‘Remember there is that thing called confidentiality’: Experiences of institutional discrimination in the health system among adolescent boys and young men living with HIV in the Eastern Cape province of South Africa

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Abstract

Adolescents and men are two populations that perform poorly within the HIV cascade of care, having worse AIDS-related health outcomes, and experiencing higher levels of HIV-related stigma. This paper explores institutional health system discrimination as experienced by adolescent boys with perinatally-acquired HIV, situating them within the social and gendered contexts of the Eastern Cape Province, South Africa. Life history narratives (n=36) and in-depth semi-structured interviews (n=32) with adolescent boys living with HIV aged 13-22 were conducted in 2017/2018. In-depth semi-structured interviews with biomedical and traditional health practitioners (n=14), analysis of health facility files (n=41) and clinic observations were also conducted. This article contributes to the limited extant literature on the experiences of young men within the HIV continuum of care, focusing on how stigma influences how young men experience and engage with the health sector.

Keywords: stigma, adolescence, masculinity, South Africa, HIV, care

Introduction

Adolescents in Eastern and Southern Africa experience poor HIV-related health outcomes due to challenges with adherence and retention in care (Hudelson and Cluver 2015; Nachega et al. 2009). HIV-related stigma and discrimination have been documented as significant barriers to antiretroviral treatment (ART) adherence, retention in care, and the health of people living with HIV (Rueda et al. 2016), and this is also true for adolescents. A South African study of adolescents living with HIV found that discrimination experienced in the healthcare system was associated with reduced medication adherence and retention in care both directly, and through increased internalised stigma (Pantelic et al. 2020). Similarly, a study with refugee and internally displaced youth in Uganda found that healthcare mistreatment and confidentiality concerns acted as deterrents for HIV testing and healthcare engagement (Logie et al. 2021). Further research is urgently needed to understand and reduce the institutional discrimination experienced by young people living with HIV within the health system.

Adult men are another group that experience poor HIV-related health outcomes, and are less engaged in HIV services in many settings (Tsai AC 2015). This is true in South Africa, where men are significantly underrepresented in HIV testing, treatment and psychosocial support (Johnson et al. 2013; Cornell et al. 2010). They are more likely to default or die while receiving ART, seek treatment less and at a later stage than women, and are less likely to be retained in the HIV cascade of care: that is, HIV-testing, initiation onto ART, and retention in HIV care services (Cornell et al. 2010; Johnson et al. 2013). The reasons for these gendered health outcomes are complex (Colvin 2019). One such reason is that acceptance and disclosure of an HIV-positive status may be different for men and women because of conventional views of male identity, fear of shame, secondary stigma and isolation from loved ones (Iwelunmor, Sofolahan-Oladeinde and Airhihenbuwa 2015). Men are less likely to discuss their HIV status with friends, and more likely to report being treated differently since they tested positive (Simbayi et al. 2007). This is also true in other contexts. A US study found that stigma impacted retention in HIV care for men more than women (Kalichman et al. 2020), and a study in Mozambique found that men with anticipated HIV stigma were less likely to access HIV testing (Ha et al. 2019). Programmes and interventions that target the unique challenges and needs of men, including addressing the ways that stigma articulates and shapes health care access in this group are essential to promote the engagement of men in HIV- related care (Ha et al. 2019).

Adolescent boys and young men living with HIV remain underserved and understudied, with notable gaps in the research literature. First, despite well-documented associations between gender, adolescence and retention in care, scant research has explored experiences of adolescent boys and young men living with HIV within the health system. This is a crucial area for enquiry, given evidence that adolescent adherence and virological outcomes may also be gendered, with older boys experiencing worse outcomes than girls and younger boys (Denison et al. 2018; Brittain et al. 2017). A growing literature also points to evidence gaps in research on HIV-positive adolescent masculinities, highlighting the importance of considering and exploring the challenges and needs of boys as well as girls (Shefer, Kruger and Schepers 2015; Hensels et al. 2016). Beyond this, the broader literature on adolescent HIV-related stigma and discrimination has largely focused on interpersonal dynamics and psychological manifestations, despite calls ‘to conceptualise these as “social processes that can only be understood in relation to broader notions of power and domination' (Parker and Aggleton 2003, 16). This has limited the scope of evidence-based interventions to address HIV-related stigma. Few well-established adolescent-centred anti-discrimination interventions exist, and most adult-centred ones privilege psycho-educational approaches over institutional change (Parker and Aggleton 2003; Stangl et al. 2013).

