social situations because ‘imagine that the question arises, that you have a conversation and things come up and you think, “I have to tell them”’ (HIV-positive Antillean man).

Participants also conveyed that they not only find it difficult to maintain their old social circles, they also find it hard to meet and spend time with new people.

When I meet new friends, I don't feel like I will tell them about myself because if I like people, I don't want to lose people like I lost the other friends, and that is very difficult for me. It is living with your friends without telling them who you are, what you are, and what about your health and all these kinds of things. It is not easy. It makes life kind of difficult. (HIV-positive Kenyan man)

Again, participants emphasised the impact of stigmatisation on dating and romantic relationships. A number of PLWH conveyed the difficulties they experienced when starting a new relationship.

Whenever you want to start a relationship, that's when it comes to mind: stigma. . . . Right now, I don't have a relationship but I have met a guy, and, for me, it's really hard to talk about it. I sometimes throw things into the conversation, some topics, so I can get an idea of what he thinks, and then I think, 'Wow, if I tell him, that'll be the end of it'. . . . I asked him whether he would have a relationship with someone who has HIV and he told me, 'I wouldn't do that. It would be a hindrance in my life, for my sex life', and, from that, you know how someone thinks about it. . . . If you want to start a romantic relationship, you are going to have to tell that person at some point or another and that person will choose to do it or not to do it but nine out of ten times, they won't do it. (HIV-positive Antillean and Surinamese man)

Some participants indicated that their fear of rejection from a potential partner is such that they no longer bother with new relationships because they believe that disclosure to a new sexual partner will inevitably lead to stigmatisation.

Anytime you want a relationship with someone, you have to think, 'I am sick. I have HIV and how am I going to tell this person?' After a while, you reach a point that you don't want to do it. . . . I am alone and I don't have a partner, and I don't want a partner because you'll tell that person and maybe he will push you away because you have HIV. No, I'd rather be alone with my kids. (HIV-positive Antillean woman)

In fact, two male participants said they would never have sex with a woman again: 'I have never told a girl that I have AIDS. It's been four years since I've made love. I don't do it because I am scared to infect someone and I don't want to do that to someone' (HIV-positive Surinamese man).

Health consequences

HIV-related stigma affects health both indirectly through its influence on psychological well-being and social support, and directly by complicating HIV treatment adherence. Quite a few PLWH in this study outlined situations in which fear of stigmatisation has prevented them from taking their antiretroviral medication on time. One participant said, 'If I am at a party and I need to get up and take my medication, people will ask why I do that so I just don't do it' (HIV-positive Surinamese woman). Another stated, 'One of my sisters is a nurse. If she sees my pills, she'll know so I don't take my pills if I'm with her' (HIV-positive Surinamese man). Yet another illustrated, in detail, the difficulties HIV-related stigma poses for treatment adherence.

During the summer vacation, I often went to amusement parks and then you are in the bus and you agree to meet back at the bus at 17:00 so you can go home and then it is 18:00 and I am in the bus. I am sitting there with all sorts of people around me. There is someone sitting next to me who doesn't know and someone in front of me and

she doesn't know it either, and she keeps turning around to talk, and there was no toilet in the bus, and, even if there was, it would be weird because like who would go to the toilet in the bus with a cup? So it was weird and I needed to take them so I was thinking, 'Oh God, how am I supposed to do this? How am I supposed to do this?' (HIV-positive Surinamese woman)

Clearly, for some PLWH, keeping one's HIV status a secret takes priority over taking one's medication on time.

Coping with HIV-related stigma

In an effort to mitigate some or all of the negative psychological, social and health-related consequences of stigmatisation, PLWH employ, often simultaneously, a number of coping strategies.

Problem-focused coping

Problem-focused strategies can target the self, the situation or others (Miller & Major, 2000). A self-focused strategy frequently cited was concealment or selective disclosure. A number of PLWH indicated that they are very selective in their disclosure because it reduces the likelihood of stigmatisation: 'I don't want my problem known to people. I try as much as I can to keep it secret' (HIV-positive Nigerian man).

