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SEX WORKERS VIEWS ON PRE-EXPOSURE PROPHYLAXIS IN SOUTH AFRICA:
the influence of trust and stigma

Coriëtte van Hoek, 5808766

Social Policy & Social Interventions

First assessor: J.B.F. de Wit

Second assessor: T. Knijn

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Universiteit Utrecht

Abstract

In South Africa, sex work is criminalized, exposing sex workers to stigmatization and discrimination. Stigmatization is found to impede access to healthcare, making sex workers particularly vulnerable to HIV infection. Sex workers are a high risk group for HIV: 60 to 70% of sex workers is estimated to be HIV positive. Recently, Pre-exposure Prophylaxis (PrEP) has been introduced in South Africa as a new HIV prevention method and made available for sex workers. Taking PrEP consistently can decrease the risk of getting HIV by more than 90%. Since PrEP is relatively new and is not broadly distributed in South Africa, not everyone knows about it yet. Important factors in the acceptance of PrEP are knowledge about it, positive promotion, trust in the healthcare system and its workers, and faith that a medication will benefit you. So far, PrEP has not been generally accepted by sex workers,. This qualitative researched focuses on social factors that influence sex workers views on PrEP, specifically on the role of stigma and trust. To uncover the dynamics between stigmatization, trust in healthcare and views on PrEP, key stakeholders were asked about their opinions and experience with sex workers and PrEP. Seventeen semi-structured interviews were conducted with health professionals and peer educators, either over the phone or by Skype.

Thematic analysis revealed four relevant themes by which the results were structured: (1) *awareness* of PrEP and health knowledge are key in acceptance, (2) structural *stigmatization* of sex workers impedes on access to care, (3) *trust* in healthcare and healthcare workers is shaped by experiences of stigmatization and discrimination and (4) *the position of sex workers* in society impedes the potential benefit of PrEP. It can be concluded that education for both the sex worker and non-sex worker population, sensitization of healthcare professionals and the decriminalization of sex work could increase PrEP acceptance among sex workers.

Introduction

Over the last 40 years, the Human Immunodeficiency Virus (HIV) has spread widely, especially through South Africa, which with almost 7 million people infected, is the country with the largest number of people infected (Joint United Nations Program on HIV/AIDS [UNAIDS], 2015). A population with particularly high prevalence is people working in the sex work industry. There are several factors which put sex workers at a high risk of contracting HIV, such as substance abuse, violence (both physical and sexual), having a higher prevalence for STDs, having multiple and changing sexual partners, and having limited access to health care services (Aids Fonds, 2016; Fisher, Bang & Kapiga, 2007; Halperin & Epstein, 2006; SANAC, 2016). Reportedly almost 60% of all sex workers in South Africa is HIV positive (South Africa National Aids Council, [SANAC], 2015). Several reports show that HIV is also transmitted from and to the general population, adding to the need for workable prevention methods (e.g. Gould & Fick, 2008; Scorgie et al., 2013). Condom use has been promoted to stop HIV transmission and although sex workers in Sub-Saharan Africa report high levels of condom use, infections rate show it is nowhere near sufficient to end HIV (UNAIDS, 2016).

Now there is PrEP (pre-exposure prophylaxis), a combination of two antiretroviral medications which have to be taken daily to reduce the chance of HIV infection by more than 90% (Anderson et al., 2011). Trials with PrEP show promising results but there are several challenges for acceptance among sex workers. The criminalization of sex work, violence, the regular testing, the fear of being labeled as sick when taking medication, stigmatization and distrust in health care are factors that can make one decide not to take PrEP even when they are at substantial risk for HIV (Venter, Cowan, Black, Rebe & Bekker, 2015).

People at a substantial risk of HIV are likely to be traumatized and mistrusting (WHO, 2015). The study by SANAC (2011) shows that stigma and discrimination and mistrust are the main barriers for sex workers to get tested or treated for HIV, suggesting that stigma and trust could also play a substantial role in PrEP acceptance. Additionally, several publications highlight the need for research on PrEP, specifically on the experienced stigma and other social factors influencing PrEP use (Celum et al., 2015; WHO, 2015; Eaton et al., 2017). More insight into the social factors influencing PrEP acceptance among sex workers will contribute to creating policy and setting up PrEP related interventions for South Africa that help eliminate HIV. Sex workers and stakeholders experiences are needed to discover how PrEP can benefit them and what pitfalls there could be. In this study, the dynamics of stigmatization and trust in healthcare and the influence on the acceptance of PrEP by sex workers will be explored.

Theoretical framework

The possible impact of PrEP

Several reports show and predict that PrEP could have many benefits for its users and beyond. The greatest benefit of PrEP is that it has the ability to prevent further spread of the HIV virus. PrEP could make it possible for sex workers to protect themselves against HIV despite structural barriers and prevent new HIV infections (Anderson et al., 2011; Cowan & Delany-Moretlwe, 2016; Venter et al., 2015; WHO, 2015). PrEP can be taken daily, independent of sexual activity. Police and clients don't have to be informed or involved in PrEP use, and financial troubles no longer form a barrier to using protective measures (Cowan & Delany-Moretlwe, 2016). PrEP user also report feeling calmer and less worried about possibly infecting a potential partner (Ware et al, 2012). Even a small PrEP uptake could increase the impact of existing HIV interventions for female sex workers (Bekker et al., 2015). Also important is providing PrEP to the most vulnerable groups, groups at a substantial risk of HIV infection, is most likely to be cost-effective (WHO, 2015).

These articles mainly emphasize the promises of PrEP, but there is another side to it. Wrong implementation of PrEP could lead to increased stigmatization (WHO, 2015). Other research among MSM show increased sexual risk behavior when taking PrEP, indicating that risk-compensation behavior by sex workers might be underestimated (de Wit et al., 2015). Furthermore, a prerequisite for PrEP to become a well-used prevention method is acceptance of the new drug. So far, uptake of PrEP among risk populations remains a challenge (Cowan & Delany-Moretlwe, 2016).

