

## Transgender sex workers' experience of tuberculosis: A reflection on embracing the everyday and convivial research

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### *Abstract:*

*Focusing on two individuals, Ayanda and Flavia, this paper discusses the experiences of transgender sex workers in Cape Town, South Africa, who had tuberculosis. The discussion stands as an ethnography that embraces the everyday to showcase some of the complexity of the participants' lives as opposed to solely focusing on the experience of the disease itself. With a focus on locating stigma, an often-oversimplified concept in the realm of tuberculosis research, I look at the act of staring and how stigma operates in this taken for granted act majority of people enact every day. Alongside this, I also discuss the importance of methodology and argue that with a convivial approach in the research process by 'writing together' and negotiating research, it becomes possible to do more ethically sound research and to do justice to representation, especially with the notion of positionality and 'incompleteness' in mind.*

**Keywords:** Tuberculosis, Transgender, Negotiated research, Conviviality, Ethnography

Transgender<sup>1</sup> issues in South Africa have largely been a topic unexplored in scholarship and when it is explored it is often done from the cisgender<sup>2</sup> and heterosexual gaze (Jobson et al. 2012). There has been a call to urgency to address the knowledge gap that exists around transgender issues in scholarship as transgender individuals face several forms of violence in South Africa. Access to public health care facilities (Müller 2017; Meer and Müller 2017), public bathrooms (Patel 2017), obtaining identity documents from the Department of Home Affairs (Bhagat 2017), and several other facets of social life and basic needs remain obstacles for many transgender individuals who face discrimination, violence and stigma. The problem of active exclusion and violence not only goes against being treated like a human being but it also goes against the constitution of South Africa that is supposedly in place to protect and advance the dignity of all who live in the country. When using an intersectional lens (see Crenshaw 1991) to explore this issue, most of the violence faced by transgender individuals becomes apparent as the violence is situated (see Haraway 1988). Black transgender individuals who have a lower-socioeconomic standing than white transgender individuals for example face a multiplicity of violence in everyday life. It is the element of race and class, but not limited to these two, that speak to the current and historical politics playing out in South Africa and how transgender individuals with particular intersections experience life.

South Africa as a contemporary democratic nation has a history of settler colonialism together with the reign of the apartheid regime that ended in 1994. Despite the progress over the past 24 years, the country's racist history with the rule of white supremacy and oppression of people of colour is still

visible today. Being a country with one of the highest gini-coefficient rates in the world (StatsSA 2017), South African society is extremely divided along the lines of class, making it a country with different worlds within it. The public health care system remains a challenging component of social life within the unequal society. Considering the quadruple burden of disease<sup>6</sup> (Bradshaw et al. 2003) facing the public healthcare system, where several lives are lost due to the overcrowded and under-resourced facilities to only name two problems, the country is in dire need of a resolution. Sexual violence is not a new phenomenon in the country but remains a key social ill. South Africa has one of the highest incidence rates of sexual violence in the world (Africa Check 2015), especially among female presenting bodies and children. Alongside this social ill, trans- and homophobia resulting in violence is also a prominent occurrence which goes as far as claiming the lives of several individuals. These are just a few problematic elements of South African life and it is possible to see how they all intersect to make life for a black or coloured<sup>3</sup> transgender individual from a lower-socioeconomic background hard to navigate.

Sex work in South Africa has recently been gaining attention with the growing call to decriminalize the form of labour (Richter 2017). Within the literature available, there has been a big focus on the experiences of cisgender men and women sex workers (Gould and Fick 2008; SANAC 2017), and not that much of a focus on transgender sex workers. Webber (2014) takes us through the missing voices of female transgender sex workers in Cape Town, and showcases what it means to be a transgender sex worker in Cape Town. The author discusses several factors such as stigmatization,

discrimination and exploitation - that these individuals have to face in various spaces they move in. This research offers an insight to experiences but does not utilize a research approach that engages with the voices of the research participants in way that offers the reader a new or different perspective from knowledge that is already in circulation.

