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Marginalization and social change processes among lesbian, gay, bisexual and transgender persons in Swaziland: implications for HIV prevention

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ABSTRACT

Swaziland has among the highest national adult HIV prevalence globally. There is limited knowledge of HIV vulnerabilities and prevention engagement among lesbian, gay, bisexual and transgender (LGBT) persons in the context of Swaziland's criminalization of consensual same-sex practices. This study explored social processes of marginalization to assess how they could potentiate HIV vulnerabilities and limit engagement in HIV prevention services. Additionally, we assessed positive change to better understand existing strategies employed by LGBT persons to challenge these HIV prevention barriers. Guided by community-based research methodology and conducted in Mbabane and Manzini, Swaziland, data were collected by LGBT peer-research assistants (PRA) in collaboration with an LGBT community organization in Manzini. Semi-structured interviews were conducted by trained PRAs and explored HIV prevention, including experiences of stigma and coping. Audio files were transcribed verbatim, translated to English, and analyzed using thematic techniques. Among participants ($n = 51$; mean age: 26.47, SD: 4.68), 40 self-identified as gay or lesbian (78.4%), 11 bisexual (22.6%), and 12 (23.5%) identified as transgender. Findings highlighted three primary processes of marginalization and positive change in structural, community, and internal domains. First, structural marginalization, which included criminalization, healthcare discrimination, and a scarcity of LGBT tailored HIV prevention resources was challenged by grassroots networks created to access and share specific HIV resources with LGBT persons and the Ministry of Health. Second, community marginalization included stigma and multi-dimensional forms of violence, however, this was met with LGBT persons providing mutual peer support, including for accessing HIV testing services. Thirdly, internal marginalization comprised of self-stigma and associated sexual risk practices was contrasted with coping strategies focused on self-acceptance, stemming from social support and leading to healthcare utilization. Jointly, these findings can inform the implementation of community-based and rights affirming HIV prevention and care cascade strategies that improve coverage of services with LGBT persons in Swaziland.

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Swaziland; lesbian; gay; bisexual and transgender; stigma; HIV prevention; qualitative

Background

Swaziland has a high national adult HIV prevalence, estimated at 27.0% (ICAP & Swaziland Ministry of Health, 2017). Men who have sex with men (MSM) in Swaziland are also vulnerable to HIV, with estimates of HIV prevalence close to 18% (Baral, Sifakis, Cleghorn, & Beyrer, 2007). Lesbian, gay, bisexual and transgender (LGBT) communities are excluded from HIV surveillance systems in Swaziland, as in many sub-Saharan African contexts, and subsequently their experiences and priorities are often overlooked in HIV initiatives (Baral & Phaswana-Mafuya, 2012; Kennedy et al., 2013; Rispel, Metcalf, Cloete, Reddy, & Lombard, 2011; Stahlman et al., 2016). As a result, there is limited

knowledge of experiences of how LGBT communities in Swaziland engage with the HIV prevention cascade. The cascade includes HIV awareness, adoption of HIV prevention technologies, and HIV testing uptake (Hargreaves et al., 2016).

Same sex practices are criminalized in Swaziland and there have been convictions (Carroll & Ramon, 2017). The criminalization of same-sex practices can reproduce sexual stigma and institutionalized exclusion of LGBT persons in families, communities, education, healthcare, religion and employment systems (Oldenburg et al., 2016; Poteat, Wirtz, et al., 2015b). Sexual stigma – social processes of devaluing sexually diverse practices, identities and communities – is a driver of HIV vulnerability

