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“We talk, we do not have shame:” Addressing stigma by reconstructing identity through enhancing social cohesion among female sex workers living with HIV in the Dominican Republic

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Abstract

This study explores social cohesion as a strategy used by female sex workers to address layered HIV and sex work-related stigma through a thematic analysis of 23 in-depth interviews and two focus groups with female sex workers living with HIV enrolled in a multi-level HIV/STI prevention, treatment, and care intervention in Santo Domingo, Dominican Republic. Drawing on Foucault’s conceptualisation of modern power, discipline, and resistance, we argue that social cohesion provides the psychosocial space (of trust, solidarity, and mutual aid) to subvert oppressive societal norms, enabling the reconstruction of identity. Among study participants, identity reconstruction happened through the production, repetition, and performance of new de-stigmatised narratives that emerged and were solidified through collective interaction. Findings highlight that enabling collective reconstruction of identity through social cohesion—rather than solely attempting to change individual beliefs—is a successful approach to address stigma.

Keywords

stigma; social cohesion; female sex workers; people living with HIV; Dominican Republic

Introduction

In the Dominican Republic, female sex workers are severely marginalised. They are typically women with low levels of education, limited economic opportunity, and at least

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one child who they often financially support on their own (Kerrigan et al. 2012). They face layered stigma and discrimination related to working in the sex industry and for those living with HIV. The situation is more challenging as they also face discrimination due to their HIV status (Kennedy et al., 2013). The negative effects of stigma on various HIV outcomes and behaviours are well documented in the literature (Mahajan et al. 2008; Stangl et al. 2013; White and Carr 2005). Thus, effectively addressing layered stigma constitutes the foundation to improve the health outcomes of female sex workers living with HIV, an understudied and under-served group. This study analyses layered stigma from a Foucauldian perspective and explores the effects of social cohesion on stigma.

Background

Ervin Goffman in his seminal theory of stigma defined it as an “attribute that is deeply discrediting” and that reduces the bearer “from a whole and usual person to a tainted, discounted one” (Goffman 1963: 3). According to Goffman, stigma occurs when society attaches a negative social meaning to an individual categorising the person as part of a group perceived to have a spoiled identity (Goffman 1963). Building on Goffman’s work, some researchers have sought to develop socio-cognitive frameworks, which focus on how stigma is experienced and enacted by individuals and how categories of stigmatised people are created and linked to stereotypes (Hatzenbuehler 2009; Earnshaw and Chaudoir 2009; Holzemer et al. 2007).

As a reaction to the socio-cognitive perspective predominant in the literature, a growing number of researchers have analysed stigma from a socio-political perspective, conceptualising stigma as related to power. Link and Phelan (2001), for example, propose that power is essential to the social production of stigma given that it takes power to stigmatise. Focusing on HIV-related stigma, Parker & Aggleton (2003) take a structural perspective and posit that HIV stigma is a social process that produces and reproduces social inequities related to class, race, gender, and sexuality. Furthermore, work around HIV stigma highlights that socially marginalised groups affected by HIV, often face layered stigma based on their occupation (i.e. sex work), gender identity (i.e. gay, lesbians, trans-sexual), personal characteristics (i.e. ethnicity) and behaviours (i.e. drug use) (Reidpath and Chan 2005).

In their analysis of HIV stigma, Parker and Aggleton (2003) drew on the work of various scholars including Foucault’s work on the relationship between culture, power, and notions of difference. They highlight Foucault’s insights into the new power regimes characteristic of modernity whereby social control is exercised not through physical force but through the production of conforming subjects. Drawing on Foucault’s work on the production of differences in the service of power, Parker & Aggleton (2003) propose that stigma and stigmatisation function at the point of intersection between culture, power, and difference and that a full understanding of stigma requires understanding the relationships between these categories. They indicate that Goffman’s and Foucault’s work taken together allows for a more nuanced understanding of culturally constituted stigmatisation as key to the establishment and maintenance of the social order.