This paper contributes to the limited extant literature on the experiences of young men in HIV-related care. We explore and document their experiences of institutional discrimination, and how these in-turn influence how they experience and engage with the health sector. Most research on HIV-related discrimination focuses on inter-personal dynamics, overlooking structural discrimination. We define institutional discrimination as the failure of health systems to provide an appropriate service to a group of people based of their identity and/or health condition (Sir William MacPherso of Cluny 1999). Institutional discrimination occurs due to systemic flaws that allow for—and at times perpetuate—both conscious and unconscious discrimination against specific users and, in doing so, disadvantage their ability to equitably access care (Cunningham and Light 2016). Institutional discrimination may manifest itself as 'inaction in the face on need' (Jones 2000), and has profound effects on patients who experience a multitude of psycho-social stressors in their lives, such as adolescent boys living with HIV. In this paper, we examine the limits of a discriminatory health system to retain adolescent boys and young men in HIV care, against the backdrop of the context-specific masculine norms they navigate as they transition into adulthood.

Materials and methods

Data were collected in rural, urban and peri-urban areas in the Buffalo City Metropolitan Municipality and Amathole District of the Eastern Cape Province of South Africa over 16 months in 2017 and 2018. The Eastern Cape is among the poorest provinces in South Africa. The province has the second highest rate of child poverty, with 78.7% of children living in poverty (Statistics South Africa 2016), and the highest rates of unemployment: 40.5% in the first quarter of 2020, climbing still further to 47.9% in October-December 2020 (Statistics South Africa 2021b).

Data were collected from adolescent boys and young men living with vertically-acquired HIV (n=35, ages 13-22) using health-focused art-based life history narrative interviews followed by in-depth, semi-structured interviews (n=32) one to four months afterwards. Health facility files containing medical charts (n=41 files of 30 participants) from 14 health facilities were reviewed, photographed and analysed alongside interview data. In-depth semi-structured interviews were conducted with traditional and biomedical health workers (n=14). Research tools were piloted, and then developed iteratively, in response to emergent findings. The research team discussed each interview within 2 days of its completion and periodically adjusted tools. Observational data were collected in the form of fieldnotes from health facility visits and recorded conversations with research team members who lived in the study area.

Interviews with boys and young men were conducted by two young, isiXhosa-speaking male researchers (SM and PK). Health worker interviews were conducted by the lead author (LG). All interviews were audio-recorded, translated into English, and transcribed. Interview data, health facility file photographs and fieldnotes were coded with the aid of Nvivo Software. Both interview and clinic file data were analysed inductively, using thematic analysis (Braun and Clarke 2006). Participant-selected pseudonyms are used in the presentation of findings. We engaged an iterative approach to analysis and interpretation, validating emergent findings with participants and researchers throughout stages of data collection. Further details concerning data collection and analysis methods can be found elsewhere (Gittings, Colvin and Hodes 2022). The University of Cape Town (HREC 314/2017) and the Eastern Cape Department of Health (EC_201709_13) provided ethics approvals. Informed consent was provided by all participants, and in the case of legal minors, their caregivers.

Results

Findings suggest two institutional discrimination-related deterrents to retention in care: (1) lack of confidentiality due to health facility layout and practices that visibilised people living with HIV; and (2) mistreatment by healthcare providers in the form or shouting and gossip. Further, results suggest that the same stigma-related factors that deter adult men from accessing HIV care begin to affect adolescent boys as they become older, and that feeling disrespected, powerless and emasculated at health centres are sequelae of institutional discrimination with far-reaching consequences for boys and young men.

