



**“Those who want to know now and can act later”:
An investigation into perceptions of HIV self-testing
for South African sex workers**



Universiteit Utrecht

Author:

Anna Devereux

MSc Social Policy & Social Interventions

Utrecht University

Supervisor:

Prof. dr. John de Wit

Head of Interdisciplinary Social Science

Utrecht University

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Abstract

The objective of the study at hand was to discover how the South African community, which provides health care services for sex workers, perceives HIV self-testing. In order to gain a thorough understanding of this outlook the context of health care for sex workers was also addressed. The role of stigma in impeding sex workers access to governmental health services is also highlighted in this research.

A qualitative approach was undertaken utilizing an adapted, community-based participatory research strategy. Interviews were conducted with peer educators, sex work activists, health care coordinators and researchers [n=17].

Opinions regarding HIV self-testing were very mixed. Prior knowledge of HIV was found to be very important in the ability manage the emotional stress of self-testing, and to seek follow up care. Concerns raised regarding the possibility of suicide were related to stigma of HIV and exacerbated by low levels of understanding of HIV. The perceived advantages of self-testing are linked to the stigma that sex workers face in government clinic settings. The research implies that self-testing ought to be promoted amongst individuals who are deemed to possess a high level of prior knowledge of HIV.

“Those who want to know now and can act later”: Perspectives of the health care community for sex workers in South Africa on HIV self-testing.

Sex workers in South Africa are a highly stigmatized group and are a key population at risk of contracting the human immunodeficiency virus [HIV] (The South African Health Monitoring Survey [SAHMS], 2014). Stigmatization of sex work has an influence on health behaviour and access to health care (Scrambler & Paoli, 2008; King, Maman, Bowling, Maracco & Dudina, 2014). Goffman defines stigma as being a characteristic or attribute which is regarded as undesirable according to social norms. Stigma, conceptualized in this manner can lead to prejudice and discrimination (Goffman 1963). Simbayi, Strebel, Cloete, Henda & Mqeketo state HIV/AIDS is, “...perhaps the most stigmatized medical condition in the world” (2007, p. 1). Stigma intertwines with other social factors such as race, class, gender and sexuality, reproducing a myriad of existing inequalities (Parker & Aggleton, 2003). Contemporary norms in South African townships surrounding stigma relating to sex workers affects how they themselves engage with available HIV treatments. Stigma of sex work affects how sex workers engage with the HIV treatment cascade as they face considerable barriers in accessing health care (Scheibe, Richter & Vearey, 2016).

HIV prevalence is high amongst the sex work community in South Africa. The South African Health Monitoring Survey [SAHMS] (2014) estimates that 39.7% of female sex workers in Cape Town are living with HIV. This figure is estimated to be higher in other parts of the country as 53.5% of sex workers in Durban are HIV positive while 71.8% of sex workers in Johannesburg are living with the virus (SAHMS, 2014). These statistics are high in comparison to the general female population aged between 15-49 years old. The national prevalence rate for this group stands at approximately 23.2% (Shisana et al., 2014). However,

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these figures do not capture the inclusive HIV prevalence rate amongst all sex workers however as there are no reliable figures available for male and trans* sex workers. (This is despite male and trans* sex workers making up a significant section of the sex work sector¹.) Approximately 45% of all HIV positive women and 62% of all HIV positive in South Africa are unaware of their status (Shisana et al., 2014). These figures are utilized by the international public health community to promote an urgency to increase an uptake in HIV testing.

The 90-90-90 goals have been established for the prevention and treatment of HIV (UNAIDS, 2014). With the 90-90-90 goals, UNAIDS calls on global stakeholders to attain that 90% of all HIV positive individuals are diagnosed, 90% of all persons diagnosed are on a treatment plan and finally, 90% of those receiving treatment are virally suppressed by the year 2020 (UNAIDS, 2014). HIV self-testing has been presented as an innovative technology which can facilitate an uptake of testing and work towards achieving the UNAIDS 90-90-90 goals (World Health Organization [WHO], 2016). Self-testing is endorsed especially for hard-to-reach communities, for example, sex workers who face barriers in accessing prevention and treatment interventions (UNAIDS, 2016). However, ethical concerns remain about HIV self-testing, particularly in relation to vulnerable groups (Scott, 2014).

While public health bodies argue that self-testing ought to be promoted on utilitarian grounds, concerns regarding linkage to care and whether self-testers require counselling services are reiterated throughout research on the acceptability of self-testing (Lee et al., 2007; Krause, Subklew-Sehume, Kenyon & Colebunders, 2013). Despite claims that South African sex workers would benefit from self-testing, there is a lack of data available to

¹ It is estimated that 5% of all sex workers are male and 4% of the sex work population are trans* for the year 2013 (Stacey et al., 2013).

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support this assumption. Thus although self-testing could indeed propel the number of individuals testing for HIV, the question remains whether this is a suitable and acceptable approach for sex workers. Research into the perceptions of the community which provide health care for sex workers could provide policy makers with the relevant data to inform effective self-testing policies and interventions.

