Fear of job loss and anticipated stigma are deterrents for disclosure of HIV serostatus in the workplace; narratives of domestic workers in affluent suburbs of South Africa

Elsie POS\textsuperscript{1}, Naomi HLONGWANE\textsuperscript{2}, Sphiwe MADIBA\textsuperscript{3}

\textbf{Affiliations:}
\textsuperscript{1} Department of Public Health, School of Health Care Sciences. Sefako Makgatho Health Sciences University. Pretoria, South Africa. E-mail: elsiapos037@gmail.com. ORCID: 0000-0001-8850-485X.
\textsuperscript{2} Department of Public Health, School of Health Care Sciences. Sefako Makgatho Health Sciences University. Pretoria, South Africa. E-mail: naomihlongwaneot@gmail.com. ORCID: 0000-0003-3045-6407.
\textsuperscript{3} Department of Public Health, School of Health Care Sciences. Sefako Makgatho Health Sciences University. Pretoria, South Africa. Email: sphiwe.madiba@smu.ac.za. ORCID: 0000-0002-3735-1248.

\textbf{Corresponding author:}
Prof Sphiwe Madiba, Department of Public Health, Sefako Makgatho Health Sciences University, P.O. Box 215 Medunsia 0403, Pretoria, South Africa. E-mail: sphiwe.madiba@smu.ac.za.

\textbf{Abstract}

\textbf{Introduction:} Domestic work is a large sector of employment for women who are rendered vulnerable to HIV by their disadvantaged backgrounds. The domestic work sector has been identified as one of the areas where disclosure of HIV status remains a challenge. Although South Africa is one of the southern African countries with a sizable number of domestic workers, there is lack of data on issues related to HIV and disclosure in the domestic work sector. This study explored the context within which domestic workers would disclose or conceal their HIV status in the workplace setting and examined the outcome of disclosure to their employers.

\textbf{Methods:} We conducted a qualitative explorative study with domestic workers in an affluent suburb of Gauteng Province of South Africa. We used purposive sampling to recruit 32 domestic workers living with HIV to participate in six focus group discussions. Data analysis was inductive and followed the thematic approach.

\textbf{Results:} All 32 domestic workers were female aged between 20–60 years, 19 were living on the employers’ premises, and nine were migrants from outside the borders of South Africa. The reported positive working relationship with their employers did not translate to disclosure and intentions to disclose in the future. Fear of job loss and stigma and discrimination were the major deterrents to disclose to the employer. Living-in increased the risk of unintended disclosure due to the lack of privacy. The post HIV diagnosis relationship with the employer was characterised by silence, lies, and deceptions in an attempt to protect their serostatus.

\textbf{Conclusion:} The threat of dismissal was distressing for most of the domestic workers, whereas for some the threat of actual dismissal was real. The acts of stigma experienced by the domestic workers call for specific HIV prevention interventions that focus on the domestic work sector.

\textbf{KEY WORDS:} Domestic workers; female; HIV serostatus disclosure; migrant workers; South Africa; stigma; workplace.
INTRODUCTION

Disclosure and stigma are some of the main work-related issues for people living with HIV (PLHIV) globally. The workplace has been identified as one of the areas where disclosure of HIV status remains a challenge. HIV is a highly stigmatized health condition and the dilemma of disclosure and stigma plays an important role in interactions at work, making disclosure of HIV status in the workplace a complex decision [1]. PLHIV consider multiple personal and environmental factors in their decision to disclose or to conceal their HIV serostatus [1–3]. A scoping literature review of studies investigating disclosure and stigma in workplace in western countries documented a low level of disclosure at work, ranging from 22–50% [1]. Research across different work sectors shows that HIV-related stigma remains one of the most significant reasons for nondisclosure [1]. Fear of discrimination, job loss, and social isolation are barriers for disclosure in the workplace [3–7]. Several studies documented evidence of discrimination and dismissal of workers after disclosure in the workplace [3, 8–11]. In the workplace, the various forms of HIV-related stigma may come from co-workers and supervisors. In Tanzania, HIV-related discrimination is prevalent in about 61% of the workplaces [12]. Beside the fear of job loss, concerns that may prevent an individual from disclosing at the workplace include anxiety about losing opportunities for advancement [2, 3, 13].

