

Unsilencing the silent South African HIV-positive RESEARCHER: An HIV-positive researcher's reflection on negotiating insider- outsider positionalities whilst conducting a HIV study in eThekweni, KwaZulu-Natal, South Africa

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The research study that informed this article's discussion, critically interrogates an HIV-infected research team's positionality whilst conducting a mixed-methods' study on HIV-positive patients' experiences of the public ART programme at four ARV clinics in KwaZulu-Natal, South Africa. It primarily utilises the principal investigator's (PI) narrative to explore insider/outsider positionality, reflexivity, bracketing and participatory action research through exposure of feelings, emotions, challenges, engagements, relationships and observations. The fluid positionality of the HIV-positive research team presented both challenges and opportunities. However, the opportunities for more HIV-infected researchers to engage in HIV-related research to assist with destigmatising HIV, close research gaps and the creation of a trustworthy research environment to achieve an ethical and reliable health science study, far outweigh the challenges. Further, such research can improve patients' support and healthcare, healthcare workers' perceptions of patients, and provide a guide for policymakers to better understand the recipients of HIV policies. Lastly, the term 'HIV reflexivity' is coined as a result.

UNSILENCING THE SILENT SOUTH AFRICAN HIV-POSITIVE RESEARCHER: AN HIV-POSITIVE RESEARCHER'S REFLECTION ON NEGOTIATING INSIDER- OUTSIDER POSITIONALITIES WHILST CONDUCTING A HIV STUDY IN ETHEKWINI, KWAZULU-NATAL, SOUTH AFRICA

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INTRODUCTION

Over the past three decades many HIV-related studies have been conducted by social scientists, clinicians and anthropologists, to name a few. Most of these studies emphasise epidemiology, stigma, prevention, microbicides, treatment side effects, patient adherence and retention. However, few focus on HIV positionality, reflexivity, participatory action research and an insider/outsider dichotomy (Engler, Lènart, Lessard, Toupin & Lebouché., 2018; Mariam, Olshansky & Lakon 2018; Meintjies, Moorhouse & Carmona 2017; Reynolds, Camlin, Ware & Seeley 2016; Vernooij, Mehlo, Hardon & Reis 2016; Gerard, Birse, Holm, Gajer, Humphrys, Garber, Noël-Romas, Abou, Mccorrister, Westmacott, Wang, Rohan, Matoba, Mcnicholl, Palmer, Ravel, & BURGNER, 2018). This could be perceived as prioritising HIV biomedicalisation rather than ethnography (Montgomery & Pool, 2011; Hardon & Moyer, 2014).

As an HIV-positive woman, who has accessed and been involved with public ART programmes and studies for over a decade, it was inevitable that my PhD would be HIV-related. Hence, my mixed-methods study addressed the experiences of HIV-infected patients at four public ART sites within the eThekweni District, KwaZulu-Natal which is the region where I access treatment. In preparation for the study, I conducted literature searches on patients' experiences of the public ART programme, patient-centred care and positionality. These searches included books reviews, government policies, guidelines and protocols, theses and academic studies (Adams, 2016; Berger, 2015; Gilmore & Kenny, 2015; Department of Health, 2012; Skovdal & Abebe, 2012; Erikson, 2011; Department of Health, 2002). I was also aware that apolitical or neutral studies were rare as researchers' beliefs, identities, values and backgrounds can influence them and affect scientific decisions. These include what to research and which study methodology and analysis techniques to use (Vanner, 2015). Hence, I committed to pursuing a credible, ethically sound study which is attainable through consistent, honest, transparent reflection and avoiding compromising interpretation and the data analysis. Subsequently, I investigated the notion of positionality on a sensitive, vulnerable population (Court & Abbas, 2013). Positionality is the degree of relatedness and identity of the researcher to the study participants and/or study setting along the intersections of ethnicity, class, lived experiences, illness or sex, to name a few aspects (Chereni, 2014). It is never fixed and stable but fluid due to its changing and fluctuating nature which changes according to the context, content, feelings, ideas expressed and the study environment. Furthermore, I wanted to ascertain the scientific contribution of HIV positionality as well as its potential challenges within a sensitive and vulnerable study population.