Institutional Discrimination: Health Facility Layout and Practices

Adolescent participants described confidentiality concerns as a deterrent to accessing treatment and care. Institutional practices instilled a profound fear of 'being seen' to be accessing HIV services by other patients and peers. Informants highlighted several practices that compromised their confidentiality in health facilities, including separate seating areas for people living with HIV and other patients, as well as different coloured folders and patient 'books' in which details about their HIV-related health practices were recorded. Participants tried to keep their HIV-positive status a secret within this challenging environment by lying or leaving the facility if they saw people they knew. In trying to keep their HIV-positive status a secret and practising stigma avoidance, participants were also deterred from accessing HIV treatment and care.

> There are a lot of people I know there, like I am not ready for my status to be known by other people. So when they see me if I am there, there is no use. I just feel down when I have been seen by someone who knows me while I am fetching my medication… there is separation of departments between HIV, TB and others. I would (rather) like us to sit in the same waiting room. Remember that there is that thing called 'confidentiality' so we don't need to know... I don't feel good when I'm about to go to the clinic because even yesterday I was supposed to fetch my medication, but when I arrived after taking my folder I noticed pupils from my school at the other room so I went back home. (Luya, 17)

> At the clinic people that are living with HIV, it's like they are making a joke out of them. What I mean is being given those folders you see? … What I don't like is those folders. (Svij, 25)

The above excerpts speak to how the facility layout and other practices that visibilise people taking chronic medication were sources of stigma, stress and discomfort. Such concerns were most pronounced in health centres in smaller communities (rather than large public hospitals), and in facilities where patients with HIV, tuberculosis and/or chronic conditions were separated from others. For example, one health facility had a specific bench where people collecting medications for chronic conditions were required to wait. This bench was separate from, yet visible to, other clinic patients and staff. When it was a patient's turn to be seen, their name was called. In this facility set-up, people picking up chronic medications were thus visually and audibly identified. Other health facilities visually identified patients in receipt of ART through the use of specifically coloured folders, or labelling areas for patients with HIV. Local researchers and participants elaborated on how community-level surveillance and institutional discrimination coalesce. They suggested that people picking up chronic medications are assumed to be living with HIV, and are thus the targets of HIV-related stigma.

> It is the eyes of the people. It seems like they are talking about me… I lie to them and tell them that I am here to collect medication for someone else… (Nkweza, 18)
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> People are curious - why are you sitting on that bench?... in our community, people are tested (for HIV) by eyes. (Researcher, Male, 28)

Institutional discrimination: mistreatment by health workers

Adolescent boys and young men spoke about being how being shouted at, othered and discriminated against by health workers was causing psychological distress, deterring them from clinic appointments.

> Some people treat us badly, like there is nurse who is taking care of us at the HIV side, she is rude and I don't like her. She likes to shout and insult us by saying that we are going to die… So she is always insulting for unnecessary things but she was trained and she should know how to treat people. I don't like her. When I am going to the clinic I don't like to be attended by her…. People are talking at the clinic that this woman is silly, you know mos, rumours. (Luya, 17)
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> They shout at me… My nurse is upset with me because I don't take my treatment well, she doesn't want to talk to me she just wrote on the book and tell me to go and fetch my medication on the other side…It's painful. (Nkweza, 18)

Participants described their experiences of being treated poorly at the health facility, which they linked to being singled out on the basis of their HIV-positive status, and being scolded by nurses. They spoke about their fears of being gossiped about, not trusting nurses, and seeing them laughing and wondering if they were talking about them behind their backs. These experiences acted as deterrents from accessing health services and speaking openly with nurses about the challenges they face in living with HIV and accessing care.

Clinic files gave insight into health worker perspectives, which often used judgemental and stigmatising language, describing young men and adolescent boys living with HIV as 'chronic' defaulters, who 'mess around' and are 'in need of repeat education'. Exasperation and frustration were evident in health workers' notes, which often described participants they were unhappy with as defaulters, who required repeat education to change their ways. Files also showed various approaches that health workers took in response to non-adherence. These ranged from incentivising pill-taking (e.g. gifts for improved viral load), but more often, ultimatums (e.g. 'I'll give him another chance to prove himself'), education and reprimand. The clinic file notes were limited and often short, but were demonstrative of how some health workers perceived adolescent boys and young male patients as problematic, individually responsible for not taking ART or attending the health facility, and in need of correction and obedience. Moreover, the language and tone of the notes is illustrative of an environment where the judgement of adolescent boys and young men living with HIV is sanctioned and acceptable.