The objective of this research was to gain an understanding of sex work sensitive perceptions of HIV self-testing in South Africa. The role of stigma in sex workers' health behaviour is explored within this research. Qualitative research was deemed the most suitable method to gain insight into the context of health care for South African sex workers. According to Dutta (2015) knowledge about context and qualitative research are strongly related. By virtue of gaining an understanding into the specific meanings and experiences that are context dependant, one can grasp the intricacies of the issues of importance to that group (Dutta, 2015). The secondary purpose of the study was to understand the context of health care for South African sex workers and their compatibility with self-testing. This aspect of the study was carried out by interviewing members of the sex work health care community. This community is defined as the cluster operating at the intersection between sex work activism and health care promotion. This paper utilizes Scheibe, Richter and Vearey's definition of sex work as adults who consent to the sale of commercial sex (2016).

Theoretical Exploration

Empirical Evidence

The context of Sex work in South Africa. The 1957 Sexual Offences Act section 23 prohibits sex work in South Africa (Richter, 2008), while brothel keeping and solicitation are also criminalized (Thusi, 2015). Actors calling for the repeal these laws suggest that criminalization exacerbates the stigmatization of sex work (for example see the Commission

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of Gender Equality, 2013). Recent research has demonstrated the harmful effects of criminalization policy in terms of human rights violations and health outcomes (see: Richter, 2008; Mgbako et al., 2013). Criminalization of sex work is said to have deep effects on how sex workers seek justice (Gould, 2011), and access health care (Stradler & Delany, 2006). It is necessary to take this policy context into account when attempting to understand how sex workers seek out health services. Stigma relating to sex work has been shown to affect health service utilization by several international studies (King et al., 2013; Duff et al., 2015).

Criminalization and stigma of sex work infiltrates perceptions of trust in health care (Shannon et al., 2015) and has a lasting adverse effect on health service take up (Scheibe, Richter & Vearey, 2016). According to Scorgie et al. (2013a) in a study of three South African locations, sex workers claim to conceal their sex work status to avoid becoming targets of abuse in health care settings. Due to the fears of verbal or physical abuse from health care staff, sex workers claimed to have avoided clinics on a routine basis (Scorgie et al., 2013a). Findings from a study conducted by Pauw and Brener reiterate the claims that sex workers face discriminatory attitudes when seeking health care (2003). Conducted in Cape Town, this research highlighted sex workers' experiences of feeling degraded at clinics and hospitals (2003a). Stradler and Delany (2006) report that sex workers in Johannesburg seek out specialized care for sex workers instead of government clinics due to their perceptions of stigma and they would face at governmental sites due to past experiences of abuse. The lack of comprehensive non-judgemental services is a barrier in reaching the 90-90-90 goals outlined by UNAIDS as sex workers are routinely avoiding the clinic. While self-testing is positioned as a mechanism to bypass the clinic, those who test positive must seek follow up care independently. This research aims to gain an insight into how stigmatization of sex work affects sex workers' compatibility with self-testing in this context.

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The current state of self-testing in South Africa. Policy relating to HIV self-testing is presently being developed in South Africa. Although the country's National Strategic Plan for 2017-2022 states it shall promote self-testing as an innovative intervention, the document lacks specific detail on how this will be achieved. Currently, there are few laws or legislation governing the sale of HIV self-testing in South Africa. Until as recently as 2016, a ban prevented the sale of HIV-self tests in pharmacies (Independent Community Pharmacy Association, 2016). Self-testing kits are now readily available in pharmacies, and are available for consumption.

There have been several international studies undertaken on HIV self-testing - including research undertaken in South Africa. While most studies have focused on the accuracy of testing kits and whether individuals can test accurately (for example see: Dong et al., 2014), some studies did gather information on perceptions of self-testing in different South African population groups.

For instance, Pant Pai et al.'s (2013) study concerning health care workers' (n=251) usage of self-testing found that participants claimed to value the privacy and confidentiality of self-testing (Pant Pai et al., 2013). Research by Makusha et al. (2015) demonstrates key perspectives' of health and policy stakeholders [n=12] in South Africa. According to Makusha et al. (2015) self-testing was regarded as a mechanism to increase testing in hidden populations due to the privacy and confidentiality self-testing offers, thus similar to the study of Pant Pai et al. (2013).

In relation to the perceived negative aspects of self-testing, counselling and linkages to care are recurring themes in literature on self-testing in South Africa (for examples see: Gardner, 2012; Spyrelis et al., 2017). Intimate partner violence and coerced testing is also a concern that has been raised in the research (Makusha et al., 2015; Martínez Pérez et al.,

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2016). In one South African study evaluating diagnostic preferences of participants [n=466], counselling prior to HIV-testing was also found to be important to 68.5% of the sample (Van Dyk, 2013). However this evidence is in relation to the general population rather than sex workers. Issues of linkages to care and forced testing are necessary to consider when analysing HIV self-testing, especially for vulnerable populations such as sex workers. Since sex workers face considerable barriers in accessing health care (Scheibe, Richter & Vearey, 2016) and systems of justice (Scorgie et al., 2013a), it is vital to question whether the pitfalls of self-testing could have an adverse effect on this group. While the privacy and confidentiality of self-testing may offer sex workers opportunities to visit the clinic less often while still test regularly, there are issues with follow up care and potential violence.

Theoretical Perspective

In order to understand the underlying mechanisms which impede sex workers' access to health care, the concept of stigma shall be considered. Erving Goffman first mapped the concept of stigma in the book *Stigma: Notes on the Management of Spoiled Identity* (1963). This concept is based on the theory that individuals have a social identity which is comprised of their social status and attributes in relation to norms in society (1963). A differentiation is made between those individuals who possess 'good' attributes according the social norms in that context and those which are perceived as 'undesirable'.