Ongoing criminalization of sex work “restrict the skills, ability and resources of sex workers to negotiate safer sex and to access HIV prevention, treatment and health care services” (Richter 2008). At times, sex workers are denied medical treatment and there is an absence of government intervention when it comes to specialized health or social programs for sex workers. It is problematic as the National Health Act 61 of 2003 clearly states that the country’s healthcare system “endeavours to protect, promote, improve and maintain the health of the population” (DoH 2014). It is evident that the law is not being upheld, therefore contradicting the constitution. It is clear that there is a need for research among transgender sex workers and their experiences of public health care access in South Africa in order to gain an understanding about where exactly the forms of oppression stem from and what are possible ways to make a change.

Locating the realities of tuberculosis in contemporary South Africa unravels in a complex intersection between socioeconomic disparity, historical remnants and co-infection diseases such as HIV and AIDS. “Among the 22 countries with the highest burden of tuberculosis, South Africa has the highest estimated incidence and prevalence of tuberculosis, the second highest number of diagnosed multidrug-resistant tuberculosis cases, and the largest number of HIV-associated tuberculosis cases.” (Churchyard et al. 2014, 244).

Tuberculosis remains one of the leading causes of death in South Africa, contributing to 12% of deaths in 2009 (StatsSA 2014, in Soul City Institute for Social Justice 2015, 7). The Western Cape Province ranks as the third highest province regarding tuberculosis incidence with 730 cases per 100,000 population in 2013/2014 (Health Systems Trust 2014).

Using tuberculosis as a lens, I explored the experiences of Ayanda and Flavia, two individuals who identify as transgender sex workers and who live in Cape Town, South Africa through an ethnographic research approach. Both Ayanda and Flavia have had tuberculosis and accessed public healthcare facilities for their treatments. It is not that tuberculosis operates biologically any different within transgender sex workers, it is rather the social effects that become important to investigate in order to understand not only transgender sex workers' experiences more generously but also to understand the social and political life that underpins their experiences. Not only are these individuals excluded from the literature on social effects of tuberculosis in South Africa, they are repeatedly left behind when even discussing the politics around sex work, feminism and gender equality. Sociologist and activist Zethu Matebeni writes the following in a satirical piece *How ~~not~~ to write about queer South Africa*:

“In your writing, transgender people should never appear. Those are the confused lots. You should not be bothered to write about them because your feminist politics does not agree with the idea of transitioning.” (2014, 61)

These satirical words speak to the exclusionary politics that are at play in South Africa, even in movements for social change. This piece of work seeks to reclaim some of the space that has been dominated with cis- and heteronormative research and speaks to the inclusivity that is needed in the realm of social research on tuberculosis and beyond in South Africa. In one way, this paper then stands as a critique in the sense that as researchers we need to be careful not to reduce people to their disease such as tuberculosis and be mindful that several other elements of social life operate in shaping experiences that can inform our understandings better. This critique then aligns itself with what Macdonald et al. (2016) point to when arguing that a research methodology and approach that is centred around the researcher's choices (for example, solely focusing on tuberculosis) does not do justice to the ethical demands in terms of the representation of participant voices.

#### **Negotiating a hostile *cistem*<sup>4</sup>**

Stigma is present in multiple parts of Ayanda and Flavia's lives and emerged almost as a 'thing' that could be felt through multiple encounters in my research. Ayanda and Flavia both experienced stigmatization because of having tuberculosis, something that social science research has focused on predominantly (Abney 2011), but other forms of stigma were also at play. Gender, sexuality, race and labour are all attributes that should be read alongside one another when looking at the process of stigmatization both Ayanda and Flavia face. Goffman (1963) defines stigma as a moral process whereby an individual forms a social identity in relation to how they would be classified. It is the process of classification

or categorisation that is rooted in the ‘othering’ of what deviates from what Goffman calls, ‘the normals’. With this notion of stigma being a moral process, to stigmatize or to be stigmatized then “describes distinctions among people, their physical traits, what is done to them, who does it, and what it means” (Garland-Thomson 1997: 31). It is important to note that what it means to be normal is deeply rooted in social, cultural and political historical and contemporary processes and are manifested in the everyday. The stigma regarding particular things or people today have cultural histories and are intertwined with those histories in the present day (Garland-Thomson, 1997).