The position of sex work in South Africa

Criminalization of sex work stems from the disapproval of sex outside marriage or promiscuity. Although sex outside of marriage is no longer illegal, the law prohibiting sex work remains (Martins, 2007). Sex work, defined by Bekker et al. as ''exchange of sex for money or goods'', in South Africa has been criminalized since 1957 (Bekker et al., 2015). The Sexual Offences Act (23 of 1957) states that it is a crime to commit an act of 'indecency' or to have 'unlawful carnal intercourse' with any person for reward. When one has sex with someone other than their spouse, it is considered 'unlawful carnal intercourse', and selling sex as well as buying sex is criminalized under this law.

Criminalization of sex work makes it very difficult for sex workers to protect themselves. HIV prevention methods are available, the main one being condom use in combination with regular health check-ups, counseling on proper usage and regular testing (Scorgie et al., 2013). Protection through

condom use is not always possible for sex workers and they are used inconsistently (Fisher et al., 2007). More money can be offered for condomless sex, and in those cases sex workers have to make a trade-off between being protected and earning money. Additionally, ex workers are often met with resistance when they insist on condom use, or worse, with threats and violence (Wojcicki & Malala, 2001). When sex workers are confronted with situations of discrimination of violence in their work situation they lack means of enforcing justice. How can they go to the police when what they are doing is illegal and disapproved of (Pauw & Brener, 2003)? This is a cause for mistrust among sex workers towards authorities and enforces stigma on sex workers (Commission on Gender Equality, 2013). This reciprocal relationship between the criminalization of sex work in South Africa and the stigma on sex work largely shapes the societal position of sex workers.

The double stigma regarding sex workers

Stigma is defined by Erving Goffman (1963) as an attribute that someone has that makes that other people perceive that person as negative or undesirable. Social settings allow people to set standards for what is considered to be normal. In case of stigmatization, one's identity is reduced to that attribute that deviates negatively, instead of also taking into account other characteristics. This is usually a subconscious process (Goffman, 1963). Goffman first published about stigma in 1963 and this conceptualization was extended by Link and Phelan (2006), who added five components of stigmatization. The first component is labeling other people because of a certain attribute they have is not common and therefore 'different', and this is dependent on social constructions in society. The second part is the grouping of people who have a certain label, called stereotyping. This separation then leads to a notion of 'us' and 'them', which can be said to be discrimination. One's identity is discredited and they can be socially excluded. The last step of the process of stigmatization is that people can exercise power over others based on the stigma that lies on them (Link & Phelan, 2006).

Stigmatization is complex and integrated with South African culture. Gender attitudes, for example, also play a role in this stigma: while in South Africa it is accepted for a man to have multiple sexual contacts, a woman will be stigmatized for this (Delius & Glaser, 2002). This individual-level stigma is imbedded in the structural stigmatization of sex workers (Hatzenbuehler, 2016). This is visible in policy (sex work is criminalized) and in societal norms about sexuality (Hatzenbuehler, 2016; Martins, 2007). Living with structural stigmatization has a large impact on one's self-esteem and can be a source of stress.

The Global Network of Sex Work Projects (2015) reports that stigmatization occurs in healthcare settings and that sex workers are being treated unfairly, rude or not at all by health care workers because of their occupation. Sex workers express distrusting the clinic staff to keep their HIV

status confidential and fear that they will not receive proper care when going to a state clinic (NSWP, 2015). For sex workers, the stigma is two-sided; they are stigmatized for being sex worker and are associated with HIV. Stigma regarding disease has been around a long time, it's main root being misinformation about the causes of the disease (Herek, Capitiano & Widaman, 2002; Sontag, 1978). This stigmatization by healthcare workers causes sex workers to be hesitant to visit clinics and to be honest with the staff about their problems (Dunkle et al., 2005).

Trust in a healthcare setting

When seeking care, people tend to look for someone they feel they can trust to take care of them (Carr, 2001). Gilson and colleagues note that important requirements for trust are respect and partnership, which can be expressed in various ways. To communicate respect it is important that patients are heard and that their knowledge about and experience with their own body is valued. Respectful treatment encompasses fair treatment as well as a positive attitude and thoroughness from the healthcare provider (Gilson, Palmer, Schneider, 2005). Partnership is about the patient and the healthcare provider sharing knowledge and understanding of the disease (HIV) and of the patients life experiences (Dawson-Rose et al, 2016). Trust is needed both at the institutional level (practices and procedures) and the interpersonal level (provider behavior) (Gilson et al., 2005). Building this trust takes time but restoring trust even more effort (Carr, 2001). Specifically related to HIV care, trust at these two levels, between care provider and patient and trust in healthcare and government, was indeed identified as important for healthcare access (Cunningham, Sohler, Korin, Gao, & Anastos, 2007). In addition to access, trust is necessary to accept treatment from a practitioner. This trust is necessary regardless of the objective expertise of the care provider (Semmes, 1991).

Acceptance of new medication

Trust in healthcare, healthcare providers and trust that a certain medication will benefit you are important requirements for acceptance of new medication, as well as knowledge about the medication, the feeling of choice and positive promotion (Delany-Moretlwe et al., 2016; Gilson et al., 2005). For example, a major challenge in introducing voluntary testing and counseling (VTC) were lack of knowledge about HIV transmission, what testing could mean and lack of trust in counselors and healthcare services (Baiden, Akanlu, Hodgson, Akweongo, Debpuur & Binka, 2007).

There are lessons to be learned from the acceptance of birth control that can be applied to PrEP. Slow acceptance of a new medication should not be seen as a sign that it is not feasible for general usage (Delany-Moretlwe, et al., 2016). After all, poor adherence and slow uptake as well as concerns about decreased use of protective measures (e.g. risk-compensation) were big challenges when contraception was introduced. Today, more than fifty years later, is it widely accepted as birth-control. This process of accepting new medication or new medical technologies can take some time, as seen with contraception and VTC, and can especially take long if the new medication works differently from known methods (Bass, 1969). In the case of PrEP, medication as prevention is a different approach than earlier prevention methods, and this may be met with hesitance.