Goffman theorizes that people with perceived undesirable characteristics suffer from stigma (1963). Stigmatized characteristics are contextual and dependent on the ideation norms of society. Goffman claims that there three forms of stigma: physical stigma which relates to the body, character stigma which is dependent on personal traits and the last category is composed of stigma of nationality, race and religion (1963). Goffman states that

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discrimination occurs on the basis of assumptions caused by stigma – it is a mechanism of rationalization of animosity (1963). Shame and concealment are said to be an integral reaction for stigmatized individuals (Goffman, 1963).

Link and Phelan (2001) present noteworthy critique on literature pertaining to stigma. Firstly they observe that most criticism of the theory is associated with the variation in how it is applied. They claim however that this is due to its wide usage in a variety of disciplines which have different frames of reference. Another issue noted is that a large proportion of literature produced about stigma is not written by stigmatized individuals themselves. This has led to the “perpetuation of unsubstantiated assumptions” (Link & Phelan, 2001, p. 365). Lastly, they suggest that the concept of stigma has been applied too frequently on an individual level, without sufficient recognition of structural issues (Link & Phelan, 2001). Literature produced on the subject of stigma is also often critiqued for positioning stigma as a fixed attribute rather than as a social process which changes and varies (Parker & Aggleton, 2003).

The concept of stigma to explain barriers sex workers face in accessing health care services. As Goffman (1963) theorized, multiple layers of stigma overlap and exacerbate each other. Both sex work and HIV are highly stigmatized. Over the past decades, there has been an increase in literature on stigma, especially with reference to HIV. Novick (1997) highlights the “peculiarly stigma-sensitive epidemiology of HIV” due to its association with stigmatized activities and populations (p. 54). Novick (1997) put forward the idea that key populations vulnerable to HIV most likely already exposed to stigma and discrimination due to other identity factors such as their race, sexuality or class. Sex work is one such domain (Logie, James, Tharao, & Loutfy, 2011).

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Historically sex workers have been portrayed as vectors of disease and “sources of contamination” (Outshoorn, 2005, p. 143). The stigma of HIV and sex work are said to interrelate and reproduce further inequalities (Lekas, Siegel & Leider, 2011). Discrimination of these stigmas perpetuates social inequalities and deepens health disparities. These stigmas are understood to work bi-directionally as the stigmatized group’s experiences of stigma influence their own perceptions of themselves and are a factor which shapes their behaviour (Liu et al., 2011). Self-stigmatization in this way affects the self-esteem and self-efficacy of the stigmatized group. This is a factor in why stigma of HIV is a barrier to uptake of HIV testing and treatment (Chan et al., 2015; Kelly, Weiser, & Tsai, 2016).

Research question

While there has been research conducted on South African perspectives of self-testing, no inquiries have been published specifically targeting sex workers’ perspectives. As self-testing policy is not clearly defined in South Africa and still developing, it is crucial to conduct research to gain a better understanding of whether self-testing ought to be promoted in the sex work community. With the 90-90-90 targets, there is international pressure to increase HIV testing rate, however, it is important to question whether the possible pitfalls of self-testing justify the ends. As concerns of forced testing and qualms about suicide are raised within the literature (Pant Pai et al., 2013; Makusha et al., 2015; Martínez Pérez et al., 2016), it is vital to ask whether the sex workers are more vulnerable to the possible adverse effects of HIV self-testing. The research aims to take a more holistic approach to conceptualizations of self-testing by also taking into account the context of sex workers’ access to health care and their perspectives of such. The aim of the study is thus to learn qualitatively how the

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South African sex work health care community perceive HIV self-testing. By taking in these contextual factors, one can develop more effective and efficient policies and interventions.

Thus the research question at hand is as follows:

How does the community providing health care for sex workers perceive HIV self-testing?

There are three sub-questions integral to answering this research question:

1. What is the context of health care access for sex workers in South Africa according to this community?
2. What are the underlying values present in the perceived advantages and disadvantages of HIV self-testing?
3. How do these values relate to the stigmatization of sex work?

Methods

Procedure

A constructivist approach underlies this research, reflecting the assumption that individuals hold their own subjective meanings of their experiences (Creswell, 2014). Constructivism emphasized that there are multiple truths and realities specific to local contexts and actors (Creswell, 2014). Therefore a qualitative method of inquiry was incorporated into this study using semi-structured interviews [n=17]. Principles of community-based participatory research [CBPR] as formulated by Israel, Schulz, Parker and Becker (1998) were remodelled and adapted with regard to feasibility. This approach is becoming more common in health promotion research and it marks a shift away from

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disease-centred approaches to health promotion and emphasizes socio-cultural ways of understanding (Winterbauer, Bekemeier, Van Raemdonck & Hoover, 2016). The purpose of CBPR is to combine this local knowledge with action in order to diminish health disparities. Hence it is utilized as a means of gathering local knowledge to produce effective policies and interventions (Bogart & Uyeda, 2009). Israel et al. (1998) promote nine key principals intrinsic to the application of CBPR:

1. CBPR recognizes community as a unit of identity.
2. CBPR facilitates collaborative, equitable partnerships in all phases of the research.
3. CBPR builds on strengths and resources within the community
4. CBPR integrates and achieves a balance between research and action for the mutual benefit of all partners
5. CBPR emphasizes local relevance of public health problems and ecological perspectives that recognize and attend to the multiple determinants of health and disease.
6. CBPR promotes co-learning and capacity building among all partners
7. CBPR disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process.
8. CBPR involves a long-term process and commitment
9. CBPR involves systems development through a cyclical and iterative process.