that reduces access to HIV prevention information, resources and services (Baral et al., 2013a; Beyrer, 2010). In Swaziland, research with MSM revealed that sexual stigma was negatively associated with uptake of HIV prevention strategies (e.g., condom use) (Brown et al., 2016; Kennedy et al., 2013; Risher et al., 2013). Limited data exists on the experiences of transgender (trans) women in Swaziland. Global and regional literature provide evidence that stigma, violence, social and economic exclusion reduce trans persons' access to HIV prevention services (Poteat, Reisner, & Radix, 2014b). For example, a study with trans women in Cote d'Ivoire, Togo, and Burkina Faso revealed that stigma was associated with condomless anal sex (Stahlman et al., 2016). Limited scholarship assesses HIV vulnerability among lesbian, bisexual and other women who have sex with women (WSW) (Logie, 2014; Logie & Gibson, 2013). However, among WSW in South Africa and Lesotho, (Poteat et al., 2014a; Poteat, Logie, et al., 2015a; Sandfort, Baumann, Matebeni, Reddy, & Southey-Swartz, 2013) HIV vulnerability is associated with stigma and homophobic forced sex (also referred to as "corrective rape").

Community-level expertise, support, and mobilization can help to mitigate the deleterious impacts of stigma on HIV vulnerabilities among LGBT persons. A study with MSM in Swaziland reported that trust, social participation, and social cohesion were associated with improved access to HIV-related care and HIV prevention practices (Brown et al., 2016; Grover et al., 2016). For example, condom use during last sex was associated with communication with sexual partners about condom use, as well as trusting relationships with service providers where sexual practices could be disclosed (Brown et al., 2016). Active engagement with social networks increased MSM's willingness to engage in health promoting and HIV prevention practices (Grover et al., 2016).

The current study explores social processes that shape HIV vulnerabilities, and engagement in the HIV prevention cascade, among LGBT persons in Swaziland. We address knowledge gaps regarding the experiences of WSW and trans persons in Swaziland, and ways in which LGBT persons in Swaziland navigate HIV prevention barriers. Knowledge of LGBT persons' experiences in Swaziland may be leveraged to challenge heteronormativity in HIV research and programming (Logie & Gibson, 2013). Focusing on the LGBT community at large (rather than solely on MSM) brings to the fore the voices of sexually and gender diverse women in Swaziland – voices often erased and marginalized in HIV research (Logie, 2014). Increasing the representation of LGBT narratives in Swaziland can help researchers and practitioners to "move from the production of meaningful knowledge to the implementation of truly liberating

practice in relation to sexual health and wellbeing" (Correa, Petchesky, & Parker, 2008). In this current study we examine the social processes that (1) elevate HIV vulnerabilities, and present barriers to engaging in HIV prevention, and (2) are enacted by LGBT persons to challenge these barriers to HIV prevention.

Methods

Conducted in 2015 in Manzini and Mbabane, Swaziland, this study was a collaboration with The Rock of Hope, a community-based LGBT agency focused on LGBT rights, wellbeing and support. The Rock of Hope (VM) in partnership with academic researchers (CL, WN), provided direction into all study elements (i.e., study design, methods, data collection, analysis) and trained 3 LGBT persons as peer research assistants (PRA) to provide input into study questions, conduct participant recruitment and data collection. Institutional review boards at the University of Toronto and the Ministry of Health Scientific and Ethics Committee in Swaziland approved the study protocol.

Eligibility criteria included persons aged 18 years and older who identified as a sexual and/or gender minority. Peer researchers conducted 51 in-depth semi-structured interviews in English or SiSwati, depending on the participant preference, lasting 60–75 min with gay, bisexual and other MSM ($n = 23$), lesbian, bisexual and other WSW ($n = 16$), trans persons (TG) ($n = 12$), and key informants ($n = 5$) identified by the Rock of Hope due to their engagement in LGBT work in healthcare, community, government and non-government settings. All interview participants were compensated the equivalent of \$10 CAD for their time and transport. Peer-driven purposive sampling of participants was employed to ensure a diverse population of study participants (Magnani, Sabin, Saidel, & Heckathorn, 2005; Tiffany, 2006). PRA invited persons from their social networks, and in addition to snowball sampling and word-of-mouth approaches, participants were also recruited from venues including community organizations, public socialization spaces, and LGBT events. Semi-structured interviews explored experiences of stigma and discrimination, as well as attitudes and practices surrounding HIV prevention, testing and care and were conducted in a confidential private space.