Gilson's explanation of acceptance of new medication is relevant but limited. It does not question if one should always aim for acceptance, while this is relevant for PrEP. It should be considered whether it's social implications might weigh up to the medical benefits. (Krakower et al., 2012). Secondly, it is limited in the sense that it does not take into account certain beliefs people might have about the medication. The *necessity concerns framework* theorizes that there might be certain beliefs about the necessity of the medication, and certain concerns. Limited belief of necessity and high believe for concerns are related to the rejection of medication or treatment (Horne, Weinman & Hankins, 1999). A big concern during a study into Antiretroviral Therapy (ART) was potential side effects of the treatment (Horne, Cooper, Gellaitry, Leake Date & Fisher, 2007). Based on this research one might assume that beliefs about PrEP and HIV might influence how PrEP is perceived.

Research question

Important factors that can influence PrEP acceptance have been identified: access to healthcare, knowledge of and about the medication, positive promotion of the medication. trust in healthcare and healthcare workers, stigma and the feeling of choice (Delany-Moretlwe et al., 2016; Gilson et al., 2005; Horne, Weinman & Hankins, 1999). Stigmatization and trust have played a large role in the acceptance of anti-retrovirals (ARV), and are expected to play a large role in the acceptance of PrEP as well (SANAC, 2011). This research aims to provide insight into how sex workers in South Africa view PrEP and the dynamics of stigmatization and trust in the process of acceptance. Experiences and opinions of peer educators and healthcare professionals, people who work closely with sex workers, will be studied. More insight into the social factors influencing PrEP acceptance among sex workers will contribute to creating policy and setting up interventions for South Africa that help eliminate HIV. Participants' experiences will make the role of stigma and trust in the rejection or acceptance of PrEP visible. Thus, research question is:

What are the views of sex workers on PrEP as an HIV prevention method and what is the role of stigma and trust in the process of acceptance in South Africa?

Methods

Study visit

Before conducting a study into a population from a country unknown to the researcher, it is important to familiarize oneself with the context of that country. Therefore a six-week study visit to South Africa was undertaken to get a better understanding of the context sex workers live in and to have the ability to visit key organizations and informants in person. The Wits Reproductive Health Institute (WRHI) facilitated meetings with health professionals such as program coordinators, nurses, pharmacists and researchers. Additionally, several clinics were visited in Johannesburg, Pretoria, Cape Town and Durban, where connections with peer educators were made. These visits were organized in cooperation with Aids Fonds and North Star Alliance. Peer educators in this setting are (former) sex workers who are recruited and then trained in health care knowledge and communication skills. The peer education system is used at different clinics and activist organizations in Johannesburg, Cape Town and Pretoria. Their network allows these organizations to get in contact with otherwise hard-to-reach groups. This participatory approach allows for effective promotion of healthy behavior and more sex workers getting tested and treated for HIV (Ngugi, Wilson, Sebstad, Plummer & Moses, 1996). The study visit was successful in providing information about PrEP as a prevention technique in the context of sex work in South Africa and informed interview topics.

Participants and procedure

The aim of this research was to get insight in how sex workers view PrEP and how trust and stigma influence acceptance. Because sex workers are a vulnerable population they were not asked to take part in this research; instead stakeholders participated. Stakeholders can be a valuable source of information to confirm and validate the results of the interviews with the target population and can offer a broader context in which to place participants experiences (Quinlan, Kane & Trochim, 2008). The appropriate and most feasible way to get insight in sex workers' experience with and views on PrEP was to conduct interviews with these stakeholders. This qualitative method provides the possibility to gain in-depth information and is likely to raise the issues that are most important (Hollway & Jefferson, 2000). Participants were selected through contacts acquired during the study visit. They were approached via e-mail or text message with an explanation of the research and after confirming understanding of the research were asked to participate. Appointments were made at time and date of their preference. Interviews were semi-structured, meaning that standardized questions and probes were used to explore each topic, but they were not brought up in set order and follow-up questions were asked (Hollway & Jefferson, 2000). Data was collected between the 11th of May and the 22nd of June by means of interview by phone or through Skype from the Netherlands. The interviews were recorded using either a voice recorder or the recorder of a cell phone and transcribed. The interviews were conducted in private, in a closed room at the internship office. Participants were free in choosing a location where they felt comfortable doing the interview. During the interviews, notes were taken to reflect on interview skills and remarks from participants that stood out.

The sample consisted of seven peer educators, five health care professionals, two sex worker activists, one lay counselor and two sex worker community leaders chosen based on availability and accessibility, through convenience and snowball sampling. All participants came from either Cape Town, Durban or Johannesburg, and health professionals had different work and educational backgrounds. A list of all participants can be found in Appendix A. The sample consisted of 5 males and twelve females, all 25 years or older of age. Most peer educators, often still sex workers, in South Africa are women, around 90% (Aids Fonds, 2016). This is reflected in our sample which contained one male and six female peer educators.

Instruments

Following the study visit, a topic list was made based on theory and guided by experiences from South Africa. This topic list eventually resulted in two similar interview guides, which can be found in appendix B and C. The interview guides were different for health professionals than for peer educators and counselors because of the nature of their job and their different fields of knowledge. Since a fellow researcher was conducting research on a different subject in the same context, questions related to PrEP, my main topic, and questions about self-testing, the subject of a fellow researcher thesis were addressed by each researcher. Conducting interviews that included both topics provided an opportunity to acquire more data and to get a sufficient number of participants. This approach also prevented participants from being interviewed twice with a large amount of similar questions.