A frequently reported situation-focused coping strategy was disengagement or social withdrawal. As mentioned earlier, many PLWH in this study reported intentionally avoiding situations in which stigmatisation is likely. One participant said, 'One of my brothers is very disappointing to me because he won't let me be around his children so I decided not to visit him anymore' (HIV-positive Kenyan man). Another participant conveyed the following:

My own aunt said to my sister, 'If your sister comes here, she needs to sit off to the side, and we'll give her her own glass and spoon'. I heard that and, of course, you feel down because your own family thinks that. Then I said to my sister, 'Ok, I don't need to go visit her anymore'. (HIV-positive Surinamese woman)

Avoidance of stigmatising situations and people who stigmatise often parallels increased identification with people who share the same stigma, as exemplified by the excerpt below.

You realise that society is now taking a negative attitude toward you so you tend to look for those people who are in the same situation like you because these are the people who understand. You share the same experiences. Maybe they are also facing the same things that you are facing from society so you tend to click now with those people and, when you come together, when you discuss these things, you kind of develop coping mechanisms to deal with the situation. You help each other when these things happen. [You ask,] 'How have you done it?' and someone gives you an advice: 'It happened to me and I did it this way'. So it is after society is showing a negative attitude towards you, and then you lean on those people who are in the same boat. (HIV-positive Zimbabwean woman)

PLWH not only sought support from other PLWH but also from non-judgemental friends and family. In fact, many participants said that social support from their immediate environment helps them to cope with stigmatising experiences: 'As long as the people in my immediate surroundings, like my kids, are good about

it, I don't really care what anybody else thinks' (HIV-positive Surinamese woman). Another example is as follows:

If the people close to you accept you as you are and support you in who you are - it's because of that that I feel strong, that I can take on the rest of the world. I don't care how the rest of the world thinks of me and how they'll react to [my HIV infection]. (HIV-positive Surinamese man)

A final problem-focused coping strategy geared to others is activism. Among the PLWH in our study, collective action and efforts to educate others occurred infrequently perhaps because of the cultural taboo surrounding HIV in these communities. Only two participants in our study (both Surinamese) engaged in some form of activism to change perceptions about HIV and PLWH.

Emotion-focused coping

In addition to problem-focused strategies, PLWH reported a number of emotion-focused coping strategies. One was distraction or focusing on things or people other than stigmatising experiences. One participant said that stigmatisation 'makes you sad but I have two children and I just keep going. I think if I were alone that it would be much harder but I've got these two kids. They are my comfort and they keep me busy' (HIV-positive Surinamese woman).

Another emotion-focused coping strategy is positive reappraisal. A number of PLWH sought positive meaning in stigmatising experiences, as exemplified by the citation below.

I go out a lot with friends. I see my family – visit my family. I can say that [HIV] makes you realise that life is too short and, also, I help others. Before it was like 'me and my family', 'me and my kids' but now, where I can help others, I go out of my way and help them. (HIV-positive Zimbabwean woman)

A number of participants also indicated that they cope with stigma by seeking comfort in their faith.

You see, the Bible says that my life is in his hands. You understand? The word of God offers me a lot when it comes to dealing with these things. Like I said, if I didn't have the Lord, I wouldn't know how to deal with all this HIV misery and the way people talk about it. (HIV-positive Surinamese man)

Other PLWH reported engaging in external attributions. They claimed that stigmatisation is the result of ignorance on the part of others.

When I think about [a stigmatising experience], I still feel angry but then again I feel for those people because I know now that they are doing no better. They did what they thought was protecting themselves. It was a lack of information and education. (HIV-positive Rwandan woman)

Still others coped by distancing themselves from their stigmatised identity (disidentification). Many participants made comments suggesting that they would rather not base their personal identity and self-worth on their HIV infection.

Up until about two years ago, I was someone who always carried HIV with me and now I have kind of left it behind. I don't carry it with me anymore. I can laugh now. I can make jokes. I can feel good on my own if I want to. I think I have mourned enough. I've given it a place and if I want to go there, I do, and if I don't want to do that, I don't. (HIV-positive Antillean man)

A final emotion-focused coping strategy observed was acceptance that stigmatisation is bound to happen. One participant said, 'If I accept the fact that I have HIV, I also need to accept that which comes with it, and that is what I do. It's hard to accept but you have to' (HIV-positive Surinamese woman). Another said, 'I had to go through [stigmatising reactions]. There was no other way. You just have to fall down and push yourself up again' (HIV-positive Rwandan woman).

Discussion

This study documents, in detail, how HIV-related stigma manifests in African and Afro-Caribbean diaspora communities, what the consequences of such stigma is for the psychological well-being, social lives, and health of these PLWH, and how these PLWH respond to and cope with stigmatising experiences.