All interviews were digitally recorded, transcribed verbatim, and for those conducted in SiSwati translated to English. Thematic analysis was used on the English transcripts to identify, analyze, and report themes in data in an iterative process (Attride-Stirling, 2001). Thematic analysis condenses raw data into summaries, or themes, of recurrent patterns in the experiences of participants (Attride-Stirling, 2001; Braun & Clarke, 2008). Codes

were organized in descending order into global, organization, and basic levels. First, line-by-line review of the transcripts was performed, and first-level codes – descriptors of important categories – noted. All codes were then entered into NVivo (QSR International) and tagged to associated chunks of text. Text corresponding to each first-level codes was reviewed by 3 independent investigators (CL, JJ, APB) to verify interpretation, repetition and consolidate/recode. Sub-codes were then established using a constant comparative method to divide first-level codes into smaller categories (Braun & Clarke, 2008; Corbin & Strauss, 1990).

Results

Across the 51 in-depth interviews conducted (mean age: 26.47, SD: 4.68, range: 18–45), participants identified their sexuality as gay or lesbian ($n = 40$, 78.4%) and as bisexual ($n = 11$, 22.6%). Emergent themes highlighted: (a) *processes of marginalization* that contribute to HIV vulnerability, and (b) *processes of change* employed to navigate HIV prevention.

Processes of marginalization

Processes of marginalization were described as contributing to HIV vulnerability and reducing access to the HIV prevention cascade across multiple life domains: (1) *structural marginalization*, where persons experienced the intersection of legal discrimination and healthcare barriers; (2) *community marginalization*, where stigma and violence targeted LGBT persons; and (3) *internal marginalization* through self-stigma that shaped sexual practices.

Structural marginalization

Criminalization of same-sex practices emerged as a collective experience that left LGBT persons feeling as if they had unequal access to healthcare resources. As a participant articulated: “It is illegal in the country [being gay] so we are scared to come out.” (MSM #108). Criminalization contributed to fear of coming out as LGBT in healthcare settings: “Because we are not legal, people are afraid to go to the health centers for medication, because they are afraid of discrimination. That makes HIV to be on a high level.” (WSW #117)

Fear of stigma and discrimination was widely discussed as a barrier to seeking healthcare. Mistreatment by healthcare providers included “being ridiculed” (KI [key informant] #509) and negative “attitudes of the health care workers”. (KI #3) Specifically a male participant recounted:

“It becomes difficult to show the nurse that you have an STI in your anus. Health personnel have a tendency of

making fun of LGBT persons as they seek help. They just leave you in the room and call one another just to make fun and laugh at you before they even begin to provide help.” (MSM #312)

Stigma in healthcare may be exacerbated for trans persons. A key informant highlights trans issues as a key area for health education in Swaziland:

“I feel that it is even more difficult for trans people to access health care. They get a lot of those common questions, ‘what are you?’ And those are the questions that make trans people take a step back. I feel that Swaziland is at a stage whereby we are not quite understanding as a country when it comes to trans people, it is a space whereby a lot needs to be done”. (KI #7)

Participants also described feeling excluded by HIV and STI policies and resources. One such policy was a requirement for persons seeking information or testing to bring their sexual partners with them. This presented barriers to accessing information:

“You can’t go to the hospital as a couple to get information on safe sex because of fear of discrimination. This results in the two of you staying in a shell practicing unprotected sex because you don’t have a clue on how to protect yourself.” (TW [trans woman] #309)

It also presented problems in accessing sexually transmitted infections testing and care:

“You go to a clinic and then they would say ‘you have an STD and we want to see your partner’ and you start to hesitate because you can’t bring your partner here because he is a male and you also are a male.” (MSM #104).

Participants described a lack of access to prevention tools, such as condoms and lubricant. For example, one stated “It’s hard for me, cause I do not even know where to get the protection.” (TW #313). Another participant knew where to access prevention tools yet noted: “Due to the stigma that’s everywhere, it’s hard for a gay person to go to the hospital to get condoms or lube.” (MSM #203) Participants also discussed that LGBT persons were excluded from larger HIV prevention discourses centered on heterosexuals:

“The problem is with HIV education, we have all heard the story, but the story is directed to a man and a woman ... they never talk about when a man sleeps with another man, when a woman is with another woman.” (WSW #314).