After an introductory part which handled consent and demographics, six main topics with several sub-topics were addressed, namely sex work policy, health responsibility, healthcare access, PrEP, self-testing and personal stories. All literature discussing health care for sex workers mentioned the influence of the legal climate of sex work, or sex work policy on stigma. I wanted to know how health professionals saw the influence of the criminalization of sex work of the healthcare access and if peer educators had also experienced this. Secondly, peer educators and professionals were asked about the accessibility of general health care, possible other care options for sex workers, about the quality of care, and by which means sex workers were informed on how to stay healthy. General HIV knowledge was also discussed. Awareness of healthcare options and good access to healthcare are essential for learning about and accessing PrEP. When discussing health care from both the provider and the user point of view, the question about who is responsible for health arose and was discussed. To learn first-hand about PrEP experiences, peer educators that were on PrEP were asked about their motivation to take it and possible difficulties. Healthcare professionals discussed uptake and received feedback on PrEP implementation and willingness to use. Lastly, peer educators were given the opportunity to share how they feel about sex workers position in society. This information allowed me to place their opinions in the context of their experiences through life.

Analysis strategy

To answer my research question, I found the most suitable analysis strategy to be thematic analysis. Data was analyzed by using Nvivo, a program to make qualitative data more insightful and structured. The first step was to identify main themes that would encompass most of the relevant data. Five general themes emerged when reading through the data and these themes were coded (Foley & Timonen, 2015). Since this method has a high dependency on interpretation I compared my themes

with the one my fellow researcher did. The themes that were found were largely similar and refined through the cooperation, enhancing reliability (Guest, MacQueen & Namey (2014). This was followed by more specific coding of every statement expressing views on PrEP and everything relating to stigmatization or trust, as to make the data more insightful. Reading through the interviews, subthemes were discovered and codes emerged during the reading process. Definite subthemes were eventually developed and were combined to fall under the main themes. This resulted in a coding tree that displayed the data and showed the relationship between the themes. Lastly, the findings were structured as to answer the research question.

Validity, reliability and reflection

A researcher always brings one's own beliefs, experiences, values and assumptions to the study. These also play a role in data collection (Moody, Darke & Shanks, 2000). Being a Dutch woman I am used to taking pills, hence the idea that taking pills could be difficult for someone was new to me. Although this experience did not influence the questions I asked it might have influenced the meaning I ascribed to the remarks about medication use. Other examples of factors that could have influenced my perception is that sex work is legal and regulated in the Netherlands, and that I was raised with traditional Christian values. By founding the interview questions on what I had seen and heard in South Africa and what I read in other research, I aimed to minimize the influence of my own presumptions on the research (Evers & de Boer, 2011). Fortunately, I was able to speak to a lot of people about what I had read in the literature during the study visit to South Africa. What I learned from the literature was in accordance with what I learned during that visit, making the eventual topic list more valid. For example, peer educators I met spoke about not visiting clinics due to unfair treatment compared to other patients. This was also mentioned as important for trust in healthcare by Gilson and colleagues (2003).

Adding to the validity is the cooperation with my fellow student in deciding on the topics. Since the interviews were semi-structured it left room to phrase questions differently, ask them in another order or ask additional questions (Hollway & Jefferson, 2000). This interview strategy ensured reliability of the answers because I could assure the participant understood the questions and that our conversation was flowing according to the topics the participants brought up. That way in each interview overall same topics were addressed, but not necessarily in the same order and detail.

Results

In this section the findings of this research regarding views on PrEP, stigma and trust will be presented. When conducting the analysis, I found that the stories that were told were in line with what was found in the theoretical exploration. The findings will be presented accordingly, structured by theme. The theme 'awareness' encompasses health knowledge, such as awareness of HIV status and treatment options, but also peer education, as this contributes to this knowledge, and sensitization efforts, such as awareness of sex worker needs among health workers. The theme 'healthcare access' contains mentioning of access difficulties and clinics that are accessible for sex workers. The theme 'trust', covers mentioning of trust or distrust towards healthcare, health care workers and the system as well as whether someone feels they can be open about their status as a sex worker. The fourth theme 'position of sex workers' encompasses mentioning of the consequences of criminalization, various forms of stigmatization or discrimination and violence. The relationships between these themes form a narrative that provides insight in the mechanisms that influence PrEP acceptance.

Awareness

Awareness of ones HIV status is an important first step in obtaining HIV treatment or prevention methods (Delany-Moretlwe, Mullick, Eakle & Rees, 2016). Program coordinators from Durban and Johannesburg estimated awareness of HIV status among sex workers as high, but not universal. General health knowledge seems to be limited and there and, as Jenny states, sex workers can be misinformed about health:

"Oh before I became a peer educator!! No! We learn from other sex workers. We were having the wrong information, not the right information," (Jenny, PE-J) [1]

Health professionals mention that awareness efforts are sometimes undermined by rumors about side effects of PrEP:

"And I think one of the pieces that we are interested in learning more about is sort of like the group thinking. One person experiences it [side effects] and because of the fabulous peer network does that become sort of amplified in the broader community." (Emma, HP-J).

[1] Codes indicate whether the quote is from a health professional (HP), a peer educator (PE), a community leader (CL) or an activist (AC) either from Cape Town (CT), Johannesburg (J) or Durban (D).