Our findings show that HIV-related stigma manifests as social distance in the forms of avoidance, rejection, abandonment and exclusion; physical distance from PLWH and objects they come in contact with; words through gossip, blaming, negative remarks and disdain; and through silence and denial. These findings are corroborated by research conducted with African and Afro-Caribbean people in diaspora communities (Anderson et al., 2008; Dodds et al., 2004; Gardezi et al., 2008; Kinniburgh et al., 2001; Lawson et al., 2006; Ndirangu & Evans, 2009) and in their countries of origin (Bond et al., 2002; Duffy, 2005; UNAIDS, 2010; Varas-Diaz et al., 2005). For example, in research conducted by Kinniburgh et al. (2001), African PLWH in the UK reported being judged by their families and abandoned by their partner. They also reported a climate of secrecy regarding HIV in their community, as did Gardezi et al. (2008) in their study with African and Afro-Caribbean communities in Canada. A climate of secrecy about HIV is unsurprising as African and Afro-Caribbean communities are often reluctant to discuss issues pertaining to sexuality (Lawson et al., 2006; Stutterheim et al., submitted). Further, in a study conducted by Anderson and coworkers (2008), Jamaicans living in the UK reported gossip and verbal abuse by members of their community, and excessive protective measures (e.g. disinfecting clothes, forcing PLWH to use separate plates and silverware) by family members. Our finding that PLWH are excluded from preparing food and given separate eating utensils is particularly interesting in light of work done by Okoror et al. (2007) in South Africa. They documented how the separation of utensils and exclusion from food preparation and communal eating is an expression of rejection in cultures where food serves to establish and validate relationships and belonging. Thus, these forms of stigmatisation not only reflect a fear of infection but also social rejection. Community members' concurrence with the manifestations reported by PLWH reinforces the fact that these manifestations permeate their culture and shape the treatment of PLWH.

With respect to the consequences of HIV-related stigma, our study has shown that PLWH experience emotional pain, sadness, loneliness, anger and frustration because of stigmatising experiences. Some PLWH also internalise the stigma they experience. These findings parallel those reported by Nyblade et al. (2003) who demonstrated that PLWH in Sub-Saharan Africa experience despondency, despair and a loss of hope and internalise stigma. The social consequences of HIV-related stigma reported in our study, namely decreased social network size, limited social

support and social isolation, were the result of not only enacted stigma but also self-imposed social withdrawal as a means of avoiding stigmatisation. This has been previously noted among African women in the UK (Doyal & Anderson, 2005; Ndirangu & Evans, 2009) and is in line with the work of Smart Richman and Leary (2009) who claimed that chronic and pervasive rejection increases the likelihood of withdrawal and avoidance. It also corresponds with Flowers et al. (2006) who found that HIV-related stigma leads to a lack of social support and isolation among Black Africans in the UK. In addition, we found that a particularly important context in which PLWH keenly feel the consequences of stigma was romantic relationships. This corresponds with Anderson et al. (2008) who found that Afro-Caribbean PLWH in the UK find it difficult to enter into and maintain long-term romantic relationships because of disclosure concerns and fears of rejection. A final consequence of HIV-related stigma reported in our study, pertaining to the health of PLWH, was poor treatment adherence. Similar difficulties with treatment adherence among migrant PLWH in the Netherlands were previously documented by Shiripinda and van Eerdewijk (2008).

Our study also elaborated coping strategies employed by African and Afro-Caribbean PLWH in the Netherlands and found that PLWH employed, often simultaneously, both problem-focused and emotion-focused coping strategies. The problem-focused coping strategies included selective disclosure or concealment, avoiding situations where stigmatisation is likely (disengagement), affiliating oneself with similar others, seeking social support, and, to a lesser extent, activism. The emotion-focused strategies included distraction, positive reappraisal, religious coping, external attributions, disidentification with the stigmatised identity and acceptance. These findings are in line with the theoretical literature on coping with stigma (Crocker et al., 1998; Miller & Kaiser, 2001; Miller & Major, 2000). They also correspond with work conducted with African and Afro-Caribbean PLWH. For example, Dodds and coworkers (2004) found that African PLWH in the UK cope by seeking support from other PLWH and their families. In the Caribbean, Carr (2004) found that PLWH cope with stigma by selectively disclosing, seeking social support from friends and family, and by turning to their faith. In Africa, problem-focused (e.g. connecting with other PLWH, seeking support and educating others) and emotion-focused coping responses (e.g. positive thinking, acceptance and religious coping) similar to those found in our study were comprehensively documented by Makoe et al. (2008).