Positionality literature searches highlighted positive and negative reviews. It further highlighted its importance in research, its changing dynamics, how it provides relevant information about the researcher, the researched and the research environment, and how it contextualises many studies (Jaffar, 2018; Nero, 2015; Nowicka & Cieslik, 2014). Hence, I was able to identify the importance and challenges of acknowledging and disclosing the team members' positionality in relation to the participants and study setting, understanding its changing dynamics during the study and the researchers' power, biases and privilege from the onset. This endeavour assisted in creating awareness and developing strategies to address transparency, trustworthiness, ethics, study methodology and the researchers' perspectives within the study.

As positionality incorporates researchers' insider/outsider identity, all three research team members were implicated and connected to the research population through their HIV-positive status, blood tests, medicalisation, ethnicity, lived experiences, illness, sex and them accessing public ARV clinics. Hence, they were insiders in terms of their identification with the researched. Insiders refers to "researchers who share a similar background as the group they are studying and have an advantage in collecting qualitative data" (Flores, 2018:2). They were also outsiders as their experiences as patients were not the subject of the study. Flores (2018:2) further defines outsiders as researchers who do not share similar backgrounds or experiences with the group under study. The insider/outsider identity promotes an understanding of the researchers' positionalities and multiple identities, which can affect the research process, validity, trustworthiness and findings. Such multiple identities have been recorded in a Mississippi study which found that insiders lessened, "the distancing effects of the outsiders", even though outsiders were perceived as playing a prominent role in community studies (Muhammad, Wallerstein, Sussman, Avila, Belone & Duran, 2015:4).

Positionality and insider/outsider identity have been discussed and appropriately used in several HIV studies with researchers identifying as insiders through sex, race, class, gender, language, being carers and family and community members (Akhurst, Van der Riet, M. & Sofika, 2018; Banks, Zuurmond, Ferrand & Kuper 2017; Angotti & Sennott, 2015). However, worth noting is that although the HIV-related stigma still exists, looking for evidence of HIV-infected researchers disclosing their status within HIV studies revealed a deafening silence. It is unknown, however, whether researchers explicitly choose not to disclose or identify as HIV-positive within HIV studies.

This study differs as the research team comprised of an HIV-infected primary investigator (PI), two HIV-infected research assistants and 412 HIV-infected patients participating in an HIV study. It aims to fill the HIV-infected researcher and patients positionality gap within HIV literature and actively unsilence HIV-infected researchers.

METHODOLOGY

The research team and their positionality

The research team comprised of the PI and two research assistants who were conversant in isiZulu, Afrikaans and English. The research assistants' training included a discussion of the length and breadth of the research process, their positionality and unique patient experiences who accessed three public ARV clinics in eThekweni (Vukotich & Yearwood, 2014). During this training, the PI and the research assistants collectively chose to voluntarily disclose their HIV-positive status to eliminate any divide between researchers and participants (us and them). They thereby evoked the notion of 'disclosure' as agency. This decision was based on their past experiences of participating in other research studies whereby those researchers assumed superior positionalities. These researchers and those study participants interpreted their behaviour as stigmatising and discriminating against HIV-infected people (Råheim, Magnussen, Sekse, Lunde, Jacobsen & Blystad, 2016).

During the pilot stage, five patients were sought from the four sites to test the questionnaire in order to ascertain if it comprehensively addressed the unique processes of four ART clinics and if it was expressed in a way that all participants could understand (Gumbo, 2014). To create open and transparent engagement in the light of the study aims and objectives, the research team members' observer roles as well as their HIV-positive status was explained and disclosed to the pilot patients and hospital staff, and was later disclosed to study participants (McAreavey & Das, 2013). The five patients stated that it was the first time their opinion was sought in a research study.