Due to resource and time limitations it was not possible to incorporate each of the nine principles of CBPR in this research design. However Bogart and Uyeda (2009) note that this does not necessarily mean the integrity of the design is compromised so long as meaningful collaboration is formed with key members of the community. Seven out of the nine principals have been followed as shown in Appendix 1.

As the CBPR approach emphasizes the importance for research to be as participatory as possible, an onsite study visit was conducted in order to build relationships with the sex

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workers' health service community. In total six weeks were spent in South Africa. The researcher spent time becoming familiar with the community, attending outreach services with peer educators and visiting health facilities. During this initial phase of the research, the researcher collaborated with several NGOs and research institutes on the ground in an informal manner. Data collection began when the researcher returned to the Netherlands. Therefore the study took place remotely. Individual interviews were conducted via telephone or Skype [n=17]. The average duration of an interview was 34 minutes. This community participating in this research is defined as the health care sex work [SWHC] community which is comprised of actors who promote health care for sex workers in South Africa.

Participants

The study was conducted among the community which provides health care for sex workers in South Africa. The SWHC community is varied and ranges from grass roots level, peer educators and activists to health care coordinators and researchers. Given the participants' lived experiences or high levels of participation and knowledge of the sector they are taken as experts in the field (Davis & Wagner, 2003). The sample has been categorized into two groups: 'peer educators' [n=9] and 'professionals' [n=8] as shown in Table 1. Peer educators are current or former sex workers who have been trained in sexual health promotion. Peer educators are trained in health promotion and conduct outreach to other sex workers. Also included in this group are sex work community leaders that are advocates for pre-exposure prophylaxis [PrEP] usage. The second set in the sample are termed professionals. This category is a conglomerate of professionals: two HIV self-test researchers, two sex work activists who have also worked in the sex industry, three health care coordinators that work in NGOs on the ground, and one counsellor. Eleven members of the total sample are current or former sex workers [n=11].

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Table 1.				
Research Participants Listing				
Identified as:	Profession	Location	Current/former sex worker	Topic List
Health Care Coordinator A	Site Coordinator of regional clinic	Gauteng	No	Professional
Health Care Coordinator B	HIV Prevention Manager at NGO	Gauteng	No	Professional
Health Care Coordinator C	Site Coordinator of regional clinic	Durban	No	Professional
Self-test Researcher A	Leading Researcher into Self-Testing at WRHI	Johannesburg	No	Professional
Self-Test Researcher B	Researcher into Self-testing	Durban	No	Professional
Counsellor	Clinic Counsellor	Gauteng	No	Professional
Sex Worker's Rights Activist A	National Coordinator Sisonke	Cape Town	Yes	Professional
Sex Worker's Rights Activist B	Coordinator Sisonke	Cape Town	Yes	Professional
Sinazo	Peer Educator	Johannesburg	Yes	Peer Educator
Luthando	Peer Educator	Johannesburg	Yes	Peer Educator
Zenzele	Peer Educator	Gauteng	Yes	Peer Educator
Buhle	Peer Educator	Gauteng	Yes	Peer Educator
Khethiwe	Peer Educator	Cape Town	Yes	Peer Educator
Teboho	Peer Educator	Cape Town	Yes	Peer Educator
Jabulile	Peer Educator	Cape Town	Yes	Peer Educator
Lakiwe	PrEP Community Leader	Gauteng	Yes	Peer Educator
Zindziswa	PrEP Community Leader	Gauteng	Yes	Peer Educator

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Sampling procedures

The sampling procedure followed a CBPR approach by depending on the community network to find participants. This was facilitated by connections the researcher had established with local organizations on the ground in South Africa. An indirect method of recruitment was employed for peer educators, utilizing the community network. This method of sampling minimized the risk of potential harm to participants. The researcher reached out to professionals to arrange an interview via email following the study visit using a purposive sampling technique.

Instruments

As the research sample was not homogenous, two topic lists were drafted order to guide the interviews in a semi-structured manner. A separate topic list was formulated for peer educators and professionals. The topic lists were designed with reference to issues that were raised by the SWHC community during the study visit. Therefore the topic lists were guided by empirical observations. However, the researcher was aware of gaps in the research by having previously conducted a literature study. The topic lists were designed in collaboration with a fellow student who shared the research sample. As such the topic lists included questions relevant to both research questions. The participatory approach adds to the validity of the topic lists' content (Winterbauer et al., 2016).

Context has an emphasized importance in the CBPR approach (Israel et al., 1998). Consequently; in order to gain an improved understanding of the social and contextual factors affecting the health care of sex workers questions were posed in relation to health care for sex workers. This includes gathering opinions on where sex workers prefer to access health, the quality of health care sex workers receive and the barriers they face. Questions relating to awareness of sexual health, health services and sex workers' experiences accessing health

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care were selected as indicators of health care access. Questions pertinent to their opinions of the advantages and disadvantages of self-testing for sex workers then followed. Questions relating to stigma were not directly posed.