While Goffman's work focused on the social construction of meaning through interaction, Foucault's work analyses the cultural production of differences (in our case stigma) in the service of power (Parker and Aggleton 2003). According to Foucault, in pre-modern times power was characterised by the ability of the monarch or sovereign to take life (juridical power) (Foucault 1978). While power has continued to function juridically, Foucault proposed that in modernity a new form of power surfaced: the power over life. Thus, the ancient right to take life has been replaced by a power to foster life or disallow it to the point of death (Foucault 1978). Foucault sees this new form of power as productive, endeavouring to "administer, optimise, and multiply life while subjecting it to precise controls and comprehensive regulations" (Foucault 1978: 137).

One of the ways in which the power over life is exercised is through social norms (Foucault 1978). Thus, from a Foucauldian perspective, HIV stigma can be understood as a strategy to enforce oppressive social norms around sexuality and personal responsibility for one's body and health (or healthism) (Rose 1999) in order to maintain the social order. Furthermore, from this perspective, stigma and the resulting marginalisation is a strategy to discipline those who have engaged in behaviours that are deemed to violate established norms and threaten the social order.

This modern type of power is not only exercised by society but by individuals themselves. In his book *Discipline and Punish: The Birth of the Prison*, Foucault (1977) highlights "the gaze" as an important disciplinary practice of modern power. The gaze is a surveillance technique employed in panopticon-styled prisons where inmates were organised so that they could be constantly seen, known, surveilled, and controlled. One of the characteristics of the gaze is that it becomes internalised, resulting in prisoners policing themselves as they do not know when they are being watched (Foucault 1977). Such policing and disciplining includes self-castigation and self-marginalisation when norms have been transgressed, including those related to gender and sexuality as may be the case in relation to female sex workers living with HIV.

Despite Foucault's contribution to the understanding of power, his work has come under heavy criticism from political theorists who highlight that it does not fully address resistance and agency to bring about change (Allen 1999; Cronin 1996). According to critics, Foucault's de-centring of the knowing and wilful individual from being at the centre of history--or its protagonist--to being a subject of history--or its object--places the individual in a position where resisting and rebelling against normative conceptions of truth and injustice are limited (Cronin 1996). However, some would argue that this criticism is undue as Foucault does open the possibility for resistance by clearly indicating that power generates the opportunity for resistance and personal and collective agency through subverting established norms (Thompson 2004; Pickett 1996).

In our view, Foucault's conceptualisation of power serves as a robust analytical framework to understand stigma and its deployment, and as the basis to develop a better understanding of possibilities for resistance against stigma. In this paper, we use Foucault's conceptualisation of the power over life to analyse stigma as a tactic of modern power and to understand how it is deployed through disallowing life via marginalisation and the

normalisation of violence against those who transgress social norms. Additionally, we draw on the concept of the internalisation of the gaze as a micro practice to understand the process of self-stigmatisation and its negative psychosocial consequences.

In addition to using Foucault's concepts to understand stigma, we analyse social cohesion as a strategy of collective resistance and subversion against oppressive social norms. Thus, we take a group/social perspective to analyse how a marginalised group may challenge stigma collectively. Social cohesion has been shown to be an integral component of community empowerment approaches among female sex workers in various contexts which bring them together to analyse, articulate and demand their human rights including access to quality HIV services (Kerrigan et al. 2014). Hence, social cohesion has surfaced as a necessary first step for community mobilisation and it has been related to processes that seek to alter the existing power structure (Kerrigan et al. 2014). Groups and communities that are cohesive may come together to analyse, articulate, and demand their human rights and entitlements (Kerrigan et al. 2014; Peterson and Hughey 2004). Indeed, community or collective empowerment develops when individuals work together to achieve a larger impact than they could have on their own. According to Rolands (1997), empowerment not only entails individual conscientisation (power within) but also the ability to work collectively (power with others) and this provides the ability to bring about change (power to) (Rolands 1997). Indeed, empowerment involves exercising rather than possessing power (Parpart, Shirin, and Staudt 2002), and exercising power with others necessitates the existence of group cohesion. Thus, unlike stigma which can be used as a strategy to preserve existing power relations (Link and Phelan 2014), social cohesion can serve as a strategy to change these. Social cohesion is conceptualised as the level of trust, solidarity, and mutual aid in small groups and society, and it is related to empowerment (Carrasco and Bilal 2016). Analysing how social cohesion may allow for resistance against multiple forms of stigma can offer critical insights to determine effective ways to address stigma.