Community marginalization

Many participants highlighted the intersection of HIV-related and LGBT-based stigma. This intersection perpetuated anti-LGBT attitudes and constructed sexual orientation and gender identity as integrally linked

with HIV risk. Specifically, these narratives underscored the pervasive belief that HIV is a “gay/lesbian” illness. As articulated by a participant:

“I went to an all-boys school and the person who was taking blood said ‘we do not take blood from gays because their lifestyle is very risky so we don’t want to risk giving their blood which might be infected to someone else’. Then the class had a field day with that.’ (MSM #202)

Several accounts revealed how HIV-related stigma operates as a barrier to HIV testing. For example, “It’s the feeling that comes with being (HIV) positive, feeling insignificant, it is painful. You may feel rejected and desolate.” (WSW #101). Participants discussed fears of rejection and isolation if they tested positive, as illustrated, “for me I think what can make me decide against going for a [HIV] test, is that I would be scared to disclose my status to my partner.” (MSM #105).

Most participants discussed experiences, and fears, of harassment and violence directed towards LGBT persons in community spaces. For example, “You hear ‘here comes the *‘inkonkoni’* [Xhosa word for LGBT]. I hate this thing, if I had a chance I’d just kill all of them’.” (TW #309). And “violence totally freaks me out. I don’t care about the name calling and opinions about us because we can get over that. But the whole violence thing that’s really scary cause it can happen to you any time.” (MSM #303) This violence may be exacerbated for trans persons who may also be less connected to LGBT community and services: “Most of the trans, they are not known. Those that have been brave enough, well it’s just recently that we are hearing of violence and rising incidences of hate crimes.” (KI #508).

Furthermore, sexual violence was discussed, particularly in the context of homophobic “corrective” rape that aimed to change one’s sexual orientation. A trans participant detailed:

“Some group of guys say ‘you know that guy he wants to be a lady so let us rape him so that he will leave this thing of being gay’. He must date girls, let us rape him because if he continues like this he will continue to be gay, so let us rape him. One of my friends told me that, but there were two of these guys, they raped him, but he never reported the case not even to the police because he was having fear that what will the police say and even the other people, they will laugh at him.” (TW #213)

This quote further describes the common the sentiment across narratives that there was no recourse for justice for LGBT persons who experienced violence.

Internal marginalization

Participants discussed the harmful effects from internalized stigma (or self-stigma), the processes by which

negative attitudes and beliefs about LGBT persons were accepted by LGBT persons themselves. Self-stigma may inhibit persons from forming relationships, as persons may anticipate stigma and rejection: “It is self-stigma because you are already thinking ‘oh my God they are thinking I’m gay so they are going to hate me.’” (TW #208). Internalized stigma also constrained the possibilities and the potential of LGBT persons: “It limits me, because there are things that I cannot do just because I am LGBT. You think that what you can do is different from what a straight person can do, so it sabotages one’s progress in life.” (MSM #217).

Participants discussed three ways by which self-stigma might result in condomless sex. First, participants discussed how they may engage in condomless sex to validate their gender and sexuality and be accepted by sex partners: “You try to please people, prove to them that you can be a female. To prove a point you might wind up having unprotected sex with a man.” (TW #309). Second, participants discussed that some persons may engage in concurrent heterosexual and same-sex partnerships to hide their sexuality. For example, “multiple concurrent sexual partnerships are rife, others who have not accepted themselves, would also engage in bisexual relationships.” (WSW #217). Others described that engaging in sexual practices in secret in order to hide one’s sexuality can limit access and uptake of condoms: “people have sex in secret, whether or not there’s a condom. Some are married and did it to hide that they are gay.” (MSM #211).

Processes of change

To challenge and circumnavigate existing systems that marginalize LGBT people, participant narratives described the following strategies to engage with HIV prevention: (1) LGBT persons accessed and shared HIV resources (*structural domain*); (2) LGBT persons provided and received peer support (*community domain*); (3) participants described journeys to self-acceptance (*internal domain*).