There were disadvantages with the remote interview strategy. The most significant issue was a consequence of poor phone connection during some interviews which impacted on the quality of the data being collected. The reliability of the data was affected by the difficulty in hearing the responses of some interviews with peer educators. Another factor which perhaps affected the reliability of the interviews was the lack of opportunity or ability to observe or record the body language of the participant due to the remote format. On the other hand, the validity of the research was strengthened by the trust the researcher had gained due to the connection established during the study visit. The study visit also added to the interpretive validity of the research.

Data analysis

A thematic data analysis was undertaken. An inductive approach was taken utilizing this method to answer the research question. Hence, the data guided the theory. Within thematic analysis the researcher extracts concepts, perceptions and interpretations through the identification of themes within the data (Braun & Clark, 2006). A critique of this method is that it is foundational, rather than theoretical (Javadi & Zarea, 2016). This was an issue that was encountered in the later stages of data analysis. However, while data analysis strategies are often connected to particular theoretical positions and research designs (such as in-depth interviews and narrative analysis) thematic analysis is flexible in its approach (Braun & Clarke, 2006) therefore thematic was chosen as a suitable method of data analysis.

The approach to thematic analysis is guided by Braun and Clark (2006). The first step taken was become familiar with the data through active reading and note-taking. Next

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primary themes were coded following in the data analysis program Nvivo. There was a low level of interpretation related to these themes. The next step was to consult and collaborate with the research partner in forming overarching categories in relation to the broadest themes distinguishable: awareness, responsibility, health care access, trust and the position of sex work. In the next stage of data analysis, secondary themes were addressed and coded on a higher level of abstraction with consultation of the literature. This process was repeated several times. Data relating specifically to self-testing was coded in a separate coding tree. The final stage of this level was a review of themes whereby some codes were collapsed into each other and others' refined. Finally, a thematic map was formulated manually with the fully work themes. Themes referred to in this way imply a pattern in the data. The data was iteratively interpreted with reference to the literature.

Results

This section presents the results of the interviews with the HCSW community. Peer educators are identified by a pseudonym while professionals are labelled by their job title. The three main findings are described in the following section. These are:

1. There is an association made by respondents between prior knowledge of HIV and the capacity to self-test.
2. Concerns being raised by the community regarding suicide are related to the stigma of HIV, exacerbated by a lack of counselling.
3. The perceived advantages of self-testing are linked to sex workers' avoidance of governmental clinics due to stigma of sex work.

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Awareness of HIV and the capacity to self-test

Prior knowledge of HIV. There were various viewpoints within the community regarding the general level of awareness and understanding sex worker's had of HIV treatment and prevention. There were conflicting views on how much prior knowledge sex workers had of HIV. Some respondents claimed that there was a lack of awareness of prevention techniques, while others pointed toward a misunderstanding of the mortality rate of HIV and the treatment options. While the two activists claimed that sex workers were well informed about sexual health, peer educators disputed these claims:

"We didn't know much about HIV, about STIs, things we mustn't do as sex workers. I didn't have that knowledge before [I became a peer educator]." (Sinazo, PE)

"Some sex workers know [how to stay healthy] and some they don't. They just know they have to get tested but they don't know the ways to survive around it." (Khethiwe, PE)

Low levels of awareness however could be reflective of the general South African population. Questions were raised by participants about level of knowledge the general South African population have of HIV prevention, treatment and life chances:

"I think if you talk about HIV and AIDS today you can ask anybody and they will have heard of it, but if they fully understand it, that's the main question." (Health Care Coordinator A)

Issues around knowledge of HIV may be a wider problem in South Africa, as Meiberg, Bos, Onya and Schaalma (2008) found that South Africans had very different levels of understanding of HIV and many correlated the virus with death. The South African National HIV Prevalence, Incidence and Behaviour Survey (Shisana et al., 2014) reports that only

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26.8% of South Africans over the age of 15 were knowledgeable about sexual transmission and prevention of HIV. Therefore it is not unusual that there are low levels of knowledge about HIV present in the sex work community.

Importance of awareness and the capacity to cope with HIV self-testing results.

Generally respondents made an association between a person's level of prior knowledge of HIV and their ability to self-test. Prior knowledge was not defined exactly by participants, for some this implied prevention methods and others made a link between life chances and treatment options. Comprehensive knowledge about HIV was linked to having the ability to stay engaged with the treatment cascade. Peer educators often stated that they felt they had the capacity to cope with the results of a self-test as they were informed and aware of HIV. Coping is defined as having the ability to seek treatment and to manage the emotional distress. It was reiterated by these participants that HIV is not a death sentence and that they knew how to seek treatment; therefore they found self-testing unproblematic:

“Yes, for myself I can do self-testing. I'll do that because I think that I have got enough information about sexual health and things. Yes.” (Luthando, PE)

Health care professionals also understood health education as an important variable in the ability to self-test and seek care successfully. However there was distinct anxiety demonstrated for those sex workers that might not have an understanding of the virus at a meaningful level. These results are comparable to a study undertaken on the South African general population whereby individuals felt they had the capacity to test themselves due to their self-reported high levels of understanding of the virus (Kelvin et al., 2016). This study also found that participants felt that prior knowledge of HIV was an important element of coping with a self-test result (Kelvin et al., 2016).