Methods

The Abriendo Puertas (Opening Doors) intervention

Abriendo Puertas was initially implemented as a pilot intervention in 2013 over a period of 10 months to improve HIV outcomes among female sex workers living with HIV in Santo Domingo, Dominican Republic. The intervention was offered to a cohort of 250 female sex workers living with HIV, who met the following criteria: being 18 years of age, HIV-infected, and having exchanged sex for money in the last month. The study was implemented by Johns Hopkins University and the University of North Carolina in partnership with the Instituto Dermatológico y Cirugía de Piel Dr. Huberto Bogaert Díaz, COIN (Centro de Orientación e Investigación Integral), and MODEMU (Movimiento de Mujeres Unidas) based in Santo Domingo. The intervention had four components: 1) individual counselling and health education; 2) peer-led health care navigation and support; 3) sensitivity training for clinical care providers; and 4) community solidarity and mobilisation activities.

The latter component was implemented by MODEMU, a female sex workers-led civil society organisation based in Santo Domingo. MODEMU facilitated the community

solidarity and mobilisation component with *casas abiertas* (open houses), that provided opportunities for participants to come together once a month to discuss topics of interest such as financial security, resources available for people living with HIV, exploring partnerships among each other to start micro-businesses, challenges taking care of a family member living with HIV, and the importance of taking care of their health. The *casas abiertas* offered women space to share and learn from their common challenges and jointly examine potential avenues for creative action. They also offered specific skill building workshops geared to promote better health and increase financial security among the women and their families. Approximately half of the parent study participants attended at least one *casa abierta*. Participants were also able to meet each other and build cohesion as they waited for the counselling sessions received through *Abriendo Puertas* and through informal small group meetings organised by the study *navegadoras* (peer navigators).

Sample

In January of 2013, 34 women enrolled in the *Abriendo Puertas* cohort participated in semi-structured in-depth interviews (23 women) and two focus group discussions (11 women) as part of this qualitative sub-study. We sought a purposeful sample of individuals who had and had not participated in the *casas abiertas* component of the intervention. Of the 23 women who participated in in-depth interviews, 14 had participated in the *casas abiertas*. The two focus groups were comprised of one group with women who participated in the *casas abiertas* (n=5) and another group of women that did not (n=6). Focus groups were conducted to understand the group dynamics among the participants and also to determine if there were any major differences between women who participated in the *casas abiertas* and those who did not. Recruitment of participants for the study was conducted by the first author and the intervention counselling team, who helped to select women with varied experiences and who were likely to provide rich data.

Data collection and analysis

Interview and focus group field guides were developed in collaboration with the study team based on formative research conducted in preparation for the intervention (Kennedy et al. 2013). Key domains explored in the interviews included: how HIV diagnosis impacted their lives, what it meant for the participants to be part of *Abriendo Puertas* and the *casas abiertas*, how they had changed (physically and mentally) since participating in *Abriendo Puertas* including changes in HIV outcomes, and what power meant for them. The focus group among *casas abiertas* participants focused on experiences in the *casas*, experiences of stigma, physical and mental well being before and after the intervention, and the process of building social cohesion in the context of individual and community empowerment. The focus group among those who did not attend the *casas abiertas* focused on the reasons why they did not participate, their common challenges, experiences of stigma, physical and mental well-being before and after the intervention, and their ideas about how to strengthen cohesion among female sex workers. Interviews were approximately 60 minutes long and focus group discussions were approximately 90 minutes long. All interviews and focus groups were conducted by the first author of this paper, a female, native Spanish speaker in a private room at the Instituto Dermatológico y Cirugía de Piel Dr. Huberto Bogaert Díaz. All

interviews and focus groups were audio recorded, transcribed, and analysed in Spanish using Atlas.ti 7.0 (Frieze 2013).