The effects of workplace discrimination are significant. Anticipated and enacted workplace discrimination has hindered the search for work, thwarted employment opportunities, and increased the risk of employment loss [14, 15]. Although disclosure prior to employment is not legal, some employers in different work sectors demand pre-employment HIV testing and often those that test HIV positive would not succeed in being employed [16]. However, in some workplaces, the di-

TAKE-HOME MESSAGE

Fear of job loss is a source of distress for most of the domestic workers and influenced their reason for actively concealing their HIV serostatus from the employer. Moreover, living in the employers’ household increased the risk of unintended disclosure for them.
Disclosure of HIV status can lead to shortened or flexible work schedules, change in work locations, time off for appointments, adaptations to work tasks and increased access to support systems [3, 8, 10]. Research suggests that the type of work and nature of the work environment influence HIV serostatus disclosure [17]. For example, in a study conducted with women migrants from Bangladesh, the majority of domestic workers who disclosed to their employers either suffered dismissal or were exposed to severe discrimination and stigmatisation [18]. The International Labour Organization (ILO) defines domestic work as any type of work performed in or for a household, and a domestic worker as any person engaged in domestic work within an employment relationship [19]. Domestic workers are generally women who do not work alongside other co-workers, but in isolation behind closed doors [20]. The ILO also refers to domestic work as typically gendered, as it is a major source of employment for women from marginalised and/or disadvantaged backgrounds [21].

In 2015, the ILO estimated that there were more than 67 million domestic workers globally [19]. South Africa is one of the southern African countries with a sizable number of domestic workers. Domestic work in South Africa is mainly characterized by the interconnections of race, gender and class, and is inherently dominated by black women who are poorly paid [22, 23]. In South Africa, approximately 953,000 black women are currently employed as domestic workers, representing 5.8% of the total South African labour force and approximately 8% of the informal employment sector [24].

Little research has been conducted, and there is a lack of data on issues related to HIV in the domestic work sector. Domestic work is a large sector of employment for women from marginalised backgrounds [21]. Domestic workers are rendered vulnerable to HIV as a result of their gender, migration, social isolation, poverty, low levels of education, and lack of access to healthcare services [25]. It is therefore important to investigate work-related disclosure and stigma, particularly in countries with high prevalence of HIV. Studies conducted with employees in the workplace have generally ignored domestic workers because of the informal nature of their employment. Moreover, the isolated nature of domestic work in which each worker is employed in a different household, makes it difficult to develop specific HIV prevention and health interventions that target domestic workers. Nevertheless, we hypothesised that the high stigma and discrimination against HIV positive workers that exist in many work sectors [26, 27] also affect domestic workers to a large extent.

However, there is dearth of data on HIV disclosure in the workplace in South Africa and sub-Saharan Africa in general. A few studies have examined disclosure in the workplace in developed countries, but, even there, research in this field is still in its early stages [1]. The individual experiences of workers on disclosure remain under-researched [3]. As such, there is limited literature that provides insight into the lives of domestic workers in relation to HIV. This study, therefore, explored the context within which domestic workers would disclose or conceal their HIV status in the workplace setting and examined the outcome of disclosure to their employers. The findings will highlight the need for open discussions about the vulnerability of domestic workers in the workplace and provide greater understanding about the complexity of workplace disclosure to implement coping strategies [1].

**METHODS**

**Study design and setting**

An exploratory qualitative study using focus group discussions (FGDs) was conducted in health facilities in Metropolitan Municipality in South Africa. The municipality falls under the Gauteng province and is highly urbanised with about 99.4% of the population living in elite residential suburbs. At the time of the field work the municipality had about 450,000 people living with HIV and about
167,698 receiving lifelong antiretroviral therapy (ART) in the selected health facilities. All facilities in the municipality offer a comprehensive package for HIV services for adults and children. The research population consisted of HIV-positive domestic workers who were accessing ART services in the facilities. The study used purposive sampling to recruit domestic workers to participate in FGDs. The researcher selected information-rich cases related to the topic under investigation to answer the research question [28, 29]. Participants were recruited for the FGDs by the lead author in collaboration with the facility managers. To be eligible for participation in the study the participants had to be female, aged between 19-60 years, diagnosed with HIV for six months or more, and on lifelong ART. Sampling was done to achieve diversity and the sample consisted of domestic workers of varying ages, with different citizenships, living with their employers, and those traveling to work from home.