Language, translation and participant involvement

After perusing the questionnaire, the pilot patients informed the PI that they did not identify with the study instrument, as it was not compiled by them. They expressed that they were of the opinion that the originator of the questionnaire was not HIV-positive. They further informed her that an English and isiZulu questionnaire created division and promoted isiZulu as an inferior language and preferred a simply-worded

English questionnaire. They recommended that isiZulu HIV-positive research assistants be on hand to limit language and cultural differences during the data-collection process and to provide employment opportunities for HIV-infected patients.

All five patients advocated for a patient-compiled questionnaire as they considered patients as experts of a patient's perspective of the public ART programme. They volunteered to assist the PI compile the questionnaire (Zachariae, O'connor, Lassesen, Olesen, Kjær, Thygesen & Mørcke, 2015). Another reason for their agreeing to be part of the questionnaire compilation was that they wanted to go down in history as being part of a research study where they were to some extent both researchers and the researched.

Research methodology and the research process is infused with a power dynamic which favours the researcher rather than the researched. This is evident in studies researching vulnerable, sensitive populations (Vanner, 2015). Hence, after consultation with the supervisor and other academics, the five patients assisted in compiling a new questionnaire. Thereafter, a new set of five patients from the four sites tested it. The decision to embrace participatory action research (PAR) methodology reflected the dynamic nature of research as this had not been included in the initial study planning. However, it allowed for power sharing with the PI, who provided mentorship and training on questionnaire compilation, whilst the patients provided input for a questionnaire that adequately represented their experiences and the varying facility processes (Bergold & Thomas, 2012). It also allowed for shifts in boundaries and identities as the testers were co-researchers and their decision-making capacity was elevated as they co-owned the questionnaire compilation. However, they were only involved in its compilation. This approach is similar to a Kenyan study which utilised a multimethod approach to develop implementation strategies for a cervical self-sampling programme (Podolak, Kisia, Omosa-Manyonyi & Cosby, 2017). They further recommended that a study articulating patients' experiences and challenges be accompanied by recommendations and solutions for an improved public ART programme by patients themselves, rather than by management, policy makers and government officials.

Dual positionality, reflexivity and bracketing

Reflexivity and bracketing were used as a methodology as both are suited to studies on human (patients') experiences (Chan, Fung & Chien, 2013). All the research team members agreed on the adoption of a reflexive bracketing stance, as they were both the researched and researchers. They approached their roles from subjective angles as they entered the study arena with perspectives, experiences, ideas, a 100-question questionnaire and in-depth questions for 12 interviews (Chan *et al.*, 2013). Reflexivity involves "thoughtful, analytic self-awareness of the researchers' experiences, reasoning, and overall impact throughout the research process" (Råheim *et al.*, 2016:2). It further highlights issues of agency, connection and relations to explain the team members' positionality. Although reflexivity identifies similarities between researcher and participants, some studies criticise it as focusing primarily on the power dynamic rather than the topic at hand. Bracketing entails deliberately "putting aside one's own beliefs about the phenomenon under investigation or what one already knows about the subject prior to and throughout the phenomenological investigation" (Chan *et al.*, 2013). As Ryan (2015) promotes the continuous disclosure of relational information between the researched and researchers as well as researchers' biases, power and privileges throughout the research process, the researchers' decision to implement reflexive bracketing took cognisance of this.

The PI and the research assistants were cognisant of their dual positionality within the research process, which engages with the notions of multidimensional, fluid positions and power dynamics. They were insiders in terms of being patients at various public ARV clinics themselves, and outsiders in terms of their education, familial and social backgrounds. Their patient experiences were not part of the data-collection process. This has been reported in another study (Kerstetter, 2012).

Their dual positionality did not contaminate the research process, as the researchers did not communicate this to the participants, but rather identified with them as insiders (patients), which resulted in participants volunteering in-depth information based on their experiences as patients (Razon & Ross, 2012).

PI's reflexive role

As a researcher who forms part of the researched community, the PI was cognisant of becoming too involved with the researched to avoid inhibiting the process. She was also aware of the sensitive nature of HIV-related studies due to them addressing death, grief, sexuality and chronic illness. Hence, she continuously addressed these concerns with the research assistants in the daily reflexive sessions (Pithouse-Morgan, Khau, Masinga & Van De Ruit, 2012).