On a cloudy Friday morning Ayanda and I were sitting outside of a clinic in Woodstock waiting for their medication. Two hours passed since giving in their<sup>5</sup> file at the admin desk. The reason for sitting outside was because I was not allowed to conduct research in the clinic. I never wanted to conduct any research in the clinic – it was not my plan. Ayanda took me there and insisted that I see what they have to go through when trying to get medication from a public clinic. There was a sense of urgency and the more I resisted to this, Ayanda would go on to explain to me how vital it is to the research project. Winning the battle of not going into the clinic, I sat outside with Flavia who we bumped into as Ayanda went in to get their medication. Another forty minutes went by of waiting and finally Ayanda came out with a rush and almost mouthful to tell us something. They told us about the stares of the people in the waiting area, people with white coats working at the clinic pointing at them and asking one another “is it a man or a woman?” about a person in the medicine dispensary area sitting behind a glass window, looking them in the eye,

ignoring their questions and eating cake. Ayanda could not stop talking and was furious. "It is like they actually saw a ghost!"

Violence is enacted in several forms. It does not always come in physical forms but can manifest through the ways people are stared at, pointed at, laughed at and questioned. It is the everyday violence that Ayanda and Flavia encounter that speaks to the type of society they live in. Veena Das’ (2007) notion that violence is present in the weave of life for some people is at the core of what I argue when I say that it is important to locate the everyday forms of violence. She thinks about violence not stemming from just one particular moment or event, but that every day is eventful and filled with moments, and to only locate violences in ‘the event’ or one moment is to be reductionist and not fully grasping the issue at hand (2007). The manner in which Ayanda was stared at when they collected their medication is a particular violence that is enacted where they are told they are not the norm, “matter out of place” (Douglas, 1966) and the object of fascination for the gaze of “the normals”.

Rosemarie Garland-Thomson’s *Staring: How we look* (2009) is a powerful text that speaks to something so ordinary in everyday life. Staring is regulated by a social code that makes some stares justified and others not in particular social contexts. The author argues that staring is a conduit to knowledge. Stares are “urgent efforts to make the unknown known, to render legible something that seems at first glance incomprehensible.” (Garland-Thomson 2009: 15). Together with staring as gathering knowledge about what is incomprehensible, Ellyson and Dovidio argues that “we enact social hierarchies through visual dominance displays” (Ellyson

and Dovido 1995 in Garland-Thomson 2009). There are forms of power in the ways that we stare at each other and it depends who is the *starer* and *staree* and what positions they hold in the social hierarchy of a society. It is clear to see how staring can produce the power dynamic present in a society like South Africa whereby trans people who do not fit the visual gender binary or disrupt that binary, are actively made out to be citizens from another sphere - somewhere *there*, not *here*.

This moment serves as a snapshot not only to see what it is like for Ayanda and other transgender people to go to public clinics but it illustrates also the power of staring. "At times, you will find that people don't go back to clinics because they can't handle it anymore. All the staring. Up and down. And then the pointing and whispering", Ayanda tells me. In *The cunning of recognition* Povinelli (2002) illustrates through her fieldwork how the social can set up a way of creating who is indigenous and non-indigenous and in this case, who is a citizen and who is not. What the notion of citizenship relies on here is more than just an identity document, it involves social aspects of who gets to be recognised as a citizen and who then makes and utilizes those criteria of recognition. Povinelli alludes to the "heterosexual hegemony" (2002: 231) that is at play in the social contract and law framework in Australia, and it is possible to see how this very hegemony is at play in the South African context. Staring can constitute a failure of the social contract and extend into the loss of citizenship when we consider the use of public resources for people who are stigmatised. It is the act of staring that makes people like Ayanda both visible and invisible at the same time. Like Ayanda mentioned: "It is like they actually saw a ghost!" A ghost is deemed to be invisible

but when visible, it comes as shock or horror. Staring then becomes more than just staring.