Peer educators related to a certain clinic mentioned side effects much more often than peer educators from a different clinic. A health professional had also noted this, and attributed the mentioning of side effects more to rumors than to actual experienced side effects. Faith (community leader) also mentioned that someone tried to convince her that PrEP was just a cover up that made an HIV test come up negative even when your status was really positive, making her have doubts about continuing PrEP. Research into PrEP trials conducted in Botswana indeed shows that rumors can affect medical decision making (Toledo, McLellan-Lemal, Henderson & Kebaabetswe, 2015). To make sure sex workers are correctly informed, the peer educators disseminate information about PrEP. They aim to provide health knowledge to all sex workers they can reach, to empower them in taking care of themselves. Peer educators confirm the health professionals' claim that the more people are educated on PrEP, the more they seem to be willing to take it, as predicted in early stages of PrEP research by Underhilll, Operario, Skeer, Mimiaga and Mayer (2010). Peer educators are successful in reaching other sex workers due to their (former) sex work status:

"A peer is on the same level and understands the same issues as you and has the same challenges you face. So that that person when it comes to having any support you need, can feel that challenge, can feel that pain." (Emily, AC-CT)

When it comes to treatment and prevention options, awareness seems to be varying. , According to health professional Emma, sex workers in urban areas seem to have more knowledge than sex workers in rural areas When asked about PrEP, healthcare professionals mentioned that the uptake of the drug had been lower than hoped or expected. The knowledge seems to be there, but understanding and acceptance are another thing:

"Yeah, you know what we find that a lot of them [sex workers] are aware of it [PrEP] but they don't actually know what it is. (...) it's almost like a lack of trust again. They are quite suspicious when people are pushing something, (...) and you know once they understand it fully and they have seen people on it then you'll find there'll be more acceptance of it [PrEP]." (James, HP-D)

Those interviewed that were not on PrEP could provide little information about what is was. The lack awareness about PrEP among non-users and non-sex workers seems to influence PrEP acceptance. The fact that participants reported that PrEP is mistaken for ARV's by other people is also indicative for this awareness gap. Activist organizations try to raise awareness to improve sex workers situation and reduce stigmatization:

" If they can educate people more or change laws then it will be easy for all sex workers to access the health facilities without stigma attached to them. Even for the work to be seen as professional as it

can, to see our work as any other profession that is there. Respect us, then it will be easy for us to get the stigma attached to us off." (Amelia, PE-CT).

Healthcare access

Awareness and healthcare access seem to go hand in hand and reinforce each other. This health professional from Durban describes it very well: when sex workers are aware that there are health service available for them, they will visit the clinic and learn more about their health:

"So they come in here just knowing (...) somebody. ...they actually come to our [sex worker friendly] centers, they're already aware that this is what we do,(...) and they're given good information regarding their health so they can take better decisions regarding their health." (Olivia, HP-D)

To provide more accessible care options some sex worker friendly clinics have been set-up. These clinics are essential for access to PrEP, but not always reachable by sex workers (Boudin & Richter, 2009). Participants were very positive about the quality of care and respectful and friendly treatment by the workers. Not everyone thinks this sex workers clinics are the solution and moreover, that they should not be needed for proper access to care:

"We don't want special rights. When we go to the clinic we want to be like any other community member." (Abigail, AC-CT).

Aside from these clinics, care options for sex workers are limited. Stigmatization, discrimination and refusal of treatment make it hard for sex workers to access proper care and treatment. As explained by a Mia, the structural stigmatization can be a source of stress (Hatzenbuehler, 2016). It makes sex workers reluctant to go get care at all, and their health can deteriorate:

"To coach women when they [sex workers] come to them [nurses] with these health issues…instead they make them feel more vulnerable. In some cases this might result in them staying at home, not going to the doctor, and they are sick! Some die in these cases!" (Mia, PE-CT).

Lafort. et al. (2016) indeed identified accessibility as a factor that influences whether sex workers seek care. Access to care is required for correct knowledge of PrEP, and needed to acquire the actual pills (Boudin & Richter, 2009).

Trust

The bad experiences some sex workers have in clinics influences the trust they have in health care, health workers and medication (Dunkle, 2009). Stories were shared about sex workers profession being revealed in a clinic, resulting in hesitance or refusal to visit a clinic again and feelings of mistrust. Emma (program coordinator) shared her experience about the influence of trust in accessing reaching health care:

"…because trust is an issue, there is...certainly many of these individuals have faced discrimination and other things and seeking health services and beyond in their lives, and sort of finding a place where they can feel comfortable, and are able to be themselves and can be open is, is a big piece of that." (Emma, HP-J)

Semmes (1991) theorized that trust is needed for acceptance of treatment from a clinician. An important requirement for trust in health care workers is being fair treatment and a positive attitude: respect (Gilson, Palmer & Scheider, 2005). Lack of respectful treatment leads to distrust, as a peer educator shares:

"I don't trust them! I just get there to get the thing that I want. I tell myself I am there to get better, to get my medication, to get tested if I am there to get tested. Then I'm just done with them." (Amelia, PE-CT).

Sex workers are very happy with clinics that offer specialized (and free) services to them because they feel free to talk about their lives and problems there, which is not the case for most government clinics. To get STI treatment, for example, sex workers will need to disclose they had unprotected sex, which could out them as a sex worker. Jenny shared an example of a friend who had to come in with STI's multiple times:

"She said to me: "I want to change facility because every time I can't explain" even if she's not feeling well, oh an STI, she can't tell the sisters." (Jenny, PE-J).

Trust in 'sex worker friendly' clinics is also not assumed because of stigma and bad experiences in other clinics. As noted by Carr (2001), building this trust takes time. The peer educators play an important role in building this trust:

"You know in the beginning there is always that issue of trust that we have to try and build up with them, and which is why we also got the sex worker peer educators coming in." (James, HP-D).

But when trust is built is can be strong. Health care professionals aim to provide quality care that is in the best interest of the patient. When sex workers experience they are being treated fairly, with a positive attitude and somebody listens to them without judging, they open up. As described by Dawson-Rose et al. (2016) being able to share life experiences enables trust. Especially when the healthcare workers make an effort to come to them, said community leader Faith:

"Yeah, I trust them too much. Yeah, I trust them. And the most [important] thing is they come to us. They come to you and eventually, when you are feeling sick you just go and tell them I'm feeling this, this, this and it's perfect, you know. I don't have to walk to their place, they will come to treat us." (Faith - CL-J)

Because the trust in (government) care and its workers seems to be lacking, sex workers also seem to be hesitant to trust the treatment (NSWP, 2015). Sex workers talk about being fearful of possible side effects PrEP could have and not fully trusting PrEP will benefit them.

