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HIV-related stigma, disclosure and social support: experiences among young pregnant and postpartum women living with HIV in South Africa

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Abstract

Young pregnant and postpartum women living with HIV (WLHIV) are at high risk of poor antiretroviral therapy (ART) outcomes, which may be driven partly by HIV-related stigma. We conducted in-depth interviews with 20 pregnant and postpartum WLHIV aged 19–24 years to understand how different forms of HIV-related stigma manifest in their lives, as well as their experiences of HIV-status disclosure and social support. Participants described profound levels of perceived stigma in their community, including gossip from other young women and judgement from older adults. Consequently, participants disclosed to a limited number of people to avoid being stigmatised, and disclosure to peers was especially uncommon. However, disclosure in

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certain situations was described as leading to emotional support and support for ART adherence, and disclosure to older WLHIV resulted in participants having a role model. Finally, participants expressed varied ways in which they accept, speak about, and live with their HIV diagnosis. These data provide a rich understanding of the experiences of HIV-related stigma in this population and point to the need for psychosocial interventions focussed on acceptance and coping with an HIV-positive diagnosis despite profound levels of perceived stigma, as well as navigating decisions around the targets and timing of disclosure.

Keywords

HIV-related stigma; disclosure; social support; pregnancy; young women; South Africa

Introduction

Despite major expansions in antiretroviral therapy (ART) programmes, HIV-related stigma remains a major concern. Stigma manifests in multiple forms including *enacted stigma*, or actual experiences of stigma, *perceived stigma*, or the perception of stigmatizing attitudes in the community, *anticipated stigma*, or the expectation that one will experience stigma, and *internalized stigma*, or the endorsement of negative beliefs about oneself (Earnshaw & Chaudoir, 2009; Turan et al., 2017). During pregnancy and postpartum, stigma is a barrier to the uptake of and retention in prevention of mother-to-child transmission (PMTCT) services (Gourlay et al., 2013; Hodgson et al., 2014; Kohler et al., 2014; McMahon et al., 2017; O'Hiarlaithe et al., 2014) and is a driver of suboptimal adherence to ART (Katz et al., 2013; Rueda et al., 2016; Shubber et al., 2016; Turan & Nyblade, 2013) through mechanisms which include low levels of social support, mental health problems and maladaptive coping (Turan et al., 2017).

A closely related issue is that of HIV-status disclosure to others in the person's social network. Notably, disclosure may lead to increased social support or to social rejection, a form of enacted stigma (Chaudoir & Fisher, 2010; Chaudoir, Fisher & Simoni, 2011). While disclosure to a limited number of people may be protective against HIV-related stigma (George et al., 2015), non-disclosure may lead to poor ART outcomes (Turan et al., 2017) through lower levels of social support as well as secrecy around engagement in HIV care and ART use (Heestermans et al., 2016; Omonaiye et al., 2018; Vyavaharkar et al., 2011).

Adolescents and young women living with HIV (WLHIV) are less likely than adults to disclose their HIV status to others (Nostlinger et al., 2015; Thoth et al., 2014). In addition, levels of HIV-related stigma may be particularly high in adolescent populations (Dos Santos et al., 2014), and stigma is a known barrier to engagement in care and ART adherence among adolescents (Nakubeera-Barungi et al., 2015; Williams et al., 2017). Further, stigma may play a key role in ART outcomes among young pregnant and postpartum WLHIV, a group at particularly high risk of disengagement from PMTCT services and suboptimal adherence to ART (Fatti et al., 2014; Horwood et al., 2013; Woldesenbet et al., 2015). Interventions are urgently needed to improve outcomes in this population and understanding experiences of stigma will be critical to informing intervention development. Prior to a pilot trial of a peer support intervention to mitigate the negative effects of stigma and improve retention in HIV care and viral suppression in young pregnant and postpartum WLHIV (ClinicalTrials.gov NCT04036851), we conducted formative research to explore how stigma manifests in this population.

Materials and methods

Study design

This study was conducted in the low-income community of Gugulethu in Cape Town, South Africa, where the antenatal HIV prevalence is ~30% (Myer et al., 2015). Participants were recruited from the Gugulethu Midwife Obstetric Unit and were eligible to participate if they were aged 16–24 years, confirmed HIV-positive, and accessing antenatal (n=10) or immediate postpartum (n=10) PMTCT services at the clinic. The study was approved by the Human Research Ethics Committee of the University of Cape Town Faculty of Health Sciences, and all participants provided written informed consent prior to enrolment, including consent to have the interview audio recorded.