Interview transcripts were analysed in two phases using thematic analysis techniques (Patton 2002). In the first phase, a preliminary analysis was conducted by reading all the transcripts and coding the data with codes to identify instances of societal disciplining (i.e. domestic violence, verbal abuse, social rejection, employer discrimination), self-castigation (i.e. fatalism, hopelessness, low self-esteem, loss of the will to live, suicidal ideation, etc.), and regaining power (fighting for one's life, regaining hope, self efficacy, increased self-esteem, solidarity, accessing social support, etc.). Initial coding also included identifying instances of social cohesion. Additionally, we also coded these processes in relation to HIV behaviours (i.e. accessing HIV care, treatment adherence, condom use, substance use, etc.) to more fully understand the dynamics at play and their influence on health and well-being. In a second phase, the coding conducted in the initial phase was supplemented by identifying community narratives. The latter surfaced as recurring phrases used by the participants and as actions that indicated the performance of those narratives (such as when the participants displayed solidarity). Additionally, memos written after data collection were utilised to identify information gaps, describe how participants perceived concepts such as various forms of stigma and discrimination, social cohesion, community empowerment, and document relationships between the various themes emerging in the data. The names provided in the quotes in the results section are pseudonyms to ensure confidentiality of the participants. Age and year of HIV diagnosis are provided for the women who participated in the interviews, as this information was available for them but not for the women who participated in the focus groups. Finally, we indicate whether the person had attended or not one of the *casas abiertas*.

Ethical approvals

The study was approved by the Institutional Review Boards of the Johns Hopkins University Bloomberg School of Public Health and the Instituto Dermatológico y Cirugía de Piel Dr. Huberto Bogaert Díaz. All participants provided consent at the beginning of each instance of data collection. Each participant received approximately \$10 USD (400 Dominican pesos) for participating in this sub-study.

Findings

Disallowing life: Self-disciplining through the internalisation of the gaze—

Many of the women interviewed indicated that upon being diagnosed with HIV they felt that their “world had ended” or that the “world was falling on them”. One participant expressed this sense of death clearly: “I thought that they killed me the day when they told me I was positive: that day I died” (Elena, 38 years old, diagnosed with HIV in 2012, participated in the *casas abiertas*). Some of them revealed that before being diagnosed with HIV they thought badly of people living with HIV. Once diagnosed, their negative attitudes turned to themselves through various forms of self-castigation. Thus, for many participants, from the very point of diagnosis they internalised society's *gaze* giving way to self-disciplining, which was manifested as feelings of shame and of being desolate and forsaken.

... when you fall like this [get HIV], you stop loving yourself... I believed that life was over and my self-esteem fell a lot. Before joining *Abriendo Puertas* I felt like a worthless thing (Maritza, 45 years old, diagnosed with HIV in 2004, participated in *casas abiertas*)

One of the respondents, who had worked as a peer counsellor for many years, shared that upon finding out that they are HIV positive, people living with HIV are in shock and “the first [reactions] are feelings of guilt, depression, and a profound sadness; ...feeling completely lost” (Lourdes, 53 years old, diagnosed with HIV in 1982, participated in the *casas abiertas*). Immediately post HIV-diagnosis many women could not talk, had no desire to take care of themselves, to shower or to put on make-up, did not want to leave their house, or lost their appetite for food and—perhaps more importantly—for life. These participants were, in effect, letting themselves die.

Depression kills... When you are depressed because of your HIV status you lose your appetite, you obsess thinking about that disease [AIDS] all the time and you do not eat. After I was diagnosed I became extremely thin (Teresa, 43 years old, diagnosed with HIV in 2010, participated in *casas abiertas*)

With respect to living with HIV, most participants described significant challenges accepting their diagnosis. Most women revealed that their HIV diagnosis had led to anxiety, depression, and suicidal ideation. These were just some of the self-castigating tactics of power. Internalised HIV stigma was also exhibited by an ever-present sense of guilt and shame related to their HIV status. This led to self-marginalisation and to zealously guarding confidentiality about their status. Even if they succeeded in keeping their HIV status confidential, most participants could not escape self-disciplining from the internalised gaze.

In addition to HIV-related internalised stigma, many participants also experienced stigma related to their profession. Internalised sex work stigma led many participants to hide their profession from their families, friends, and neighbours. Some had internalised sex work stigma to such a high degree that they had normalised sex work-related violence and accepted it as a fact of life.