Young masculinities and stigma: Traditional and biomedical health worker perspectives

The findings above bring up important considerations about how gender and age intersect to affect the experiences of discrimination within heath facilities. This was discussed by both traditional and biomedical health practitioners in this study.

> Now you get to the hospital, it is also a government service. People go to the hospital because they are in a weak state, it affects their mental state, it affects them… but this male is coming from this patriarchal society that favours them. He goes into this ward, (they tell him) 'Man go there, just go straight, where is your folder? Why did you leave it? Go to that room!'. He goes still, he still goes, but he dreads it. But this pain he is feeling, the sickness he has, he has to go… This man who is from this patriarchal society, then they become vulnerable in this space because they don't have authority. They are being told "go there", they are in a queue. If they go to the *sangoma*, the sangoma knows that where he stays there that has 30 cows, he is a man. He even calls him by his clan name because he knows them. But when he goes to the hospital, that clout he thought he has, it is not there. (Luthando)

Here a traditional health practitioner reflects on dynamics in relation to masculinity and feeling subject to the control of healthcare workers. He suggests that men might feel undermined and disrespected in the biomedical system, and that being abruptly instructed and bossed around by may be a deterrent to accessing services, dynamics also cited by participants in this study. These factors may not be as present with younger men, due to their young age in a culture with a strong age-based hierarchy. However, they do speak to some of the potential additional sensitivities that young men may face as they get older.

The unit manager of a large hospital suggested that adolescent boys might have more trouble adhering to ART since the HIV-related stigma that affects men also begins to affect them more as they grow up and they are not as directly under caregiver supervision:

> … When they haven't (yet) grown up to look after themselves, you find that they are adherent to treatment. But when they have been given that leeway that they must look after themselves, it's when there is a high rate of defaulting. Especially with the male adolescents, more than the girls. I'm sure it's the stigma attached, the same stigma that

> affects men… You'll find that there are other psychosocial issues that one hasn't dealt with, and they influence the way that one will behave and be adherent to treatment… (Sister Nceba)

Here, Sister Nceba suggests two factors in relation to poorer clinic attendance and retention in care: (1) age and caregiver accompaniment, and (2) gender. The first corresponds with the suggestion that caregiver accompaniment is a significant factor in retention in care for adolescents living with HIV (Cluver et al. 2018). She also is suggesting that, when adolescents gain autonomy, that they are more likely to disengage from biomedical care. Her language also suggests a need for supervision, alluding to her perception that her patients are irresponsible when it comes to medicines-taking and attending appointments. When they become older, they often access biomedical care alone, as was the case for almost all participants in this study. This may be because of gendered norms which see boys being less in need of accompaniment and support. The time when participants transitioned between types of health care, or began attending the health centre alone, may have been a point during which participants felt the effects of stigma and masculine norms related to health-facility attendance more acutely. She also asserts that boys are more likely than girls to disengage in HIV biomedical treatment and care due to the 'same stigma that affects men'.

Together, triangulated sources of data from this study (including participant accounts, clinic files and observations, and input from traditional and biomedical health practitioners) point to an incongruence between the complex needs of adolescent boys and young men living with HIV, and their experiences within the health system. Young men in particular spoke effusively about their desire to be respected and be seen as respectable as they transitioned into adult manhood. But their experience of being bossed around, shouted at and reprimanded at the health facility stood in sharp contrast to this need. Hence, decisions to disengage from the HIV cascade of care may be a reflection of their concerted efforts to meet their needs to be acknowledged as respected and respectable young men. This perspective stands in contrast to the belief put forward by health workers that they are giving up, or not interested in taking care of their well-being.