### **Staring back**

"When I walk down the street, I feel like a star. I am a celebrity you know. People, they stare at me and I love it because they always wonder who is this? Where did this person come from?" Flavia tells me as we sit under a tree in the backyard where she lives. Flavia uses the stares that she is met with and narrates a different story, one that helps us see how this process of stigmatization is also negotiated in the everyday. "I asked myself, why do people look at me, they have not seen a person who look like me? I am a star, like on TV. Always LGBT people are something else - artists! Some people are like drama, we are stars". Flavia's manner in which she makes sense of the staring she is met with is not a naive one as she continued to tell me that "sometimes you still have that stigma, it can never be done. Everywhere you are going people still point fingers at you, staring at you. It can never die. Just be proud of who you are, you can just be you and look back at them - in the eye". The negotiation that Flavia undergoes becomes more than just an attitude, it becomes embodied. Flavia utilizes the act of staring back at people and making a point of it in order to disrupt the assertiveness of the stare she is met with. This links to how Saba Mahmood (2012) understands agency and how those who are subordinates in society use the very same forms of power they are met with, to negotiate a better outcome for themselves, albeit at times what might seem to be contradictory on the surface level.

Flavia uses her understanding of the social order and code that is placed upon her through those that stare and in the

process, sees herself as a celebrity or star - allowed to take up space and be the centre of attention with a higher ranking on the social order. Livermon's notion on "the cultural labour of visibility" (2012) adds to this discussion on understanding agency in social spaces. He argues that black queer [individuals] create freedoms through acts of *visibilizing* themselves and does a particular labour of bringing "dissident sexualities and gender nonconformity into the public arena" (2012: 39). Using Judith Butler's notion of "liveable lives" (2004) Livermon goes on to argue that black queer individuals in Soweto made themselves visible to be recognised as part of the community. "It is only through the experience of recognition that any of us becomes constituted as socially viable beings" (Butler 2004:2) living liveable lives. Flavia is recognised by the way that she presents herself - how she dresses and how she carries herself with poise. She makes herself visible, knowing it will attract attention either for her beauty - which is a social standard she knows how to meet - or at times being "caught out" for being transgender. Flavia explained when she felt "caught out": those moments when she is met with the gaze and seen as not being "a real woman" according to the imagined visual gender binary and criteria. Either way, when Flavia is met with the staring rooted in the heterosexist patriarchal gaze that objectifies the female presenting body or the cis-normative transphobic gaze (Aaron 2007), she stares back in order to communicate that she is comfortable with who she is and to question those who stare.

Through my discussion on the power of staring, it is possible to see the everyday forms of violence that are inflicted upon both Ayanda and Flavia and how these occasions are negotiated. The manner in which these forms of

violence occur in the everyday is multiple and it is only with the use of an intersectional lens that one can make sense of them without excluding intersecting factors that oppress and violate both Ayanda and Flavia in the South African context. A focus on tuberculosis as a singular variable in both Ayanda's and Flavia's lives would have excluded all the narratives and lived experiences around the other intersecting social variables influencing their lived experiences (other elements that I discussed in my initial ethnography varied from love, loneliness, intimacy and 'hustling'). Through adapting my approach and methodology to the research process, I was able to explore their experiences beyond just having tuberculosis. This was done by not focusing solely on the disease but to immerse myself into the stories around what it is like being a sex worker or transgender and how those parts of who they are is inextricable from what they experience in the everyday. Cis- and heteronormativity is embedded in the everyday and as I have shown, it is enacted through something ordinary such as staring. As much as there is not one symptom of tuberculosis, there is not one way of researching the experience of this disease. Attention to positionality and reflexivity is vital in social research since it informs the power relations in the process of the research and what type of knowledge is going to be produced (Sultana, 2007:380). Geertz reminds us that the nature of ethnography is to interpret ways of being and that we need to be aware of our emic and etic perspectives that we hold when doing ethnography since it holds value about what is written and what unfolds in the research process (Geertz, 1973).