Although she doesn't believe it herself, a community leader mentioned that she heard other people being afraid that PrEP is a way of 'hiding' sex workers.

"They are afraid of major side effects, like dying. They say that this tablet is no good, I think some people they are saying it is a side effect afterwards. Then I say that it's not here, I can't agree with those people, because how can other people make this tablet to hide us?" (Hope, CL-J)

As suggested by Dawson-Rose et al. (2016) and emphasized by all participating health professionals and peer educators, trust in PrEP seems to be higher when sex workers have more knowledge about it. Some sex workers are well informed, and this means that the attitude of mistrust towards PrEP is not shared by everyone:

"So some they are taking it, some are not taking it (…)" (Hope, CL-J).

The position of sex workers

The findings show that the position that sex workers have influences the way PrEP is viewed.. It has become clear that sex workers are being stigmatized regarding their profession. Their identity

seems to be reduced to one attribute, their sex work status, as described by Goffman (2009). This stigmatization often leads to some form of social exclusion and public harassment:

"So the society doesn't accept it at all. They don't stop, they think you are weird, they make jokes, they don't accept it, yes." (Maria, PE-J).

Stigmatization also happens in healthcare settings and this seems to influence PrEP use. Participants report that discrimination in clinics prevents them from going there and asking about PrEP. Hair (2015) has reviewed the relationship between stigma and PrEP use. This research confirms the relationship between the influence of stigmatization on healthcare access and the acceptance of PrEP. Although stigmatization is mentioned often, some participants report that times are changing and that more people are becoming accepting of sex work:

"Oh, they don't all think the same. Some people look down (on you), some people understand the situation, that they are people looking for money for their kids."(Lisa, PE-J)

The policy of providing PrEP to sex workers exclusively has directly associated PrEP with sex work. This means that the stigma that already exists around sex work is now extended to PrEP use. Sex workers can be hesitant to take PrEP out of fear it will reveal that they are sex workers:

"Because if I told you that I am taking PrEP and this is the prevention of HIV, and you know that I am staying with my boyfriend and he doesn't know what I'm doing on my back. He would say why are you taking this? Yah, so for those questions, I myself prefer to hide it. " (Jenny, PE-J)

The stigma on sex work is not only visible in societal norms but also in policy, making it structural (Hatzenbuehler, 2016). The Commission on Gender Equality (2013), identifies criminalization as an enabler of discrimination. When sex workers are being discriminated it is hard for them to go to the police or press charges because of the illegal status of their profession (Pauw & Brener, 2003). This leads to sex workers not reporting discrimination or violence:

"Sex workers get to be raped (...).You don't report these cases at the police station. You are denied access to legal assistance, so in that way, that's where the challenge comes in. In order for us to fight the HIV epidemic, the sex work needs to be decriminalized. Sex workers should be able to report such cases." (Abigail, AC-CT)

When sex workers are on PrEP, going to the police or getting arrested can bring even more trouble:

"And for us looking at PrEP, if PrEP is made for sex workers that will contribute more stigma. When a sex workers says to police officers: "I'm on medication, I need to take my PrEP medication", then police will know exactly that they are a sex worker." (Abigail, AC-CT)

Structural stigma is more extensive than societal norms and policy; it also reflects on ones self-esteem (Hatzenbuehler, 2016). Several peer educators brought up the struggle for a positive self-image while being stigmatized, and activists also see this with sex workers:

"Sometimes sex workers stigmatize themselves. If I'm in the clinic and the nurse is shouting at the people at the clinic, they will think it's because they are a sex worker. That is self-stigmatizing." (Abigail, AC-CT)

The stigma on sex work is so deeply rooted that sex workers now self-stigmatize. All peer educators were asked the question: '*When you work as a sex worker, how do you feel society looks at you?*' Although some said they could rise above the negative way they knew some people saw them, others admitted it influenced them very much:

"I feel ashamed, I feel false. (…) Yes, I do. Because what I am doing it is not good." (Kim, PE-J).

Additional findings

During the interviews some important topics came up that did not directly fit under one of the four themes but are nevertheless important to be mentioned. Comments about the PrEP pill being too difficult to swallow and being troubled by having to swallow it every day were made often. Furthermore, worries were expressed about the side effects of PrEP impeding sex workers doing their job and resulting loss of income. A health professional explained that side effects are temporarily, and a try-out period of 21 days is offered to test if PrEP use is feasible for a sex worker. The side effects are mentioned too big of a strain on sex workers lives, leading them to discontinue PrEP after the try-out period.

Conclusion and discussion

The aim of this research was to obtain insight into how sex workers in South Africa view PrEP and the role of stigma and trust in the process of acceptance of PrEP. To research this, seventeen semi-structured interviews were conducted with peer educators and health professionals. Thematic analysis was used to analyze the results and four themes were identified: awareness of PrEP, access to healthcare services, trust in healthcare, its workers and medicine, and the position of sex workers in South Africa. These themes are distinguishable but interrelated. Overall, it can be concluded that the potential promise that PrEP could reduce HIV infections is not being realized yet. This study has shown that at least part of that unfulfilled promise can be attributed to social factors. The results show that stigma, both source and result of the criminalization of sex work, influences sex work lives extensively. Stigmatization impedes on the trust that is needed at institutional and at the personal level (Gilson, Palmer, Schneier, 2005). Good access to healthcare and a trusting relationship with care workers are undermined. It limits sex workers access to health knowledge and treatment, and degrades their self-image. Importantly, it influences how sex workers view and make choices regarding PrEP.