Structural domain

Participants discussed seeking out HIV prevention information to address their knowledge gaps, including finding resources online (e.g., social media). For example:

“I didn’t know what I was supposed to do when I was supposed to have sex with my first man because I didn’t know what goes on ... now because there is internet and people go on Facebook and all that they know what’s going on. They are able to get to all those resources to see ok, use a condom.” (MSM #102)

Others discussed sharing this LGBT-specific HIV prevention information, as well as general information on human rights, with other LGBT persons. These discussions framed education as a tool for empowerment: “I believe that fewer lesbians, gay guys, transgender persons are educated about our stand in the society. There could be many more ways to tell the people, to tell the world, the things that could actually help us.” (TW #113) Several participants noted the importance of LGBT persons educating healthcare workers and the Ministry of Health on LGBT-affirming language and practices. A participant explained:

“We have started engaging with the Ministry of Health, sensitizing health workers with the aim of creating a conducive health care environment or welcoming, friendly centre within the health centers, where LGBT people will access and not have much problems.” (WSW #116)

Community domain

Participants’ described how LGBT persons provided peer support to one another: “Most LGBT people they hang out with each other, they share experiences, they just support each other.” (TW #113) In turn, this peer support fostered inner strength and happiness: “It gives me strength getting to know others like me, it puts me in a happy place.” (WSW #110) Participants detailed how older LGBT persons helped the younger generation to cope with accepting their sexuality:

“One support structure is among ourselves, all of us who have come to accept our sexuality, we help the younger ones with coping. With us the older generation it was tough. I think the main one is informal, where we meet with each other, share each other’s miseries, and give each other a shoulder to cry on.” (TW #208).

Other participants discussed that LGBT persons supported one another in going for HIV testing. For instance, a lesbian participant described accompanying her gay male friend for HIV testing in order to provide a buffer from discrimination:

We used to take HIV tests like every month, because when we used to all go along it was easier for him. I felt like he didn’t want to go alone because people are going to say something. So discrimination plays a big role when it comes to HIV testing. (WSW #304)

Others described “pacts” with their friends to go for monthly testing: “I go for HIV testing quite often. We have a Cinderella pact with my friends that we go for HIV testing every month.” (MSM #209) Getting tested with partners was also a motivation: “My partner makes me test, he is an inspiration. We usually go and test together.” (MSM #108).

Internal domain

Multiple accounts highlighted participants’ journeys to self-acceptance in the context of stigma and lack of social acceptance. For instance, a participant described the important role of confidence in fostering wellbeing: “I just need to own myself and feel myself because not accepting myself, how is that going to help me? I will just hurt myself in many ways by not having confidence.” (MSM #303) Self-acceptance was at times contextualized in relation to support from other LGBT persons, including in support groups:

“The best way to resist all these things is to have a strong inner self, believe in yourself, what you are. Be strong, have support groups so you build yourself up, so you can resist all the stigma and all the hatred. That honestly would bring you much further in life.” (TW #103).

Finally, self-acceptance was described as helpful in navigating healthcare systems as one could be honest about their sexuality. For instance, confidence was discussed as important to accessing health care:

Accepting myself has helped me in that I am not bothered by people hurling negative statements at me in public. My confidence is top notch, it also helped me because now I am free to express myself and my sexuality in health care centers. (TW # 214).

Discussion

Structural, community and internal domains interact to produce HIV vulnerabilities among LGBT persons in Swaziland. Criminalization of same-sex practices and healthcare stigma reproduce and legitimize community-level stigma and violence targeting LGBT persons. These experiences of structural and community level stigma contributed to self-stigma, and result in social isolation and practices that elevate HIV exposure, including concurrent sexual partnerships and difficulties using/accessing condoms. Narratives also highlighted processes by which LGBT persons challenge these structural and social constraints to HIV prevention, including community-based knowledge sharing and peer support networks to access HIV services. Social support also helped to facilitate individual journeys to self-acceptance, which in turn fostered engagement in health seeking practices. Taken together, these findings highlight the complex and multi-level processes that constrain LGBT people’s lives and wellbeing *and* how LGBT people are reshaping healthcare and HIV education through existing community and social support networks, and by engaging in self-acceptance processes.