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HIV and stigmatization

There were distinct concerns raised by peer educators and activists about the possibility of suicide if sex workers are not given adequate information and support following a HIV positive diagnosis. Misinformation, including urban myths about how HIV is transmitted and the life chances of HIV positive individuals were seen as detrimental by some of the HCSW community. An association was made relating misinformation to high levels of stigma attached to HIV. Similarly, Visser, Makin, Vandormael, Sikkema and Forsyth (2009) found that low levels of awareness of HIV were linked to higher levels of stigma towards the virus. Stigma of HIV was also related to concealing your result following a self-test and not seeking treating:

“If we test our self we want to keep it a secret, we won’t even want the other to be helping, because you tell yourself no I cannot go to someone, I can’t trust someone. You feel like I can’t tell anyone about this” (Zindziswa, PE)

Stigma of HIV was linked to the possibility of committing suicide following a HIV positive result without counselling. Several peer educators and both activists had distinct fears about suicide following a HIV positive diagnosis:

“Now you are alone! ...they might think this is the end: “it’s better for me to commit suicide because I don’t want anyone to know about this” (Sex Work Activist B)

This understanding was linked to a lack of adequate prior knowledge of HIV combined with the lack of support that a counsellor would usually bring:

“Most of the time if you don’t have more information about HIV, you will be thinking this is the end of the world, this is the end of my life” (Sex Work Activist B).

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While several participants raised the idea of suicide, this outlook was not unanimous. There were differing opinions around sex workers' perceptions of HIV and the risk it poses. Two peer educators suggested that sex workers are aware of the high risks, and therefore take this into account and prepare themselves for the possibility that they will become HIV positive.

Support and treatment following self-testing

The issue of counselling was the most problematized element of self-testing within the interviews. The lack of counselling was reiterated as a large concern by most of the community with the exception of the self-testing researchers. Counselling was generally connected to psycho-social support, gaining a better understanding of HIV and treatment options. Furthermore, very little distinction was made between pre- and post- test counselling. Counselling was thus understood as a means to diminish the stigma of the virus for the newly diagnosed person. Peer educators and activists conflated with linkages to care to counselling services within the interviews. Counselling was also positioned as a vehicle to begin treatment. Concerns around linkages to care were directly raised in the interviews by health care coordinators. Several respondents were hesitant about self-testing due to the concern that sex workers might have difficulty finding pathways to treatment:

“You can access self-testing almost anywhere, really, then it’s just the post kind of support process that will fall flat, especially if you are positive” (Health Care Coordinator A)

Self-testing researchers brought up the issue that linkages to care remain one of the core questions in formulating an intervention relating to self-testing. Linkages to care and issues around counselling are areas of concern in the literature on HIV self-testing (for example: Gardner, 2012; Makusha et al., 2015; Spyrelis et al., 2016).

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Perceptions of self-testing in the context of governmental health facilities

Privacy and clinic avoidance. Privacy was the most cited positive attribute of HIV self-testing with both professionals and peer educators singling it out as an advantage of the intervention. Privacy is frequently cited as a benefit of self-testing in studies world-wide (Figuera, Johnson, Verster & Baggaley, 2015). There was an association made between privacy and confidentiality. Peer educators frequently expressed their fears that governmental clinic staff would not keep test results confidential. This lack of trust is indicative of the issues that sex workers face in access health care. Peer educators and professionals alike raised concerns as to the lack of trust sex workers have in governmental health centres. This included disclosing their HIV status and concerns regarding their access to appropriate levels of health care:

“I don’t trust them! I just go 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” (Jabulile , PE)

These results are consistent with current literature on sex workers’ access to health care in South Africa. Stigmatization of sex work and distrust in hospital environments are common themes in the literature of health care for sex workers (see: Scrambler and Paoli, 2008; Scorgie et al., 2013a). Other international studies concur stating that the general population also distrust clinician staff and the confidentiality of their medical test results (see Meiberg, Bos, Onya & Schaalma, 2008). It is possible therefore, that the lack of trust in government clinic environments could be more widespread and not just related to the sex work community.

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Context of sex workers' governmental health care. Peer educators stressed they feel fear of discrimination and judgemental attitudes at governmental clinics which affects the quality of care they receive:

“You end up leaving because they make you go away because of the [unfair] treatment. They ignore you - some are not even talking to you so I don't feel comfortable to keep coming there. You end up going away with your problem.”

(Luthando, PE)

According to peer educators, sex workers feel that they cannot go to governmental clinics for recurring STIs and issues with sexual health because the health care workers will judge them for repeatedly having the same problem. Peer educators claim that sex workers avoid health care settings due to the negative attitudes sex workers face at clinic settings:

“There's the drive that makes sex workers not want to get tested at the clinics because of this [discriminatory] treatment [...] They don't want to bring themselves to the clinic so they just stay at home. It's not right. Most people just stay at home or use traditional methods.” (Jabulile, PE)

Due to the hostile clinic environment, some peer educators value self-testing as they can bypass clinic sites and still regularly test:

“I think it's a good thing for those who are scared to test [because of stigma]. They don't have to go to the clinic.” (Buhle, PE)

Discrimination was repeatedly mentioned by peer educators however many stories were not first-hand accounts of discrimination. Instead peer educators' narratives often revolved around discrimination against sex workers more generally:

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“They would judge you, they would tell you that no, you’re a sex worker, you are weak, I can’t treat you” (Buhle, PE)

While most peer educators described incidences relating to friends and people they knew, Sex Work Activist B was the only participant to share a first-hand account of an experience where she directly faced judgemental attitudes and shaming at a government clinic. Both activists, who also identify as sex workers also note the prevalence of discrimination in governmental clinics and argue that this problem constrains sex workers from accessing care:

“In some sites [...] they know that you are a sex worker, they give you that attitude they give you that look and at times they don’t assist you or that problem that brought you to the clinic.” (Sex Work Activist B)

Discussion

Overall attitudes on self-testing were very mixed. Peer educators generally emphasized that self-testing would only work for those who were adequately informed about HIV. Several peer educators said they would take a self-test themselves, but this was on the basis that they were educated enough about HIV and health care to cope with the results. A portion of peer educators were against self-testing for the general sex work population, due to the fear that sex workers would not access follow up care, or receive support in dealing with a HIV positive result. Several other peer educators in contrast, supported self-testing for sex workers. They stated that it would benefit sex workers because of its privacy and confidentiality.