In one of the first conversations that Ayanda and I had where we discussed the research project, they wanted to know

what my sexual orientation and gender identity was or rather, how I identified. “So, what are you? Trans, gay, bi? Where do you fit into all of this?” Ayanda asked me. It was within this moment that I did not only become aware of the research process and that it was in fact not only going to be me asking the questions. It mattered to them whether I was part of the LGBT+ community. When I told them I identify as gay, they smiled and said, “Ah yes, that makes sense now” which I replied to with laughter and asked why. Me being gay meant to them that I had some insight as to what it feels like being “a little bit of an outsider” they told me. However, they went on to tell me that just because I am gay, it did not mean that I would understand their experiences and way of life fully because we have major differences between us.

Ayanda: "I think with *you* people it is better because you go *unnoticed* sometimes"

Pieter: “With what, or how?”

Ayanda: "Appearance and all that. You are a white gay, you will get one look and then people move on. You have become the norm.”

Ayanda was right. White gay men like me have occupied a privileged space in what we call the LGBT+ community. The intersectional analysis of race, class, gender and sexuality in the South African context, especially in Cape Town among the LGBT+ community shows us the extreme inequalities and exclusionary spaces that are at play. Matebeni contends that “whiteness and gayness in queer spaces in South Africa are assumed, implicit, accepted, and non-negotiable; however, expressions of non-normative sexuality in African populations

are made invisible and remain unrecognized” (Matebeni 2011 in Bhagat 2017, 3). The legacy of South Africa’s colonial history seeps into the present-day realities of queer<sup>7</sup> African bodies that have been “sites of curiosity, fetishism, desire, and disdain throughout colonial history as simultaneously hyper-sexualized and abhorrent” (Tamale 2011 in Bhagat 2017, 3). The racial inequality that is at play in South African society and among people in the LGBT+ community has detrimental effects and it shows in the lives of both Ayanda and Flavia. This was something I remained aware of throughout the research process and the writing of this paper through being self-reflexive and making use of a consultative approach through how I interpret the data. I propose here then that discussing elements of positionality with participants can be extremely beneficial as it enables both researcher and researched to see one another through the others eyes and how this might affect the research process.

### **Negotiated research: “I scratch your back, you cut my nails”**

As Ayanda told me the first time we met: “I scratch your back, you cut my nails” - the research approach was mainly predicated on this. I did not want the research to be a one-way stream where I get what I want and there is not reciprocity toward participants. Not only did I not want this, it was something that was made clear to me by Ayanda. Ayanda made it known that they will not be the object of research and site of extraction (as they have been several times before) and that they want their contribution to this project to be known and transparent. This made the process of the research an

interesting experience where I no longer served the imagined role as researcher, but rather collaborator or ‘listener’.