To ensure non-reaction to negative observations, the PI constantly reminded herself and the assistants of their dual role as patients and researchers. This was an endeavour to fully explore and understand the experiences of the study patients. The acknowledgement of their dual identity made it easier for the team members to temporarily cast aside their own thoughts, values, perceptions and experiences.

Positionality and ethics

To ensure rigour, the PI advocated for equal power dynamics between the researched and researchers which would not compromise ethical research or a fieldwork study (Vähäsantanen & Saarinen, 2013; Dixon, 2015). The implementation of reflexive bracketing and reflexive daily sessions assisted the research team members to identify potential biases and bracket them to ensure minimal bias (Tufford & Newman, 2012). Moreover, the PI utilised reflexive bracketing, triangulation, daily team members' check-in sessions, detailed coded transcriptions, systematic planning and ongoing liaison with her supervisor and peers to ensure research rigour.

Boundaries between the researched and researcher as an 'us and them' phenomenon is widely evident in research. This perpetuates a power dynamic which is not cognisant of the fluidity and multiple overlapping identities of individuals (McNess & Crossley, 2015). To address power and positionality dynamics, the PI endeavoured to mentally separate her personal and academic persona, and addressed this in the reflexive meetings. Another interventional process entailed noting such incidents to ensure that the research findings drew attention to the data to enhance and improve such situations for future activist engagement and for the improvement of HIV service delivery which could benefit all HIV-infected patients.

Strengths, weaknesses, opportunities and threats

All the researchers were aware of the risk of their HIV disclosure in the face of HIV-related stigma. However, their social responsibility to the research population, by providing a platform for patients' experiences to be articulated by a research team who walked a similar walk, far outweighed the risk of any potential academic, career, medical or personal backlash. They viewed the opportunity of a synergistic outcome for their fellow patients as greater than them being othered. They further viewed their positionality as challenging traditional public health research, whereby researchers' personal status or experiences are mostly hidden in an endeavour to conduct an ethical study (Greene, 2014). Furthermore, the research team members' disclosure and experiences as patients proved advantageous in probing deeper to gain rich data, as well as easier access to staff meetings and the various clinics within the hospitals (Byrne, Brugha, Clarke, Lavelle & Mcgarvey, 2015). Confidentiality did not prove a problem, as they were HIV-infected researchers who had discussed confidentiality from their initial visit to each clinic prior to the data-collection process commencing.

FINDINGS

Response of the health care workers and patients to disclosure of the PI's and research assistants' HIV-positive status

Health care workers

Although the PI and research assistants had meetings with the gatekeepers at each ARV clinic to explain the research aims, objectives and positionality prior to data collection taking place, some nurses and counsellors at the ARV clinic where the PI is a patient viewed the process with some suspicion and questioned some participants. Some patients reported this to the PI. To improve transparency,

eliminate any trust issues that staff may have had and to address any concerns about the study, the PI requested that she attend at least two staff meetings (Sankaré, Bross & Brown, 2015). The sister-in-charge agreed and the PI again informed all staff about the research and the process. No further challenges were encountered after this. On the contrary, some nurses and counsellors in fact encouraged patients to participate in the study. This highlighted the need for constant communication with gatekeepers to improve relationships and trust.

The primary questions some health care workers (HCWs) asked the researchers at the sites were:

Aren't you too close to the subject?

Is this research too sensitive for you guys?

Can an HIV- positive researcher study HIV-positive patients' experiences?

Such reactions have been noted from fellow researchers and social scientists as well as in positionality critiques based on researchers' experiences and voices being elevated in comparison to those of the researched (Esping, 2011). Further, every endeavour was made to avoid insider researcher-patient experiences compromising the study. For example, the research team members never discussed their experiences as patients with the participants, nor the facility gatekeepers. However, they regularly confronted and discussed their positionality and subjectivity in research reflexive meetings and the term 'HIV reflexivity' was coined.