Data collection
The FGDs were moderated by the lead author (EP), hereby referred to as the moderator, and a research assistant experienced in conducting FGDs. Additionally, the research assistant was trained on the objectives of the study and the focus group guide under the guidance of the last author (SM). A semi-structured guide with open-ended questions and possible probes was used. The participants were asked four broad questions: (1) views about disclosure in the workplace, (2) intentions to disclose their HIV status to the employer, (3) reactions of the employer to those who disclosed, and (4) the impact of disclosing on their relations with their employer. In addition, other follow up questions and probes were asked to clarify the responses that were given by the participants. The focus groups were conducted in a private room allocated by the facilities to ensure privacy, were audio-recorded with the permission of the participants, and conducted in either English or IsiZulu. The use of the local language ensured maximum participation as the responded in the language that they were comfortable with. Each FGD consisted of 5-6 women and lasted for about 45 to 60 minutes. The number of FGDs conducted was determined by saturation and stopped after six FGDs were held with a total of 32 participants. Data saturation was considered to have been achieved once the FGDs were no longer generating new information to contribute to the understanding of disclosure practices [30, 31]. The focus groups were conducted after the participants had finished their medical check-ups to avoid disruption of the clinic routine. A short tool containing questions on demographics was administered at the end of the interview.

Data analysis
The audio recordings of the FGDs were transcribed verbatim and those conducted in IsiZulu were translated into English by the lead author and the researcher. The thematic approach as described by Braun and Clarke [32] using both inductive and deductive approaches was employed. The deductive approach used a priori codes from the focus group guide. For the inductive approach, analysis began with the authors reading the transcripts several times to identify initial emerging codes and emerging themes to develop a framework for a codebook. After consensus about the definitions of themes had been reached by the authors, the codebook was finalised and coding was applied to the remaining transcripts using the NVivo [QSR International, Melbourne, Australia] qualitative data analysis package, which was utilised for the analysis process. Analysis continued until deep and rich themes and sub-themes that described the disclosure experiences of the participants had been achieved.

To ensure rigor and trustworthiness, we used several strategies to satisfy credibility, transferability, dependability, and confirmability as described by Guba and Lincoln [33]. We conducted the FGDs in the local language and used a good digital recorder to enhance verbatim transcription of the responses to reflect the participants’ experiences of disclo-
singing to their employers. In addition, we used NVivo qualitative software to analyse the data and all the authors analysed the data to ensure that the interpretations were free from investigator bias. The lead author kept a detailed audit trail with thick descriptions of the research processes and procedures.

**Ethical considerations**

Ethical clearance for this study was obtained from the Medunsa Research Ethics Committee (MREC) of the University of Limpopo (MREC/H/148/2012/PG). The Municipality Research Ethics Committee and the facility managers of the health facilities gave permission to collect data. Participants provided written informed consent.

**RESULTS**

**Participant context**

Table 1 presents the socio-demographics of the participants. The sample consisted of 32 domestic workers who participated in six FGDs; all were females with ages ranging from 20-60 years. Almost half (15 out of 32) were aged between 40-50 years, with the majority (23 out of 32) being single. Most (21 out of 32) had secondary education, 15 had completed grade 12, and only three had tertiary education. Nine of the 32 participants were immigrants and most (19 out of 32) were living with their employees.

**Emergent themes**

Figure 1 is a thematic representation of the themes that emerged during the analysis of the focus groups. Two major themes emerged; (1) Nature of relationship with employer and (2) Disclosure intentions.

**Nature of relationship with employer**

The nature of the relationship with their employer played a significant role in informing the participants' decisions on whether to disclose or conceal their HIV status. The narratives of the participants revealed that having positive relations with the employer did not necessarily translate into disclosing their HIV status.

“My relationship with my employer is okay because we are able to talk but not about everything because I have not told them about my HIV status or my sickness. I do not see the need to tell them anyway.”

(Participant 1 FGD 1)

“Our relationship is good; we are able to talk about everything as such I have told her about my status and she did not have a problem with that. She does not give me any problems with anything and takes care of me.”

(Participant 1, FGD 2)

However, a few participants expressed different views about their relationship with their employer. They reported that the relationship that they had with their employer was not good and spoke about the employer's attributes that make their relationship difficult.

“They are so rude..., they see it [HIV] as a serious illness and as if you are an animal, it is difficult.”

(Participant 1, FGD 3)

“Mine is cruel they don’t want to even touch my food, when you touch bread they don’t want to touch. The relation is about doing chores and nothing else.”

(Participant 4, FGD 6)

**Invasion of privacy**

The relationship with the employer for some of the live-in domestic workers is characterised by the lack of privacy. Most participants indicated that their employers invade their privacy and often enter and search their quarters without their permission. They expressed anxiety over possible unintentional disclosure for participants who did not intend to disclose. Their narratives revealed strategies that they used to conceal their ART medication to disguise their HIV positive status.