Understanding which coping strategies PLWH employ is particularly important because some coping strategies mitigate the negative consequences of HIV-related stigma better than others do. For example, coping strategies such as support seeking and positive reappraisal have been found to be positively related to psychological well-being while stigma avoidance has been found to yield greater psychological distress (Gonzalez, Solomon, Zvolensky, & Miller, 2009; Kraaij et al., 2008). Identifying which strategies PLWH use is the first step towards the development of interventions that seek to help PLWH use better coping strategies. Naturally, the onus for stigma reduction does not lie solely with PLWH. It would be unethical to limit interventions to training PLWH in how they can best cope with stigmatising experiences. Interventions in the community that tackle the manifestations of HIV-related stigma documented in this study (i.e. social and physical distance, words and silence) are thus imperative, as are interventions that seek to change the societal

and community structures that promote stigmatisation (Bos et al., 2008; Brown, Macintyre, & Trujillo, 2003; Parker & Aggleton, 2003).

Our study has both strengths and limitations. The primary strength of our study is its inductive nature and the ‘thick’ description of the data presented. Our participants, both HIV-positive and HIV-negative, were particularly candid and honest about their experiences, their behaviours, their beliefs and their attitudes. We believe that these kinds of descriptions contribute substantially to a better understanding of HIV-related stigma in African and Afro-Caribbean diaspora communities, and provide an impetus for stigma reduction interventions in these communities. We further contend that the honesty apparent in our data discredits the notion that qualitative data is laden with social desirability and reaffirms the need to study stigma using not only quantitative but also qualitative approaches. A second strength is the rigour of our study. We sought to promote study quality and trustworthiness in a number of ways. First, in contrast to most other studies on stigma in African and Afro-Caribbean diaspora communities, we triangulated data across PLWH and community members. Second, we used digital voice recorders and verbatim transcriptions to enhance rigour, and maintained a decision trail. Finally, we sought analytic integrity by seeking concurrence with previous findings (theory triangulation) and by checking our findings with relevant stakeholders (Creswell, 2009; Polit & Beck, 2010). However, given the qualitative nature of the findings, one must be cautious in generalising these results to other populations. A limitation of our study is the representativeness of the sample. Although qualitative studies do not seek to achieve representativeness through randomisation, many do endeavour to attain some degree of representativeness with regard to, for example, gender, educational attainment and age. In our study, we struggled to recruit Antillean women, Antilleans with a lower level of education and older African PLWH. Nonetheless, our study design was rooted in existing theory and evidence, and stakeholder checks confirmed our findings thus suggesting that, despite difficulties in acquiring a broadly representative sample, the findings can be taken as generally reflective of the current state of affairs in African and Afro-Caribbean communities in the Netherlands.

In conclusion, we have found that HIV-related stigma permeates African and Afro-Caribbean communities in the Netherlands, that stigma manifests in these communities through social and physical distance, words and silence and that this stigma negatively affects the psychological well-being, social lives and health of African and Afro-Caribbean PLWH. We have also found that these PLWH employ a number of problem-focused and emotion-focused coping strategies to reduce the negative impact HIV-related stigma has on their lives.

Acknowledgements

The authors thank the participants, the Dutch AIDS Fonds (grants 2006092, 7004), Abbott, the Dutch HIV Association, Humanitas, the Professional Organisation of HIV Consultants, the Community Health Services in Amsterdam, Groningen and Rotterdam and the following people: Evert van Veen, Fetzen de Groot, Gerjo Kok, Jan Prins, Jeannine Nellen, Juan Walter, Maartje Liebrechts, Mariette Hamers, Nicole van Kesteren, Onno de Zwart, Ronald Brands, Stephan Cremer, Chantal Rumanzi, Dudley Tijn-a-Kwie, Elizabeth Njeru, Emmy Markelo, Erik Beune, Germain Ackermans, Indira Snip, Juan Walter, Mikel Haman, Mirte Wibaut, Nadia Mirjals, Pamela Matinde, Rubelto Baker, Urmy Macnack,

Anne van Middelaar, Carolien van Wagenberg, Danielle Pool, Joyce van Leendert, Roy van Veldhuizen, Sanne van Lieshout and Simone Heijnen.

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