The two activists discouraged self-testing for sex workers because of suicide concerns and a general lack of comprehensive knowledge of HIV in the sex work community. Health

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care professionals' views, on the other hand, were split. Health care coordinators as a group underlined that self-testing could overcome logistical barriers people face in attending the clinic, but stated that it must be implemented in settings where sex workers can access counselling or support afterwards. Their concerns were mainly around linkages to care and counselling services. Self-testing researchers promoted self-testing kits as a way to increase testing for under-tested groups. However, they generally didn't acknowledge the hesitations sex workers had in seeking treatment due to perceptions of stigma.

The findings of this research are largely similar to results of other studies assessing perspectives on HIV self-testing in African countries. Recurring concerns in the research are related to counselling and linkages to care (Pant Pai et al., 2013; Makusha et al., 2015; Van Rooyen et al., 2015) which also feature in the findings of this study. Widely reported advantages of self-testing in the literature are the confidentiality and privacy self-testing offers (Mantell et al., 2014; Ochako, Vu, & Peterson, 2014) as well as the possibility to increase testing for under-tested groups (Choko et al., 2011; Sabapathy, Van den Bergh, Fidler, Hayes & Ford, 2012; WHO, 2016; Johnson et al., 2017). Comparably, confidentiality and privacy were commonly cited advantages of self-testing for sex workers in the findings of this research. A distinct and significant difference between this research's results and the general literature is that very few participants mentioned the possibility of coercion or violence around self-testing. Several studies have listed the possibility forced testing as a disadvantage of self-testing (Choko et al, 2015, Figueroa, Johnson, Verster & Baggaley, 2015; Van Rooyen, 2016). The only participant to raise this issue was Self-Test Researcher B who raised this concern from his review of the literature. It is striking that participants were not concerned with this concept. This could be a consequence of the fact there were no questions on the topic list which confronted this issue directly.

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Stigma relating to being a sex worker was the key barrier highlighted by peer educators and activists in explaining why sex workers did not undergo regular medical testing. Stories were shared of how they themselves and their peers had come to expect or anticipate negative attitudes towards them and discrimination at government clinics. This could be understood as a form of self-stigmatization as understood by Goffman (1963). Stigma in this manner is a dual process. Society's alienation and degradation causes stigmatized individuals to internalize and anticipate these attitudes. Corrigan, Larson and Rusch theorize that self-stigma leads stigmatized groups to question why they should even try to achieve a variety of outcomes (2009). Stigmatized groups which lack self-efficacy and self-esteem might fail to attempt visiting governmental clinic environments due to interrelated factors of stigma and self-stigmatization.

According to the health care sex work community, HIV related stigma is a factor which prevents sex workers from visiting government clinics. Peer educators emphasized that they did not trust government clinic staff to keep their results confidential. For that reason, peer educators stressed the advantage of privacy encapsulated in HIV self-testing. In other studies of self-testing in conducted in Africa, participants were fearful of testing in clinic settings due to a lack of trust in clinic staff to keep their results confidential (Meijer et al., 2008; Siedner, Ng, Bassett, Katz, Bangsberm & Tsai, 2015; Martínez Pérez et al., 2016). This was related to not trusting the confidentiality of the clinic and the need to conceal ones' HIV status due to stigma (Angotti et al., 2009; Jürgensen, Tuba, Fylkesnes, & Blystad, 2012). Pherson et al. (2011) have shown that while patients anticipate stigma during testing, it does not necessarily translate into lower testing rates. Interestingly, the stigma of being a sex worker could be interacting with the stigma of HIV, which may explain governmental clinic avoidance.

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Fear of HIV and stigma of HIV are amplified by misinformation and a lack of understanding pertaining to HIV. This can be deduced from peer educators stating that sex workers need to understand that HIV is not a death sentence. Counselling is regarded as being crucial for those who do not have prior sufficient knowledge of HIV. Results from a study of South African perspectives on self-testing conducted by Kelvin et al. (2016) reflect these views. Suicidality was heavily linked by respondents to HIV positive diagnoses on the condition that the tester has low levels of knowledge of HIV (Kelvin et al., 2016). In a review of harm subsequent to operating a HIV self-test [n=49], Brown, Dijmeu and Cameron found no evidence of reported cases of suicide following self-testing (2014). While the possibility of suicide is not clearly known, nor elucidated by the findings of this study, it is difficult to ascertain whether the concerns demonstrated by the activists and peer educators are valid and generalizable to the wider population. However, education and awareness of HIV has reappeared throughout the study as a means to safeguard self-testers, and to ensure that those diagnosed with a positive result are able to sufficiently seek out care.