“I put my treatment under the clothes because I don’t want them to see the type of treatment that I am taking. I will never put them openly because they come to my room when I am not there.”

(Participant 5, FGD 2)
Table 1. Sociodemographic and work-related characteristics of the participants.

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Figure 1. Summary of themes and sub-themes.
“I hide them [ARV] in my wardrobe where she can't see them, underneath my clothes and place my high blood treatment where she can see them in case she comes to the room.”
(Participant 1, FGD 2)

“I keep mine [ARVs] in the toiletry bag and I put the high blood pressure pills freely on the dressing table.”
(Participant 2, FGD 4)

Deceptions and lies
The relationship between the domestic workers and the employers was also characterised by lies and deception in an attempt to conceal their HIV medication and routine clinic visitations. The narratives revealed that considerations regarding disclosure involved the need to protect their HIV status, which also entailed protecting information about their medication and frequent clinic visits.

“Sometimes when I have to come to the clinic I say that I am going to home affairs, sometimes I say I am going to see my children’s schoolteachers because they want to see us at their schools. Every time I have to make a plan, sometimes I just say there’s the doctor’s note am sick and will return with a letter from the clinic and fill in the form.”
(Participant 3, FGD 3)

“I tell them that am going for my family planning and general body check-ups.”
(Participant 2, FGD 5)

“The granny is too inquisitive…, they only know that am taking treatment for high blood pressure.”
(Participant 2, FGD 6)

Disclosure intentions in the workplace
The study explored the intentions of participants to disclose to their employers. Their narratives reflected a myriad of issues that contributed to making this decision. Some considered the possible negative impact their status would have on their work environment, while others were persuaded by the possibility of getting support from their employer. Two sub-themes emerged from the data, namely the need to tell and reluctance to tell.

The need to tell
A desire for acceptance and support propelled some participants in wanting to share their HIV positive status with their employers.

“My relationship with my employer is good because we are able to talk about everything and anything as such I have told her about my status and she did not a problem with that and takes care of me.”
(Participant 1, FGD 2)

“I think it would be good to disclose your HIV status to your employer because she will be able to take to you to the doctor like mine. Mine took me to the doctor when I got sick and there after I was able to tell her about my status and now she looks after me when am sick. When I am tired I am able to tell them that I am tired I need to rest and they allow me to do that with no problem.”
(Participant 1, FGD 1)

Outcome of disclosure
Participants who felt the need to disclose their HIV positive status anticipated a positive reaction from their employer. However, data showed that the outcome of disclosure was twofold where some received support and acceptance and others faced the harsh reality of losing their jobs.

Acceptance and support
“...She was fine, receptive of me because she is able to remind me of my medication and takes care of me. She asked whether it is infectious and I explained it to her.”
(Participant 2, FGD 1)

“I got sick and they [employer] took me to the doctor, after that the doctor referred me to the clinic and when I came back, I told her. She takes care of me and when I don't feel okay I am able to tell her that I am tired and she accepts it and tell me to rest.”
(Participant 1, FGD 4)

Positive reaction to disclosure encouraged adherence and compliance with clinic dates. The participants reported that they felt free since they had disclosed.
“I always come to clinic on my day offs so I don’t have a problem with that. I am able to drink my medication freely and she [employer] does not have a problem when I tell her am going somewhere.”

(Participant 2, FGD 1)

Loss of job

“I came to the clinic and they tested me and she phoned whilst I was in the clinic to check where I was and that’s how I was dismissed, I was tested positive and I was dismissed thereafter, they dismissed me after I told them, when I was about to start the ARV treatment.”

(Participant 2, FGD 3)

Reluctance to tell

The data revealed that, despite reported good relations between some participants and their employers, they remained reluctant to disclose. The participants expressed fears that their work environment might change following disclosure to the employer.

“It is not easy to tell them because they have children, I thought they would change because of them having children; the relationship is good because they are good people.”

(Participant 3, FGD 3)

“At first I felt bad for not telling but I told myself that telling was going to destroy people. I am not happy to keep it a secret but I don’t feel like it would be good for me. I feel for them but they do not feel for me, I’d rather keep it a secret.”

(Participant 4, FGD 5)

Concealment of the HIV status was also as a result of knowing domestic workers who experienced negative reactions from employers after having disclosed their status.

“I will not talk because I see how badly people who have disclosed their HIV status are being treated by either their employer or their children.”