Discussion

Findings from this study demonstrate the complex and intersectional nature of the stigma that adolescent boys and young men living with HIV experience within what has been termed 'a space of hegemony within marginality' (Ratele 2014, 31).

Central to the enactment of institutional discrimination in this study was disrespect for a person's dignity and personhood. While experiencing disrespect in the health system is not unique to adolescent boys and young men, responses to being disrespected are gendered and participants in this study placed value of being respected as an important marker of masculinity. Congruent with a wider South African literature documenting efforts by young men to be seen as respectable within contexts of poverty and precarity (e.g. (Bhana, de Lange and Mitchell 2009; Msibi 2019)), findings from this study suggest that independence, strength, and dignity are important to, and constitutive of, adult manhood (Gittings, Colvin and Hodes 2022).

In neighbouring Kwazulu Natal Province, Mchunu (2005) and Msibi (2018) show how being respected confers dignity on the affected person. In contrast, men living in contexts of poverty and precarity struggle to be seen as respectable, as are older men living with HIV who are viewed as unable to make money and have children (Wyrod 2011; Mfecane 2008). Against this backdrop, the experience of added discrimination within the health system may render young men vulnerable to disengagement from care. Furthermore, strong implicit bias against men as clients of HIV services have been documented in Mozambique and Malawi, where men were considered to be 'bad clients', 'selfish' and 'prideful' by health workers (Dovel et al. 2022).

Additionally, while growing into adult manhood affords certain forms of power, it also may create additional and different tensions in relation to health services access and stigma within a context where men are more likely to report internalised HIV-related stigma; less resilient to enacted stigma by health workers; and more visibilised as accessing HIV services. HIV stigma may affect men differently than women in other ways, with men living with HIV in South Africa experiencing high levels of internalised stigma than women (Simbayi et al. 2007). Acceptance and disclosure of an HIV-positive status may be different for men because of fear of shame, and isolation from loved ones (Iwelunmor, Sofolahan-Oladeinde and Airhihenbuwa 2015; Simbayi et al. 2007). An HIV-positive status is often seen as an obstacle to gaining respect, status and strength, being a breadwinner, having intimate relationships and bearing children (Wyrod 2011; Mfecane 2008). For some adult men, the assumption that they acquired HIV sexually may additionally be stigmatising (in contrast to vertical acquisition, which may be more acceptable due to lack of 'choice' (Gittings, Colvin and Hodes 2022). Compounding the difficulties men face are the associations between health seeking and femininity and weakness (Jewkes et al. 2007; Chikovore et al. 2016). As suggested by traditional health practitioner participants in this study, inaccessibility and lack of privacy in public health facilities are key reasons why men may prefer traditional health services (Zuma et al. 2018). Men accessing HIV services thus face dual stigmas of contravening masculine norms by accessing a health facility, and being visibilised as living with HIV by the nature of their attendance.

When young people become old enough to access HIV services without the accompaniment of their caregivers, they may be more likely to disengage from care (Cluver et al. 2018). This aligns with how participants in this study described feeling the need to leave a health facility if they saw someone they knew there, or anticipated people might suspect they were accessing HIV services. In this study, male participants had few reasons other than HIV to attend health services (in contrast to women who might do so for reproductive health services) affecting their retention in care. More generally, poor treatment by clinic staff, including rude and judgemental female nurses, has also been documented as deterring men from accessing clinic-based services (Leichliter et al. 2011; Colvin, Robins and Leavens 2010) . Many men may also be reluctant to receive health services from women because of gendered power dynamics, a preference to share intimate health information with someone of the same gender, and, fear of gossip and disclosure of their HIV-positive status (Leichliter et al. 2011; Lesley Gittings 2016; Dageid, Govender, and Gordon 2012). It is likely that a combination of masculinity and age-related factors played a role in participants' experiences of institutional discrimination, including being visibilised, shouted at and scolded at the clinic.

In the field of public health, practice theory acknowledges the structural determinants of patterns of health inequality and the inadequacy of approaches that focus on individuals alone (Blue et al. 2016). Instead, it aims to link these patterns to social processes in an effort to show how practices and health inequalities become embodied (Blue et al. 2016). Applying practice theory to experiences such as those documented here can shed light on how stigma and discrimination can shape health practices, and in turn, outcomes.