I did not know [before participating in *Abriendo Puertas*] that there should not be distinctions between a sex worker and another woman... Both should be treated with respect (Sara, 57 years old, diagnosed with HIV in 2006, participated in *casas abiertas*)

While internalised sex work stigma appeared to affect the participants differently, it was present even in the discourse of those who seemed least affected by it. For example, toward the beginning of the interview, Luz, who has worked for over 20 years as a sex worker and was an activist heavily involved with local sex worker and people living with HIV movements, indicated that sex work is a profession like any other. While she had embraced her profession and her narrative did not indicate feelings of shame, Luz had some moments of doubt when she needed reassurance. She shared that when her son reached adulthood she asked him if he felt that she had given him a bad example given her line of work. To her relief, he told her she had been a wonderful mother.

Some participants tried to avoid internalising sex work-related stigma and the related self-disciplining by developing a financial security discourse around sex work, highlighting that their work had allowed them to provide for their children, support their parents or siblings, fulfil financial obligations, and build their own houses. Sex work provided them with financial independence and for some helped them to avoid living in situations of intimate partner violence or being dependent on partners who in some cases controlled them by threatening to withdraw financial support. The ability to provide for their children and sense of self-sacrifice as mothers was a source of pride rather than shame.

Disallowing life: Social disciplining through marginalisation and

normalisation of violence—Through their narratives, participants described many instances of marginalisation, rejection, and abuse because of both their profession and HIV status. Some participants said that policemen would force them to provide sexual services for free; and others indicated that clients would not pay them for their services or would physically and verbally abuse them. Others had endured verbal abuse from their steady partners because of their profession. Such violence often took place with impunity as sex workers were not afforded the same rights as other women such as protection from the police and social respect.

There is a lot of verbal abuse against sex workers. My steady partner never beat me but many times he insulted me [because I am a sex worker]. When he did this I felt like he was not valuing me, like he was treating me as if I was an object or an animal (Sara, 57 years old, diagnosed with HIV in 2006, participated in d *casas abiertas*)

Participants not only faced societal marginalisation due to their occupation but also due to their HIV status. Many participants indicated that people living with HIV were “treated like animals”, put to eat separately, yelled insults in public, and perceived as “rotten.” Furthermore, some participants said that HIV stigma and discrimination is so ingrained in local discourse that calling someone *sidoso/a* (a person who has AIDS) is considered an insult or a slander.

When I found that I was HIV positive I was afraid of the being rejected by people. There are still a lot of people who talk a lot; they say bad things about HIV. I laugh to avoid being found out. If they knew I have *that...* (Marinela, 36 years old, diagnosed with HIV in 2009, did not attend *casas abiertas*)

In an environment of high expected HIV-related discrimination, keeping one's status secret was of the essence in order to avoid societal disciplining through violence, abuse or marginalisation. The participants went to great lengths to avoid having their HIV status becoming publicly known. For example, many indicated that in spite of financial constraints they preferred to travel long distances to HIV clinics far away from their neighbourhoods instead of accessing local facilities where they risked meeting acquaintances, neighbours or friends who could divulge their status. A few women indicated not joining support groups for people living with HIV to avoid any possibility of their HIV status becoming public. Thus, by hiding their HIV status from others the participants often found themselves marginalised with limitations on the support they were able to receive.

Participants' lives were disallowed through the denial of resources, opportunities, and appropriate services. Potential employers denied them job opportunities and health care providers outside of HIV clinics often denied or delayed treatment, and did not provide important health information and confidentiality. A respondent painfully related the traumatic experience of being singled out and called *sidosas* amongst other patients by a doctor in a public health facility. She indicated that she fainted and did not want to go back.

Through the denial of appropriate services and opportunities their chance to "improve themselves" and achieve their potential was disallowed.

I feel discriminated because I am a *person*, an *intelligent woman* who deserves a good job, and who should not have had to go through some of the things I have gone through. But here you are discriminated; you are denied a job because of living with HIV. There are many times when you want to apply for a job, you go to apply and they ask you for lab tests. I feel very bad because the people who are hiring hand you a piece of paper and they tell you: "go get these lab tests done!" And no, they don't give you a job opportunity and the possibility to improve yourself, all because you are living with HIV (Ines, 32 years old, diagnosed with HIV in 2008, did not attend *casas abiertas*)

Participants did not discuss HIV stigma experienced from clients likely because, for the most part, they did not share their HIV status with their clients to avoid the possibility of becoming victims of violence. Additionally, disclosure to clients could mean losing their sustenance. One participant started working as a sex worker after losing her job as a seamstress because of her HIV status. Many others indicated wanting to leave the sex industry to take better care of their health as sex work often included long nights and drinking alcohol with their clients. Yet, given their financial responsibilities and lack of opportunity, this was not an option.