Participants completed a brief questionnaire assessing sociodemographic characteristics, followed by an in-depth interview. Interviews were conducted in a private room in participants’ home language (primarily isiXhosa) by a highly trained and experienced interviewer who lives within the same community. The semi-structured interview guide included questions about different forms of stigma, as well as experiences of disclosure and social support. The interviewer received on-going supervision to ensure adherence to the interview guide, assess thematic saturation, and discuss any issues that arose. Interviews were later transcribed verbatim and translated into English, with independent quality checking by an isiXhosa-speaking research assistant.

Data analysis

Anonymised transcripts were imported into NVivo 12, version 12.4, for coding and thematic analysis. An initial thematic coding structure was developed based on the interview guide. Two of the authors (KB and YG) reviewed a portion of the transcripts (15%) to verify consistency in coding approaches and then independently coded the remainder. Other members of the analysis team (JP and SN) critically reviewed the initial results, yielding additional queries and validity checks on the findings.

Results

Between March and June 2019, 20 young WLHIV were enrolled (median age: 21 years; range: 19–24 years; Table 1). Overall, 40% had completed secondary education, and 25% were employed or in school/studying. Of the 18 participants who were in a relationship, 15 (83%) were neither married nor cohabiting with their partner. Most participants reported that their current/recent pregnancy was their first pregnancy (65%) and was unplanned (85%), 35% were diagnosed HIV-positive during this pregnancy, and 60% were on ART at the time of the interview. Although not asked as part of the interview guide, one participant reported that she had acquired HIV perinatally.

Overall findings

Overall, participants reported low levels of HIV-status disclosure to others due to what they perceived as profound levels of HIV-related stigma in their community. Few experiences of enacted stigma were reported, but participants themselves ascribed this to having disclosed to a limited number of people. Conversely, participants described how disclosure could lead to emotional support and support for adherence. Finally, participants expressed varied ways in which they accept, speak about, and live with their HIV diagnosis. Each of these themes is expanded on below.

Perceived stigma towards young women

Participants described perceiving high levels of HIV-related stigma in their community, particularly towards young WLHIV, and including both gossip among young women and judgement from older adults. For example, a 24-year-old participant stated: *"We say 'don't date him/her, s/he is [HIV] positive'. Even older people say, 'don't talk to her a lot, she's [HIV] positive'."* A 23-year-old participant echoed this, saying: *"Even older people would say you are too young to be taking those pills."*

Participants recounted incidents of young women calling those living with HIV derogatory names. For example, a 20-year-old participant stated that a common insult for WLHIV is the isiXhosa word *'noRhawtini'*, meaning 'Miss Johannesburg', suggesting that women brought HIV to Cape Town from Johannesburg. In addition, participants described how WLHIV are judged because of their appearance, with others making assumptions about an individual's HIV status based on changes such as weight loss or weight gain. A 24-year-old participant stated: *"My mom in law says hurtful things about people living with HIV… She says they have lip sores and shapeless bodies due to ARV use."* Another 24-year-old participant said: *"If people notice that you have lost or gained weight, they will assume that you are sick. If you have gained weight, they say you are on treatment; if you have lost weight, they say you are sick."*

Participants reported that older adults judged young women for acquiring HIV "at a young age". Several noted the perception that young women acquire HIV through behaviours that are seen by others as "promiscuous", with a 20-year-old participant stating: *"People don't understand living with HIV at my age… You have to explain that you don't know how you got infected. People just think that you are promiscuous."* Finally, participants reported that WLHIV are avoided in their communities, with a 20-year-old participant saying: *"Other people hate anything that has to do with HIV".* A 21-year-old participant echoed this, stating: *"People are scared of the name HIV. Once you say that you are HIV positive someone will be like 'Oh, the three words', and backs off."* Others described how this avoidance extends to their babies, with a 20-year-old participant saying: *"People will not like your baby no matter how healthy she can be. They will always think the baby is HIV positive and instruct their children not to play with the child."*

Enacted stigma and disclosure

Against the backdrop of perceived stigma, most participants reported having disclosed their HIV status to a limited number of people, although all had disclosed to at least one person.