Firstly, regarding awareness, I found that views on PrEP differ broadly between two categories of people: those who are well informed about PrEP and those who are not. The results show that more accurate knowledge about what PrEP does and how it works relates positively to acceptance. The peer educators explained that one of their aims was to provide both health information and information about PrEp. However, participants also reported negative stories about PrEP being spread. Lack of information or misinformation was related to a more negative view and impeded acceptance of PrEP. Research into PrEP trials conducted in Botswana indeed shows that rumors can affect medical decision making (Toledo, McLellan-Lemal, Henderson & Kebaabetswe, 2015). These rumors are essentially negative promotion of PrEP, while according to Delany-Moretlwe and colleagues (2016) the opposite, namely positive promotion is needed for acceptance.

Secondly, the findings show that access to good healthcare services is limited for sex workers due to discrimination. Sex worker-friendly clinics are set-up but there are few and, according to participants, not always accessible. Time and distance also form barriers to seek care, which is in confirmation with the findings in study of Scorgie et al. (2013) where it was stated that discrimination is a reason for sex workers to avoid going to clinics. Access to care is not only required for correct knowledge of PrEP, but is also needed to acquire this medication (Boudin & Richter, 2009). Thus, when healthcare becomes more accessible to sex workers, their PrEP knowledge and use is likely to increase.

Thirdly, participants report that their views of PrEP are influenced by their experiences with healthcare. Mistrust is specifically expressed when participants talked about privacy. Stories were

shared about sex workers profession being revealed against their will by clinic staff, resulting in hesitance or refusal to visit a clinic again. Experience of invasions of privacy also came forward in other studies, for example Scorgie et al. (2013). Participants express mistrust in health care workers from government clinics and some related that mistrust to the fact that they are unable to share their story and the lack of respect they receive, both of which are identified as important factors for trust in healthcare providers by Gilson, Palmer and Scheiner (2005). Participants also talk about fear of possible side effects PrEP could have and disbelief that PrEP will benefit one, while trust that a certain medication will benefit you is a condition for acceptance (Gilson, Palmer & Schneider, 2005).

Lastly, the findings show that the position of sex workers, legally and in socially, influences the way they view PrEP. Because of the illegal status of sex work it, is hard for sex workers to call on their rights (Pauw & Brener, 2003). The criminalized status is a form of structural stigmatization and, as confirmed by the Commission on Gender Equality (2013), an enabler of discrimination. Sex workers are being stigmatized regarding their occupation and are associated with HIV: a double stigma. Activists pointed out during interviews that the current PrEP policy in South Africa of specifically targeting sex workers is connecting PrEP to sex work, expanding the stigma. This stigmatization is hindering sex workers in accessing healthcare and getting well informed about PrEP, while the results show the importance of proper knowledge of PrEP. Herek, Capitiano and Widaman (2000) offer an additional perspective on the link between stigmatization and knowledge. They suggest that lack of knowledge about a disease or treatment is not only a results but also a cause of stigma. The findings do not only show that trust and stigmatization are imbedded in the position sex workers have in society, but that they also relate to awareness of PrEP. This means that when one wants to change how sex workers view PrEP, all four themes need to be taken into account. Although first, actual numbers on PrEP uptake are needed to see how the broad acceptance has been so far. The findings in this study seem to indicate that PrEP uptake has not been as high as expected, but PrEP has not been available to sex workers in South Africa long enough for official numbers on uptake to be published yet.

Limitations and recommendations

The participants in this research were willing to share personal experiences and provided relevant and clear information. Despite this, the study had its limitations. Participants were selected by convenience and snowball sampling and the sample is therefore not representative (Hollway & Jefferson, 2000). However, this was not the goal of the study. Instead, in-depth insight was desired and obtained. Because the study sample consisted of key stakeholders, some of the stories and experiences participants shared were second hand. Participants shared experiences with and from other sex workers, which might be less accurate than first-hand information. This also means that not all of the

experiences shared by peer educators are accurate representations for that of non-peer educator sex workers, who have received no training. Additionally, only participants from urban areas were interviewed, and only one professional could share experiences with sex workers in more rural areas.

One has to take into account that participants have the tendency to answer certain questions in a way that they think other will want or expect. This response bias might have been weakened by the provided anonymity of the participants. I had also met most of the participants in real life before the interview and invested in creating trust during the study visit. The fact that part of the interviews were done by phone may also have affected the reliability of the data. Through the phone it is not possible to see participants facial expression or body language and pick-up subtle non-verbal signals. Although it was not possible in this study, face-to-face interviews would have been preferable.

This research focused on the influence of stigma and trust, which interplay with other social factors that influence PrEP acceptance. Besides these social factors, participants brought up other determinants of PrEP acceptance. Often mentioned was the pill being physically difficult to swallow and not feeling comfortable taking a pill every day. Worries about side effects (temporarily) hindering sex workers in doing their job, and thus earning money, were also expressed. To be able to effectively enhance acceptance these factors also need to be taken into account.

Fortunately, others have and will be doing research into PrEP. This research fits into a broad body of research into different aspects of PrEP usage and strategies to improve uptake and adherence. Stigma, discrimination and mistrust are barriers to getting tested or treated for HIV (SANAC, 2011). This research shows that these factors are also important in PrEP acceptance. Venter, Cowan, Black, Rebe and Bekke (2015) have identified several barriers to PrEP acceptance. This research expands on two of the factors, stigma and trust, which show to interact with knowledge of PrEP and the position of sex work in society. Since PrEP has only become available for sex workers in South Africa a year ago, this study of PrEP views in non-trial setting could contribute to implementation improvements and possible future implementation efforts among sex workers in other countries.

Participants in this research brought forward several points of change that could counter stigmatization, enhance trust and improve acceptance of PrEP. To start of practical, health professionals brought forward the try-out period for PrEP, during which sex workers can discover whether utilise PrEP suits them. This try-out period is 21 days, which can be too short for the side effects to go away. This can leave sex workers with negative experiences that could be spread through the community. Extending the try-out period could prevent this negative promotion, but more education is also needed to counter rumors. Based on ARV acceptance experience, health professionals expect it is just a matter of time and extensive education before PrEP gets accepted. Also, getting past the side-effects can be tough, and peer-to-peer support is needed. In addition to the support too peer educators, peer system could be set-up for one-on-one adherence support.