Resisting and subverting oppressive norms: Reconstructing identity through social cohesion—In the context of the pervasive and multiple forms of stigma and the resulting self and societal disciplining and marginalisation, the participants isolated themselves either physically by staying at home and avoiding places where they may be recognised as people living with HIV or psychosocially by not sharing important aspects of their lives with others (i.e. disclosing HIV status and profession). Many felt alone in these struggles until they participated in the *Abriendo Puertas* intervention. The community mobilisation and solidarity component of the intervention, through the open houses, provided a safe space to come together to build trust and solidarity, as well as opportunities for collective action.

The first day [that I went to *casas abiertas*] I was very scared but a *compañeras* told me: "come in, I am also like that [living with HIV] and all the women you see here are also like that and they are here. I relaxed a little bit and went inside the room and felt great because I realised that I am not the only one (Elena, 38 years old, diagnosed with HIV in 2012, participated in *casas abiertas*)

By coming together participants were able to take an important step to overcome self- and societal marginalisation. Cohesion, in particular the element of trust generated among

participant, created a psychosocial space to verbally or tacitly (by virtue of their participation) disclose their HIV status without feeling judged or blamed and to feel accepted regardless of their HIV status. Thus, participants were able to redefine their internalised sense of abnormality by being treated and acting “normal” in an environment where their HIV status was known.

Since attending *casas abiertas*, I now belong to that family. [At the *casas abiertas*] we talk, we do not have shame. If I tell the woman next to me: “Listen, I am positive.” She will tell me: “me too.” But, with an outsider, if I tell him: “I am positive,” he will likely not treat me like one of my *compañeras* (Elena, 38 years old, diagnosed with HIV in 2012, participated in *casas abiertas*)

Cohesion also provided a psychosocial space for the emergence of positive and de-stigmatised community narratives. These new narratives revolved around courage, strength, resilience, and agency for female sex workers living with HIV as a group to fight for their lives and provide for their loved ones. A cohesive community of women like them enabled study participants to develop, perform, sustain, and reinforce each other’s empowered narratives and collectively reconstruct their identity. One of the narratives that emerged was comparing life with HIV to life with other diseases such as cancer or diabetes. The participants mentioned that HIV can be treated and that HIV infection was not fatal. Other commonly shared de-stigmatising narratives emphasised not allowing HIV to take control of their lives, feeling valuable, and reclaiming life by taking care of their health.

I tell myself the truth: “I am HIV positive and I am going to die when God wants it, not when the disease decides it!” Those are words that I learned here, the other women [at *casas abiertas*] taught me this” (Marisol, 28 years old, diagnosed with HIV in 2010, participated in *casas abiertas*)

The de-stigmatised and empowering narratives that emerged at the *casas abiertas* also extended beyond that setting. Performance of these narratives through the uptake of protective health behaviours such as treatment adherence was an important way to fully integrate and embody new narratives. Embodiment of the idea that life was worth living and that they have to fight for their lives was translated into such health seeking behaviours including staying in care, as well as adherence to HIV treatment.

At the *casas abiertas*, the fact that women were living with HIV lost its central place in the women’s identities and it became a circumstance rather than a defining feature. Thus, through interaction at the *casas abiertas* and informal groups formed the women helped each other to develop a new sense of a normal self where living with HIV did not define them.

I get along with Anita very well. I met her at the *casas abiertas* and we have become great friends. [When we get together] we... forget that we have this problem [HIV]. When we get together we feel important, we talk like two civilised people, and we do not have to talk about *that* [HIV] because we already know we have it. With Anita I feel OK with her knowing that I am living with HIV. It doesn’t matter what we tell other people [about our HIV status]. The important thing is that when I am with Anita I focus on thinking: “I am the same as other people, I am not

defective” (Marisol, 28 years old, diagnosed with HIV in 2010, participated in *casas abiertas*)

Solidarity or mutual aid, an element of social cohesion, was essential in developing and strengthening a sense of agency, which the women directly link to their perception of power. The ability to help other female sex workers and people living with HIV through counselling, taking them to the doctor, or sharing their experience led to a sense of agency that had been taken away from them. Indeed, participants who were asked what power meant to them responded that power is being able to help others. Many considered powerful God and people who had the ability to help others. Through helping others the participants were able to restore the agency once lost because of stigma.