Consequently, few reported having experienced enacted stigma, but they acknowledged that this may be due to having disclosed to only a few individuals, with one 23-year-old participant explaining: *"Maybe it's because they don't know [my status], and that's why they don't act weirdly around me"*. A few participants described only disclosing to their family or partner after having given birth, including a 24-year-old postpartum participant who stated: *"I found it hard to discuss my status with anyone, even my family and my partner as well... I finally got the courage to inform him [her partner] after I gave birth to a healthy baby."*

Participants who had not disclosed described having to misrepresent their condition to family members when needing money to travel to the clinic, transferring ART medications into different containers or hiding pills to avoid inadvertent disclosure. A 24-year-old postpartum participant explained: *"When I ask for money, she [mother-in-law] wants to know what I am going to do with it. I will tell her I am taking the baby to the clinic. I always keep my pills in a pill bag to avoid the noise when I take them at night."*

Very few participants had disclosed to friends, citing a lack of trust, leading to peers being infrequently described as a source of support around HIV. One 19-year-old participant even stated that *"I don't think someone my age would be able to support me"*. Participants described anticipating that they would be gossiped about if their peers discovered their HIV status, with a 24-year-old participant explaining: *"When people are sitting around they'd talk about the person, saying that they've got this and that. So I feel like if these people were to know that I too... it's clear that I would be treated the way they speak."* Some participants reported being told by friends that they had been gossiped about, including a 21-year-old who said: *"The moment you hear that people were gossiping about you, you don't feel good about that. You wish you never disclosed."*

Although enacted stigma was largely from peers or family members, one 20-year-old participant recounted an incident of judgement from a nurse: *"I went to the clinic and a student nurse tested me and then my blood spilled so the nurse that was assisting the student said to me 'Why are you spilling your blood on me? Do you want me to take [PEP]?' I felt undermined or judged by her."* Although experiences of enacted stigma were relatively uncommon, one participant with perinatally-acquired HIV was an exception, and described being subjected to extreme abuse and neglect by her caregiver after her birth mother passed away, including being scrubbed in the bath until she bled because they believed she was "dirty", and being made to sleep at the entrance of the house so that any intruders would come across her first as she was "already damaged anyway".

Disclosure as a mechanism for support

Despite their fears about disclosing, participants described how HIV-status disclosure in certain situations was beneficial. Disclosure to female family members was most common, with family members described as a source of emotional support and support for ART adherence. Most participants had at least one family member who was also living with HIV and described that person as a role model. As a 20-year-old participant stated: *"You can share your experiences with them and learn from them"*. In particular, knowing older family members who were living with HIV was described as a source of hope, with another

20-year-old participant stating: *“And he [grandfather] would tell me about my mom’s aunt who is also HIV positive, but she is beautiful… She is a role model in the family, she is beautiful and healthy. She has been positive for a long time, I think for 10 years.”*

Participants noted that disclosure was easier if the person was known to be living with HIV, and in some cases the participant’s disclosure of her own status led to reciprocal disclosure. For example, one 20-year-old participant described her experiences of disclosure to various family members, stating: *“I disclosed to my mother in-law immediately and she told me that she is also on this treatment… I phoned my grandmother and disclosed to her when I found out about my status and she said ‘It’s not the end of the world – your mother also had HIV’…. When I told my aunt that I am HIV positive and pregnant, she said that she is also HIV positive and has three children”.* In addition, support after disclosure was described by several participants as being mutual, for example by reminding each other to take ART.

Accepting one’s diagnosis or internalizing the stigma

Participants expressed varied ways in which they accept, speak about, and live with the knowledge of their HIV diagnosis. Many referred to HIV as “this thing”, with one 23-year-old participant stating that the word HIV is *“heavy and scary… It’s frightening”.* Another 21-year-old echoed these words, stating: *“The most painful part about HIV is the term HIV”.* Some spoke of feeling ashamed and feeling as though they had disappointed their parents. In addition, several participants stated that failure to accept one’s diagnosis could lead to substance use, depression, or suicide.

In contrast, some participants described coming to terms with their HIV status, which helped them to cope. A 20-year-old participant said: *“At first you ask yourself, why me? But as the time went by, I accepted it and told myself that life should go on. At the end of the day I will live my life like any other person. It’s not written on my face that I have this.”* Many participants described seeing no difference between themselves and women living without HIV, with a 19-year-old participant stating: *“The only difference is that I am on treatment and they are not”,* although some participants did describe feeling different compared to their HIV-negative peers. Another 24-year-old described her complex feelings related to her diagnosis, and how these changed in different circumstances: *“Sometimes I don’t bother myself with it. Sometimes when I’m sitting with others I feel and act like I don’t have anything, but when it comes to being alone everything comes rushing back at me like ‘no, you are sick’, ‘you’ve got this thing’.”*

Discussion

In this group of young pregnant and postpartum WLHIV, participants described profound levels of HIV-related stigma in their community, with stigma around being young and living with HIV layered on top of HIV-related stigma more generally. Against this backdrop, participants reported high levels of anticipated stigma and, consequently, disclosure to a limited number of people. In addition to being protective against enacted stigma, disclosure to selective individuals had the potential to lead to emotional support and support for adherence, and sometimes reciprocal disclosure. Finally, participants expressed varied ways in which they accept, speak about, and live with the knowledge of their HIV diagnosis, with some avoiding the term HIV while others had accepted their diagnosis.