(Participant 1, FGD 2)

Fear of dismissal or job loss

The participants expressed how the fear of losing employment and being treated differently in the work place influenced their decision not to disclose to their employers.

“I will never disclose because they dismiss us, they have put this fear of dismissal in us otherwise I would have disclosed long time if ever they were not dismissing us. People change they might say no we won’t dismiss you but I know that people do change. So never will I tell them my employer who always say that she does not care whether she is been assisted by someone who is HIV positive as long as she is clean, but I will never disclose because they can change along the run.”

(Participant 1, FGD 3)

“I won’t tell her because I don’t know how she’ll treat me and she might dismiss me, my job is to take my treatment correctly and consistently.”

(Participant 1, FGD 2)

“I fear to be dismissed more than anything.”

(Participant 4, FGD 5)

A sense of guilt was expressed by some of them for not disclosing, but the fear of dismissal overcame this feeling.

“You do feel guilt and if they do discover that you are positive and have kept it secret, you might lose your job. I am afraid of the children as well although they are good people, they might dismiss me and where would I live, and what about my children.”

(Participant 5, FGD 6)

“I do feel guilty but I will never tell them because you can hear as they talk about HIV in general that they are against people living with HIV.”

(Participant 3, FGD 6)

The experience of previous dismissal after disclosing was a deterrent for disclosure in the current and future employment.

“So I will not tell them, they will dismiss me. I was employed by someone whom I told and they dismissed me for my status. So…, I just don’t think that I would ever tell my employer about my HIV status.”

(Participant 5, FGD 6)
“My previous employer dismissed me for disclosing so I will never disclose to any employer again.”
(Participant 2, FGD 2)

“I told her that I had TB…, I took treatment for nine months, when I finished my nine months treatment I went back to her and ask back my job but she told me that she will phone me, but to date she has not phoned me. I started to look for another job as I am now working for ten months in this new job, I am now dishonest to this new employer because I fear the same. I am a breadwinner at home for five people.”
(Participant 2, FGD 4)

Fear of discrimination
Participants expressed the fear of being treated differently as a reason for not disclosing to their employers.

“I don't think I will disclose because some of these employers think that when you are sick you are going to infect them and they will start to treat you bad, they think that when you touch their food and when you cut yourself you'll give them HIV and that's all they think of.”
(Participant 5, FGD 4)

“I think they would chase me away; they can treat me badly, when I tell them that am sick they think that I would give them my germs.”
(Participant 3, FGD 5)

One participant shared her experience of discrimination after disclosing to her previous employer.

“They stopped me to do other chores…, they told me to only do washing and stop cooking or doing other things and to come twice a week. Thereafter they said I must stop coming they will tell me when to come….bay that's where I told myself that it's because of the HIV that I was dismissed.”
(Participant 5, FGD 6)

Some of the participants narrated acts of stigmatisation and discrimination that they experienced from their employers despite not having disclosed their HIV status. This made them determined not to disclose.

“If I do disclose they might view me in another way and treat me in another way, if I cough or have some flu, she tells me to stay home”.
(Participant 3, FGD 3)

“Mine is cruel they don't want to even touch my food, when you touch bread they don't want you to touch it. The relation is about doing chores and nothing else.”
(Participant 4, FGD 6)

“Not long I has rash like allergy on my face, my job entails that I should bath the children before I go home, they told me not to bath the children she would do it herself…, you see…, and she does not like me sick. As a widow I am working for the sake of wanting money as I do want to live and be independent otherwise I would have stayed home and not work.”
(Participant 4, FGD 6)

DISCUSSION
The purpose of this qualitative study was to explore how HIV positive domestic workers experience disclosure to their employers. Traditionally, in South Africa domestic work is performed by marginalised and poor black women for middle- to upper-class households. The relationship between employers and their domestic workers in the South African context is complex, distinctly gendered and informed by varying issues of class, race, culture, and power asymmetries [23, 34, 35]. Generally, domestic workers are marginalized and powerless because of the invisible nature of their work that takes place behind the walls of private homes. Gobind et al [20] assert that the private home deprives the domestic workers of free interaction with other workers or trade union representatives. However, in the current study, most domestic workers reported a positive working relationship with their employers. The findings are comparable to those reported in a other affluent suburbs of South Africa [36]. Of note is that the reported good relationship with the employer did not translate into disclosure, as most (26/32) had not disclosed to their employers. Living-in with the employer adds further dynamics to the employer relation-
To protect their HIV serostatus, they resorted to silence, lies, and deceptions. Domestic workers are silent about many things in their domestic work relationship [35], they find it difficult to talk about issues that did not relate directly to the work with the employer [36]. To prevent unintended disclosure, they conceived ways to hide their ART medication and lied about the reasons for visiting the clinic. They further substituted HIV with chronic diseases like high blood pressure and diabetes mellitus. Page-Ship et al [11] reported similar practices. In their study, workers accessing workplace HIV care programmes would rather be seen as TB sufferers than to be seen as taking ARVs.