The team members' response to concerns regarding their disclosure was that their HIV status, positionality and subjectivity was disclosed to a) promote transparency, b) identify with the target group, c) access rich data, d) fully engage with the participants, e) be literate regarding HIV terminology and processes, and f) avoid use of insensitive language and conflictual situations. This was particularly important to the team members and the pilot patients who had participated in several HIV studies and had encountered researchers' insensitivity and ignorance. Such insensitivity included researchers referring to HIV-positive patients as *victims* and using terms such as *shame, poor, you guys, defaulters* and *infectious people*. Another example was researchers discussing patients' personal details in the corridor, in full view of other patients and healthcare workers. Other insensitive questions asked by some researchers were: *Who infected you? How did you get HIV? Are you gay?* Such questions were irrelevant to a research study addressing adherence.

The researcher took cognisance of all critique and studied and extensively engaged with issues of auto-ethnography and positionality to ensure a valid and reliable study (Benjamin-Myers, 2012; Runestad, 2016).

Patients

Patients constituted the only participants. They viewed the research team members' HIV disclosure from the onset as promoting HIV activism, providing hope for patients and displaying a great deal of respect and trust towards participants. Patients stated that this encouraged them to participate in the study. Furthermore, many patients stated that the researchers' positionality encouraged them to study and someday conduct research themselves to empower other patients, health care workers and the research community.

The insider positionality promoted a positive rapport and empathy for the patients. A patient who identified as a heterosexual woman shared details with the PI of her lacking an intimate relationship. The PI attributes the patient's comfort level in relating to her, as being due to the PI identifying as a woman, being of a similar age group and her openness about her HIV status. The likelihood of the patient sharing those details with a younger HIV-negative male PI is debatable. This view is based solely on prior observations of patients participating in HIV studies. However, this observation is similar to what has been reported in a multi-positionality study (Chan *et al.*, 2013).

Worth noting was that none of the patients expressed any interest in the PI or the research assistants' personal experiences of the public ART programme. However, all the patients constantly used terms such as "us" and "we" during the in-depth interviews. The PI perceived this as joint identification.

TEAM REFLEXIVE DISCUSSIONS

The team members' connection to the study population as HIV-positive patients was thoroughly discussed in daily reflexive meetings to explore and address any challenges, risks and opportunities that could arise whilst researching a sensitive research population. Examples of some issues discussed were research assistants' uncertainty about patients who discussed topics that were not part of the questionnaire and interview; how to refrain from making the process about themselves rather than about the participants, and how to remain objective when staff were rude to patients. Further, examples are instances when interviewed patients, who accessed the same ARV clinic as the research team members described similar emotions and positive and negative experiences to those experienced by them whilst accessing the ART programme. The daily meetings took the form of open-dialogue sessions regarding the research process. The meetings empowered each team member by increasing their knowledge of the culture and processes of all four ARV clinics, patients' personalities, their own life experiences and reflections. This promoted respect for each other and the various stakeholders involved in the study.

ETHICS

As the PI is in full support of ethical research and ethical norms, the piloting and data collection commenced only after ethical clearance was received from the University of KwaZulu-Natal (BFC089/15) and the KwaZulu-Natal Department of Health (HRKM158/15).

RECOMMENDATIONS

Based on the study findings, a comprehensive understanding and acknowledgement of researchers' positionality from the onset contributes to the trustworthiness and validity of the study. Additionally, the continuous management of this enhances the process. HIV auto-ethnography, insider/outsider and dual positionality are encouraged to promote disclosure and open dialogue and to destigmatise the disease.

CONCLUSION

Positionality of HIV-positive researchers presents both challenges and opportunities. Positionality can be fluid with the researcher fluctuating between insider and outsider roles at various points in the research process. However, the opportunities for more HIV-positive researchers to engage in HIV-related research, assist with destigmatising HIV, closing the gap between the researched and the researchers, and the creation of a trustworthy research environment far outweigh the challenges. Further research can improve patients' support and healthcare, as well as healthcare workers' perceptions of patients, and provide a guide for policymakers to better understand the recipients of the HIV policies they formulate.

Competing interests

The authors declare that they have no financial or personal relationship(s) which may have inappropriately influenced this article.

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