Despite hopes that stigma would decrease as HIV became a more normalised, chronic health condition, levels of stigma remain high in South Africa (Dos Santos et al., 2014; Hargreaves et al., 2018; Nachega et al., 2012). In this context, non-disclosure may be an appropriate response to avoid stigma (George et al., 2015). However, previous research has suggested that disclosure may have beneficial effects on both mental health and HIV treatment outcomes for some women in this setting (Brittain et al., 2019a; Brittain et al., 2019b). As such, there is a need to simultaneously recognise that disclosure to a limited number of people may be protective, while promoting and supporting disclosure within relationships where this may be beneficial. In this context of gossip and judgement, selective disclosure is clearly a helpful coping strategy, and selective disclosure to others living with HIV may lead to emotional support, hope, and having a role model.

Fears about disclosure are common (Ashaba et al., 2017), but qualitative work among pregnant and postpartum WLHIV in Uganda has described how disclosing and receiving support are integral in coming to terms with an HIV diagnosis (Medley et al., 2009). The present study included women who were presumably early in the process of coming to terms with their diagnosis and navigating disclosure within their relationships, given that one-third were diagnosed during their pregnancy, as well as women who had been taking ART for a median of 23 months and who had thus had more time to adjust. While some participants appeared to have accepted their diagnosis and integrated it into their sense of self, others resisted using the term HIV, appearing to distance themselves from the social and identity implications of being a person who is living with HIV.

A strength of the present study is the focus on young pregnant and postpartum WLHIV, a priority population, as well as the in-depth exploration of different forms of HIV-related stigma. However, participants were recruited using convenience sampling from one antenatal clinic in Cape Town, and their experiences may be unique to this context, although many of the themes mirror those from the literature. As women were recruited while accessing PMTCT care, their experiences may differ from those of women who are not engaged in care and who may have experienced higher levels of stigma. As part of the interview guide, women were not asked specifically about stigma related to being pregnant at a young age. However, given that the median age at first birth in South Africa is 21 years (Statistics South Africa, 2015) and that the youngest women in this study were 19 years of age, we hypothesise that participants may not have experienced stigma related to pregnancy. Finally, we did not quantify adherence or retention in care as part of this study, thus it is not possible to draw conclusions regarding the effect of stigma on HIV treatment outcomes in this sample.

Despite these limitations, this research provides rich data on the experiences of HIV-related stigma among young pregnant and postpartum WLHIV. In the absence of reducing stigma in communities, interventions that focus on providing psychosocial support for women experiencing profound levels of perceived stigma are needed, and effective interventions are needed to reduce the notably high levels of internalized stigma among young people living with HIV (Pantelic et al., 2019). Our research suggests that for women who are early in the process of coming to terms with their diagnosis, interventions focussed on acceptance and coping with an HIV-positive diagnosis against a backdrop of profound levels of perceived stigma, as well as navigating decisions around the targets and timing of disclosure, may be helpful. Alongside psychosocial benefits, supportive interventions among young WLHIV have the potential to lead to improved HIV treatment outcomes, given the well-documented negative effects of stigma on retention in care and adherence to ART (Gourlay et al., 2013; Hodgson et al., 2014; Katz et al., 2013; Kohler et al., 2014; McMahon et al., 2017; O'Hiarlaithe et al., 2014; Rueda et al., 2016; Shubber et al., 2016; Turan & Nyblade, 2013). For young pregnant and postpartum WLHIV who experience notably poor treatment outcomes, these interventions are urgently needed and should be escalated as a public health priority.

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Table 1

Participant characteristics

Variable	n (%)
Number of participants	20
Median [IQR] age	21 [20, 24]
Currently employed or in school / studying	5 (25%)
Completed secondary / any tertiary education	8 (40%)
Lives in informal housing	7 (35%)
In a relationship	18 (90%)
Type of relationship (n=18	
Married and/or cohabiting	3 (17%)
Neither married nor cohabiting	15 (83%)
Currently pregnant	10 (50%)
Median [IQR] gestation in months (n=10)	7 [6, 8]
Currently postpartum	10 (50%)
Median [IQR] weeks postpartum (n=10)	3 [2, 5]
Current / recent pregnancy was first pregnancy	13 (65%)
Current / recent pregnancy was unplanned	17 (85%)
Diagnosed HIV-positive during current / recent pregnancy	7 (35%)
On antiretroviral therapy (ART)	12 (60%)
Median [IQR] months on ART	23 [5, 26]