Disclosure to the employer was considered a possible cause for dismissal by domestic workers in the current study. Fear of job loss was the most common reason for all the domestic workers who did not disclose. The concealment of the HIV status takes place against the backdrop of unfair dismissal that is an ever present challenge in the domestic work sector. The Joint United Nations Programme on HIV and AIDS suggests that many employers fear that, if their domestic workers are infected with HIV, this might place their families at risk [37]. Generally, low job category workers in all work sectors are reluctant to disclose to the employer for fear of losing their jobs [3]. We found that the fear of disclosure to the employer was real to some of the domestic workers. The data revealed that one of the domestic workers lost her job following disclosure and others were dismissed by the previous employers after disclosure. Their past disclosure experience was a deterrent for disclosing to their current employer. Dismissal of employees because of their HIV status has been reported in other work sectors [3, 16].

Although a few domestic workers in the current study were aware of some aspects of labour laws, du Toit [38] argues that domestic workers continue to be exposed to inhumane treatment such as being tested prior to employment. There are legislative frameworks like the Basic Condition of Employment Act, No. 75 of 1997 (BCEA) that provides domestic workers and other lower income employees with protection within their employment contexts [39]. However, domestic workers have very limited information about their rights. As such, they remain silent when they are confronted by unfavourable work conditions because of fear of job loss [36, 40].

What compounds the matter where domestic work is concerned is that legislative protection is difficult to monitor and enforce in private households [22].

As stated, stigma plays an important role in interactions in the work environment [1] making disclosure in the workplace risky for PLHIV. We found that the fear of stigma and discrimination were deterrents to disclosing to the employer. Similar observations were reported in other work sectors [3–7]. Not only were the domestic workers afraid of perceived stigma and discrimination, some were exposed to or experienced acts of stigma and discrimination from their employers. The acts of stigma occurred without the domestic workers having disclosed, but whenever they experienced any sort of illness like coughing. Their narrations showed that they were stopped from doing chores like cooking and bathing the children. Similar observations were
reported among domestic workers in Bangladesh, majority were dismissed or were exposed to severe discrimination and stigmatisation after disclosure to the employer [18].

Concerning disclosure of HIV status, only a few domestic workers reported that they disclosed to their employers. Disclosure was influenced by having a good relationship with the employer, their failing health status, and the need for support. However, only a few of them received a positive reaction and were accepted by the employer following disclosure. They were given time off for routine clinic visits and time to rest when they were not feeling well. Studies conducted in other work sectors reported that employees who disclose their HIV status receive empathy, less workload when they were not well, and time off for their treatment and clinic attendance [3, 8, 10]. It should be noted that these benefits were observed only in cases where the employers reacted positively to disclosure.

**Study limitations**

The sample size for the current study was very small and the study used qualitative research, so there is a need for much bigger study samples using qualitative and quantitative methods to further investigate disclosure among domestic workers. Investigating the views of employers on disclosure and their reactions to learning about the HIV status of their domestic workers is crucial. Interventions should consider both views to address the fear of disclosure in the workplace while also addressing the employers’ fear of HIV transmission.

**CONCLUSION**

Disclosure to the employer was considered a possible cause for dismissal by domestic workers. We found that most had not disclosed to their employers and had no intentions to disclose in the future. Fear of job loss was the most common reason for concealing their HIV status from the employer. The threat of dismissal was distressing for most of the domestic workers, whereas for some the threat of dismissal was real.

We further found that living in the employers’ household increased the risk of unintended disclosure for domestic workers due to the lack of privacy. This affected the relationship with the employers post diagnosis with HIV which was characterised by silence, lies, and deceptions about many issues of their illness. The use of silence when confronted by unfavourable work conditions perpetuates the vulnerability and marginalisation of domestic workers.

Given that people discriminate and stigmatise when they do not have adequate HIV-related knowledge, the acts of stigmatisation experienced by the domestic workers call for specific HIV prevention interventions that focus on the domestic work sector.

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