To get more sex workers to try PrEP in the first place, trust needs to be built between providers and potential users. This can be done by increasing and expanding sensitization efforts that are already being made by activist organizations such as SWEAT and Sisonke. To fight the structural stigma, sensitization needs to happen in healthcare setting, but also within the broader community. As said, more knowledge of PrEP for non-users can reduce the stigma on PrEP use and HIV. On the other hand, there is self-stigmatization. Sex workers can limit themselves if they believe that they are doing something wrong or do not believe they are worth proper care and treatment. Believe in self-efficacy is needed when changing health behavior, such as starting medication (Strecher et al., 1986).

A last but important recommendation is one that is often mentioned. Decriminalization of sex work could reduce stigmatization and discrimination, and would allow sex workers to call on their rights, access healthcare and make it easier for them to accept PrEP. As this activist beautifully phrased:

‘*’The decriminalization it will enable all those opportunities, access to health services…they will be able to freely negotiate condom use with clients, you know so the decriminalization comes with lots of benefits. It will not just benefit sex workers, it will benefit the service delivery, it will benefit the funder, and it will allow us to treat sex workers as individuals.’’* (Abigail, AC-CT).

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Appendix A. List of participants

Pseudonym	Position (location)
Abigail	National Coordinator (Cape Town)
Amelia	Peer educator (Cape Town)
Emily	Media Liaison (Cape Town)
Emma	Manager HIV prevention (Johannesburg)
Faith	Community leader (Johannesburg)
Hope	Community leader (Johannnesburg)
Jack	Peer educator (Cape Town)
James	Office Manager (Durban)
Jenny	Peer educator (Johannesburg)
Kim	Peer educator (Johannesburg)
Lisa	Peer educator (Johannesburg)
Lucas	Counselor (Johannesburg)
Maria	Peer educator (Johannesburg)
Mia	Peer educator (Cape Town)
Olivia	Project Coordinator (Durban)
Tom	Program Coordinator (Durban)
Will	Head researcher (Johannesburg)

Appendix B. Topic list health professionals

Introduction

What organization do you work with?

Can you tell me about that?

What does your role entail?

How many years of experience do you have? Elaborate…

What does a regular day look like for you?

Sex work policy

How does the organization you work for approach sex work?

What is your opinion on the legal climate of sex work in South Africa?

How are sex workers viewed by society?

In your experience, how do you evaluate health care for sex workers?

What is your opinion on targeted specialized health care for sex workers?

If you know the P.E.S, how do you find it?

Health care for sex workers

From your experience, are sex workers generally aware of their HIV status?

Following on from that question, do you think sex workers are generally aware of their healthcare rights?

Do you think sex workers generally know the current policy on HIV treatment? (Universal Test and Treat)

Do you think sex workers are knowledgeable about HIV prevention methods?

PrEP

How do you evaluate PReP for sex workers?

What do you hear from sex workers about what they think of PReP?

From sex workers who have stopped PReP… why?

What are the biggest benefits of PReP according to sex workers?

How do sex workers, in your opinion find taking the pills?

Do you feel like people who are not targeted for PrEP (e.g. not sex workers) are informed about PrEP is? Is there knowledge about is, is knowledge being spread?

Would you for instance know what it looked like?

Self-Testing

Are you aware of self-testing kits?

Do you know about South Africa's policy on it? Can you tell me about it?

What opportunities does self-testing bring, if any?

What are the benefits of self-testing in your opinion?

Do you see any disadvantages of self-testing? Can you tell me about this?

Do you think self-testing is suitable for sex workers? Why/Why not?

Do you think sex workers would pay for self-testing kits?

Should clinics give self-tests out for free?

How important do you think pre- and post- HIV counselling is?

Would you take a self-test?

Do you think there is an element of empowerment to self-testing?

What do you think about a hotline for post- test counselling?

Do you think self-testing is ethical?

Responsibility

Who do you think should have responsibility for sex workers' health?

How health conscious do you feel sex workers are?

Appendix C. Topic list peer educators

Introduction

What is your name?

What is your gender?

How old are you?

Where do you live?

Do you have any children?

How long have you been a Peer Educator/Sex worker?

For peer educators:

Can you tell me what an average day looks like for you?

What is involved in your job?

Health care for sex workers

Where do you go when you need medical help?

Why do you choose to go there?

How do you feel about the quality of the care?

How do you feel you are treated by the health care providers?

When you go to get medical help, do you trust that you will be taken care of?

Responsibility

How important is health for you in your daily life?

Who do you feel is responsible for your health?

Where do you get information on health care?

Do you feel you know how to take care of your own health?

Health knowledge

How often do you get tested for HIV?

Are you aware of your status?

What treatment you can get if you are HIV positive?

Self-testing

Have you heard about the possibility to test yourself at home? This is called self-testing.

What do you think about self-testing?

What could be the benefits of self-testing in your opinion?

Do you see any disadvantages of self-testing? Can you tell me about this?

Do you think self-testing is suitable for sex workers?

Would you take a self-test?

Would you pay for self-testing kits?

Should clinics give self-tests out for free?

How important do you think pre- and post- HIV counselling is?

PrEP

How do you prevent becoming HIV positive?

What do you know about PrEP?

If you were HIV negative and were offered PrEP, would you use it?

(in the case you know someone is on PREP, rephrase question)

Why?

In case of PreP use:

What are the benefits of PrEP for you?

Do you experience any side effects

In case someone started and stopped:

Why did you stop?

What do you hear about PrEP from other people

Do you think PREP is a positive thing or a negative thing? Why?

Sex work policy

How did you become a PE/SW?

What kind of sex work do you/did you do? (Brothel, street work, escort etc?)

How do you feel society looks at you as a SW?