Limitations

Due to the relatively small sample size of this research, the generalizations of the findings are limited. The CBPR sampling technique of reaching participants through the community network had implications on selection bias in the sample, as peer educators who were willing to participate may not be representative of the general population of peer educators. The purposeful sampling technique utilized in recruiting professionals increased the possibility of selection bias. External validity could have been strengthened by a larger sample size, however, this was not possible due to time constraints. By including a variety of stakeholders, the findings of study varied greatly. The origin for this variation may have stemmed from the diverse research sample used. By narrowing the participant group, the findings could have been more exact.

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Implications

The community is concerned and alarmed regarding low levels of knowledge and information in relation to HIV amongst sex workers. The findings imply that the capacity of an individual to cope with the negative results of a self-test relies on a high level of prior knowledge of HIV. Comprehensive levels of information around HIV appear to mitigate the perceived pitfalls of self-testing, namely the lack of counselling and direct linkage to care. There is a gap in the literature with reference to the levels of awareness sex workers of the virus. While there is a current shortage of information related directly to sex workers, diverse surveys record that, on average, there are low levels of knowledge relating to HIV in the general population. This implies a national policy should be developed with the aim of raising levels of sexual education and awareness of HIV prevention and treatment. Furthermore, there is a distinct lack of a nationwide research which focuses on sex workers' access to health care. For this reason, it is recommended that large-scale quantitative research could elucidate issues of discrimination regarding health care access and serve advocacy purposes.

Conclusion

Sex workers are restricted by the stigma they experience in various facets of their lives. This study has concentrated on stigma in health care settings with respect to HIV-diagnosis strategies in particular. Alarming, experiences of stigma and expectations of discrimination at government clinics were repeatedly narrated by peer educators in this study. Health care coordinators and activists also highlighted that sex workers avoid governmental clinics because of the stigma that they face. This is in line with other research conducted on discrimination of sex workers in South Africa. This context forms the basis of the health care community's perspectives of self-testing for sex workers. In order to understand why the privacy and confidentiality of self-testing is valued for sex workers, one must look at their

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context of health care access. This research highlights the importance of prior knowledge of HIV as a safeguard in HIV self-testing.

Issues were raised in this study about the attitudes and behaviour of governmental clinicians towards sex workers due to the stigma of sex work. Criminalization of sex work was positioned as a barrier to health care access throughout interviews with peer educators, activists and health care coordinators. Several respondents outright claimed that sex work must be decriminalized in order for sex workers to be able to enact their full health care rights. From their perspective, this would alleviate stigma against them and stop society from viewing them as 'criminals'. Hence this study suggests that a policy of decriminalization would serve sex workers in gaining more comprehensive access to public health care.

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Appendix

Operationalization of adopted principals of CBPR

Six of the nine principals Israel et al. (1998) promote have been incorporated in this research. Principles six, eight and nine were not incorporated into the research due to time and resource limitations. The following section denotes how these have been operationalized:

Principle 1. CBPR recognizes community as a unit of identity.

While Israel et al. (2002) refer to community as the sharing of common symbol systems, shared norms and common interests, the community in relation to this study is the sector at the intersection of health care and sex work. The sample represents a vertical slice of the industry. Although there are distinct difference between actors within this community; activists, peer educations and professionals (coordinators, researchers, counsellors) they are bound together within similar lived experiences, networks and perspectives. Activists interviewed have also participated within the sex industry for example and peer educators share a similar public health discourse as health care coordinators.

Principle 2. CBPR facilitates collaborative, equitable partnerships in all phases of the research.

The researcher was welcomed to the community and introduced as a student interested in learning more about health care access and self-testing. To increase collaboration within the project, the researcher encouraged a two way process and welcomed

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questions throughout the research design formulation and interview procedure. Boundaries were negotiated with organizations on the ground and research protocols were established in. For instance guidance was given on how to raise sensitive topics during the interviews. While collaboration was facilitated in the beginning phases of the research, the researcher takes full responsibility of the data analysis. This is due to time limitations and course requirements.

Principle 3. CBPR builds on strengths and resources within the community.

The research utilized community resources during the context visit. Observations were made during outreach sessions and insight was developed into brothel work and culture. Strengths of the community were engaged through welcoming early participation at the design phases of the research. Peer educators were keen to demonstrate their misgivings in the system and the discrimination they face. They were enthusiastic to participate in research which gave them the opportunity to voice their opinion. The motto “nothing for us without us” was reiterated through-out this time.

Principle 4. CBPR integrates and achieves a balance between research and action for the mutual benefit of all partners.

The research undertaken has benefits as it raises issues that directly affect the participants. The research will be disseminated amongst NGOs on the ground and can be used as evidence for advocacy purposes.

Principle 5. CBPR emphasizes local relevance of public health problems and ecological perspectives that recognize and attend to the multiple determinants of health and disease.

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Local knowledge relating to health access and awareness of health are highlighted in the research. These socio-cultural factors refer to the need to understand the broader context of health inequalities in order to make meaningful improvements (Wallerstein & Duran, 2010).

Principle 6. CBPR disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process.

The results of the study will be shared with the partner organizations and participants. The research will be shared online and physical copies of manuscripts containing the main findings will be sent to peer educators who may not have a computer to access the results. This document would be provided using layman's terms. Stakeholders, during this study visit, indicated this would be preferred. This point was reiterated again by some participants in the interviews. A short video explaining the results will be shared with the peer educators using the social media platform WhatsApp.