The research process did not make me the lone ranger (Nyamnjoh 2015) I thought I would be. In fact, at times I wondered if this was ‘my’ research project at all. My participants took complete control of how the research was going to be conducted, where and how I should be conducting myself as a researcher. Ayanda, Flavia and I met up several times after I told them I got enough data to write the thesis. That I was ‘done’ with the fieldwork did not stop them. Both Ayanda and Flavia wanted to be a part of the writing process and wanted to see what I would be writing. This consulting process created a relationship of collaboration and conviviality – the way that Francis Nyamnjoh (2015) begs of us to produce anthropological works today and in the future. The process that we embarked on was me reading out loud what I had written and Ayanda and Flavia commenting on what needs to be changed and included. In the final thesis, I included the conversations we had when writing together in order to show the reader the contestations around particular descriptions and quotes I would utilise. Taking on this approach set out by my participants, showed me the power of ethnography and what ethnographic research is capable of when letting go of authoritative ideology and praxis. This disrupts the positivist heterosexist-patriarchal-capitalist remnants of research that operates within a binary of the researcher and the researched as well at the university versus the public as completely different and opposing realms of social life. This practice also challenges the idea that participants should only receive a copy of the research product after it is written by the researcher. Nyamnjoh outlines conviviality as the “recognition and

provision for the fact or reality of being incomplete. If incompleteness is the normal order of things, natural or otherwise, conviviality invites us to celebrate and preserve incompleteness and mitigate the delusions of grandeur that come with ambitions and claims of completeness.” (2012, 10). Nyamnjoh goes on to argue that “not only does conviviality encourage us to recognise our own incompleteness, it challenges us to be open-minded and open-ended in our claims and articulations of identities, being and belonging.” (2012, 10). Thinking within this realm of incompleteness, the language around vulnerability also sheds light on the point I am making through this discussion. Being vulnerable or at least accepting your incompleteness, opens up possibilities in research to produce more ethically sound knowledge together *with* people and not *about* people.

### Concluding thoughts

For most of this paper, I did not discuss tuberculosis nor the physical experiences thereof. I actively choose to do this as it was not something Ayanda nor Flavia talked about during our time together although having known that that was at the premise of my research. Were it not for embracing my own incompleteness and a convivial approach in an attempt to produce research with and not of my participants, I can easily reproduce narratives of radical alterity (Robins, 1996). Through discussing an element of everyday life such as staring that majority of people enact, I argue that this approach enables us to understand different forms of violence that are experienced alongside other more visible forms of violence. This approach is not something I came about by myself but rather through multiple discussions with Ayanda and Flavia



and through the negotiated research at play in the research process. What this allowed was more space for me to see beyond the apparent since there was a shared responsibility in terms of producing the research. Through embracing narratives of how life is experienced in the everyday instead of focusing on one variable such as tuberculosis, accepting our incompleteness, as well as striving for research practices that are convivial, I conclude then that it becomes possible to do more ethically sound research that disrupts dominant discourses on how research should be conducted.

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### Notes

<sup>1</sup> A transgender person usually refers to someone whose assigned gender does not match their assigned sex at birth. Patel (2017, 61) states that the terms also “operates as a way of promoting association between those who transgress the gender binary.”

<sup>2</sup> Cisgender “is indicative of a (non-trans) person who identifies with the gender assigned to them at birth (based on a system where the sex binary is equated to gender)” (Patel 2017, 61)

<sup>3</sup> Communicable diseases such as tuberculosis, non-communicable diseases such as diabetes, injuries and HIV/AIDS.

<sup>4</sup> Coloured is a recognized racial category in the South African context. See Mohamed Adhikari (2017) for an in-depth discussion.

<sup>5</sup> Cistem is a concept by Patel (2017) where they relay that “by cistem [they] refer to the systematised power which oppresses, subjugates, and marginalises transgender people” (2017, 51) that is rooted in cisnormativity.

<sup>6</sup> Ayanda prefers the pronoun they and them which serves to subvert the gender binary, as they do not identify as him/her, she/he or man/woman. Throughout this paper I use they, them, themselves when speaking of or about Ayanda. For the reader that might feel it is a grammatical error, I urge you to take this into consideration when reading.

<sup>7</sup> The term queer, which is at times considered derogatory, is understood and used here as a reclamation and affirmation to “refer to the range of people who transgress heterosexual and cisgender norms.” (Patel 2017, 61).

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