Power is you being able to help others like in my case, I already had to help a number of people who confide in me and confess that they are sick, that they have this problem [HIV], that they don’t feel well. And, I go to the centre where I am getting my medication and I take them there because for me this is very important (Kathy, participated in *casas abiertas*)

I feel powerful because I have been able to help some people [living with HIV] to go forward [fight for their lives]. There was one *compañero* who was not doing well, he didn’t care about anything. One day, as I was arriving to my church, he stops me on my tracks and confesses to me: “listen, *epa*, I am like you.” And I ask him: “Like me, how so?” He says to me: “I also have this and this [HIV]. I want you to take me [to the HIV clinic] where you go because I saw you when you were very ill.” He was right, I was in critical condition at one point but thanks to God and somebody who helped me I recuperated and moved forward. And I can assure you that I went with him, I took that man to the doctor, I invited him to my church, and he is doing well, with his self-esteem up high (Marta, participated in *casas abiertas*)

The opportunity to help others provided an avenue to re-organise and re-construct the self putting into practice a positive narrative, which replaced the negative narrative (HIV stigma) imposed by society and diffused the internalised gaze. Solidarity was also a way to embody de-stigmatised narratives as it was a re-affirmation of the humanity of which they had been robbed as their life was disallowed. Furthermore, solidarity also provided an avenue to create content for narratives that could be recounted and shared and that would strengthen the sense of a valuable self, reducing stigma.

Yes, I have helped a lot of people who are living with HIV. I have given them *animo* [will to fight] for life. When I see somebody who is depressed or going through a difficult situation I try to help them see things differently... Like the other girls that come here [to *Abriendo Puertas*] with me. Sometimes they tell me: “I don’t have food... I need babysitting; I don’t have money for transportation [to go to my *Abriendo Puertas* appointment].” I tell them: “listen, this is what we will do, you do not have transportation, I will find the money for you and when you have money you pay me back. As for the baby, I will take your baby and I will wait for you downstairs while you attend your counselling session.” I try to find ways to help other women go to [*Abriendo Puertas*] counselling because there people learn

about life, like me... I was living in a very dark world [before participating in *Abriendo Puertas*]. When people called me out and insulted me: “oh God, that woman has AIDS”... when people told me *that*, I used to feel offended. But now I don’t care what people tell me. I tell them: “*Mi amor* [Honey], lucky me because there is treatment for *that* [HIV]!!” (Marisol, 28 years old, diagnosed with HIV in 2010, participated in *casas abiertas*)

Examining differences among the women who participated in the *casas abiertas* and those who did not participate we found that those who participated spoke very positively about their experience, reporting enhanced trust, solidarity, and mutual aid with peers; they also discussed at length the positive influence of *Abriendo Puertas* in their lives. Women in the focus group of participants who did not participate in the *casas abiertas* were also positive about the impact of the intervention in their lives but they unanimously and strongly indicated that it was not possible to cohesion among female sex workers. Most of them had worked in *negocios* (sex work establishments) at some point in their lives and they recounted stories of intense competition and fights. The contrast with the focus group of women who participated in the *casas abiertas* was stark as the latter portrayed a more developed sense of solidarity and ensuing compassion for others and, by extension, the self.

Discussion

While several authors have written about the socio-political nature of stigma, individually-oriented socio-cognitive frameworks have informed most of the HIV stigma reduction interventions reported in the public health literature (Brown, Macintyre, and Trujillo 2003; Sengupta et al. 2011; Stangl et al. 2013). The emphasis on addressing individuals’ experiences of HIV stigma has constrained the scope of stigma reduction interventions. These have primarily included promoting empathy with and reducing fear of people living with HIV using strategies such as testimonials, dissemination of information about HIV and modes of physical contagion (Mahajan et al. 2008; Sengupta et al. 2011; Stangl et al. 2013). More recently, stigma reduction interventions have also focused on building the skills of people living with HIV to reduce internalised stigma through skills building, access to support groups, counselling, and stigma-reduction training for health personnel and other service providers (Stangl et al. 2013; Sengupta et al. 2011; Mahajan et al. 2008).