Skovdal et al. (2017) utilised a theory of practice lens to examine how people interact with HIV services in six countries in Africa. They found that interactions with HIV services were shaped by a variety of factors, which they categorised as 'materialities' including the availability of HIV medicines and services; 'competencies' of knowledge such as how to live with HIV; and 'meanings' such as HIV-related stigma. Applying this model, meanings, including HIV stigma may shift in gendered ways that pose challenges to adolescent boys as they move into adulthood. It is plausible that as adolescent boys and young men living with HIV get older and cease to have caregivers accompany them to the clinic, they may have gendered experiences similar to adult men experiencing institutional discrimination and experience similar challenges and risks around disengagement from the HIV cascade. While beyond the scope of this paper, this represents an area for further enquiry, with attention being given to understanding how caregiver accompaniment, facility type (i.e. community clinic, public hospital) and transition type (e.g. paediatric to adult services, downward referrals) shape adolescent boys' and young men's engagement in HIV care.

Beyond this, work is needed to design health facility anti-stigma programmes that are sensitive to patients' needs, age and gender. Such interventions require behaviour change among healthcare providers, alongside accountability mechanisms to enable adolescents to report mistreatment safely. To enhance success, programmes will benefit from co-production with adolescents living with HIV so as to challenge the power imbalances that exist between themselves and healthcare providers. Participants in this study expressed the need for practices respected the confidentiality of their HIV status. These included the removal of HIV-associated labels in waiting rooms and the use of colour coded patient folders. They recommended health worker sensitisation to young men's experiences, interests and concerns, the introduction peer or 'buddy' systems to provide accompaniment to health facilities; engagement with traditional health practitioners to provide psychosocial support and referral for men living with HIV and those seeking sexual wellness; and a greater number of male health providers, or specific male-friendly times or spaces for clinic attendance.

Limitations

As with most stigma-related research, this study focused largely on the experiences of one stigmatised group of people. It was unclear from participants' accounts whether the maltreatment within health facilities was directed at them as individual young people living with HIV or universally towards all patients. Nonetheless, their experiences had specific negative consequences for them as young men living with HIV and their health services engagements.

Irrespective of whether or not the reported healthcare providers' behaviours were driven by HIV-related prejudice or not, we conceptualise it as institutional discrimination because it: 1) occurred repetitively within an institution that allowed it to unfold; 2) occurred in power-unequal relationships between health workers and a group of people living with HIV whose survival depends on engaging with the health system for life-saving medication; and 3) was not sensitive to the heightened needs of adolescent boys living with HIV, who experience disproportionate AIDS-related mortality, mental health needs and HIV-related stigma within this particular setting.

Furthermore, data were collected in 2017 and 2018, and events may have changed since then. Yet, the persistence of HIV-related stigma – including in relation to men – is well-documented (Wyrod 2011; Pfeiffer 2022; Hlongwa et al. 2020) suggesting the findings have ongoing relevance.

Conclusions

Experiences of stigma and discrimination, and their role in shaping health practices is an important area of enquiry, given emerging evidence that adolescent treatment adherence and virological outcomes may be gendered, with older boys seeing experiencing worse outcomes than girls and younger boys (Denison et al. 2018; Brittain et al. 2017).

This paper has explored the experiences and impacts of institutional discrimination on adolescent boys and young men accessing HIV services in South Africa. This discrimination may act as a powerful deterrent to retention in the HIV cascade of care, that increasingly affects adolescent boys as they become older. Adolescent boys and young men experience an incongruence between their healthcare needs and experiences, which presents a particular condundrum: either accessing the care that ensures their physical survival, or protecting themselves against the psychological harms of seeking biomedical treatment. Whilst behaviour change amongst health providers is a long-term process, young men in this study also provided easy-to-implement recommendations for less stigmatising forms of healthcare.

Declaration of Interest Statement

The authors declare no competing interests.

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