While such interventions have made important contributions to the field, the predominant socio-cognitive strategies may miss important social or collective strategies to address stigma. Indeed, socio-cognitive strategies are limited to the extent that they do not address the underlying power dynamics that fuel stigma. The importance of taking a Foucauldian perspective to understanding stigma lies in the possibility of uncovering such dynamics. Given that “power is only accepted when it is hidden” (pp. 459) (Pickett 1996) such uncovering allows for a better understanding of effective ways to address stigma.

If stigma is indeed a tactic through which power is deployed, methods to effectively address it must subvert the norms through which stigmatising differences are created. From a Foucauldian perspective, such subversion entails rebelling against the ways in which we are defined, categorised, and classified (Rajchman 1983); or, more simply put, they entail

reconstructing identity. We are not born free but into various configurations of power (Rajchman 1983). Given these constraints, “freedom does not lie in discovering who we are, but in being able to construct who we want to be, thus rebelling against the configurations of power constraining us” (Rajchman 1983: 15). For the women in the study, freedom entailed rebelling against the negative, devaluing, constraining labels imposed on them by society by collectively constructing who they wanted to be: women of courage, value, beauty, and strength. Ultimately, the women found power in freedom and this freedom was achieved in community. Thus, one of the key findings from this study is that empowerment comes from freedom and that empowerment cannot be handed down to people but that it is built in a group or community bound by trust, solidarity, and mutual aid.

An important question that follows is how to construct “who we want to be” in an environment where the capillary and policing arms of power are ubiquitous, even within us. The *Abriendo Puertas* participants faced such environment. They shared numerous experiences of sex work and HIV-related stigma, which were central elements of a process whereby they lost their agency, self worth, ability to access social support, and perceived social respect. Participants were marginalised, denied opportunities, and verbally, psychologically or physically abused. These were societal strategies to discipline them for transgressing norms around sexuality and healthism (Queen 2001; Crawford 1980).

In line with Foucault’s conceptualisation of power, when it comes to understanding the hold modern power has on us social practices are more fundamental than ideologies (Fraser 1989). Study findings reveal numerous self-stigmatising practices implemented by the participants. Through their participation in the intervention the women were able to come together to develop and put into practices new de-stigmatising narratives that re-defined their identity. This finding resonates with results from a study among female sex workers who participated in the *Encontros* intervention in Brazil which indicated that having a safe space enabled the participants to gather to construct a positive social identity (Murray et al. 2010). Indeed, through being able to come together and develop, repeat, and practice new de-stigmatised narratives their identities were reconstructed. Thus, this study not only highlights the strong hold that stigma had on the participants and but it also suggests that changing entrenched stigmatising beliefs not only requires hearing de-stigmatising messages (which is the current socio-cognitive approach) but also developing and coming together to create and embody new narratives through repetition and practice. This finding underscores the importance of providing safe collective spaces to develop, repeat, and perform new narratives, which ultimately are new configurations of power.

In this study, we found that social cohesion is initially stimulated in a safe physical space and that it also serves create a psychosocial space. Women coming together and realising that they were not alone was a step to overcome marginalisation and reclaim life as part of a group or community. Through establishing trust they were able to disclose their HIV status in an environment where they felt accepted. In such safe space they were able to practice and embody a sense of being normal. This psychosocial space offered an environment for new de-stigmatised narratives to emerge and for practicing positive values such as courage, resilience, solidarity, and resourcefulness.

From a programmatic perspective, our findings highlight the importance of ensuring that interventions provide female sex workers living with HIV opportunities to challenge oppressive norms and address power imbalances by developing, repeating, and performing new, empowered narratives. These opportunities should include avenues to produce and reproduce a de-stigmatised identity and, in so doing, plant the seeds of social transformation and freedom. Such seeds could spark collective mobilisation to address structural issues underlying negative HIV-related outcomes, as well as the experiences of social inequality faced by female sex workers. Thus, these seeds can create possibilities of sustainable social change.

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