LGBT persons in Swaziland experience real threats to their existence in ways that increase vulnerability to HIV

acquisition in proximal (e.g., sexual violence) and distal (e.g., healthcare mistreatment) ways (Baral, Logie, Grosso, Wirtz, & Beyrer, 2013b). These multi-level processes are congruent with social ecological approaches that conceptualize the dynamic interactions between structural, community and internal domains as central to shaping HIV vulnerabilities (Baral et al., 2013b). Yet participants described multiple strategies LGBT persons in Swaziland employ to shift power relations in ways that reduce HIV risks. These strategies align with discussions of relational, intrapersonal and collective agency (Ahmed, 2010; Mannell & Jackson, 2014; Parpart, 2010) that center the ways in which people negotiate resistance and survival in contexts with limited human rights protections. Understanding the complexity of agency among LGBT persons in Swaziland can inform interventions that harness the creativity and resistance strategies underway, while challenging larger structural drivers such as criminalization and healthcare policies.

Findings corroborate prior quantitative research with MSM in Swaziland that highlights legal discrimination as a barrier to condom use (Brown et al., 2016) and associations between discrimination and fear of seeking healthcare (Risher et al., 2013). Participant narratives align with prior qualitative work with MSM living with HIV in Swaziland that elucidated the intersection of sexual stigma and HIV stigma, stigma in healthcare, violence, and limited legal protection (Kennedy et al., 2013). Our findings highlight how trans persons in Swaziland experience similar social drivers of HIV that impact trans persons across global contexts (Poteat, Wirtz, et al., 2015b; Stahlman et al., 2016). Lesbian and bisexual women's narratives of homophobic rape in Swaziland suggest that they share vulnerabilities to HIV acquisition with lesbian and bisexual women in South Africa and Lesotho (Poteat et al., 2014a; Sandfort et al., 2013). Finally, social support as salient to HIV prevention and testing aligns with work with MSM in South Africa (Brown, Scheibe, Baral, & Bekker, 2013), MSM and trans women in Jamaica (Logie et al., 2017), and trans women in Peru (Perez-Brumer et al., 2017).

Our study has limitations. We did not collect HIV status information due to privacy concerns, therefore we have limited knowledge of the intersectional stigma experiences among LGBT persons living with HIV in Swaziland. We worked in partnership with an LGBT community agency and worked with peer researchers to facilitate recruitment: this means we may have included persons already connected to peer support and may have missed the perspectives of more marginalized LGBT persons.

Despite these limitations, our study contributes to the literature in three ways. First, we include trans persons

and WSW and highlight their experiences of violence that influence HIV vulnerabilities. Second, we delineate the multiple ways participants described that stigma contributes to condomless sex. Third, we focus on multi-level processes by which LGBT persons in Swaziland are changing the HIV prevention landscape. Findings can inform policy and practice change to advance HIV prevention. At the structural level, both decriminalization of same-sex practices and human rights protections are required for LGBT persons in Swaziland to realize optimal wellbeing (Zahn et al., 2016). Healthcare provider sensitization training can reduce negative attitudes (Poteat et al., 2017) and build on evidence-based strategies that tackle individual, environmental and policy level factors (Charurat et al., 2015; Nyblade, Stangl, Weiss, & Ashburn, 2009). Community level strategies to reduce LGBT stigma in Southern Africa are understudied but can draw from the rich HIV stigma reduction literature to target multiple facets of stigma across social ecological domains (Stangl, Lloyd, Brady, Holland, & Baral, 2013). Building on the promise of LGBT peer education and support, future interventions can integrate community empowerment approaches to HIV prevention that engage marginalized persons working together to address social and structural barriers to health (Kerrigan et al., 2015). Finally, structural and community approaches can be accompanied by a comprehensive community-based prevention package of services to optimize HIV prevention with LGBT persons in Swaziland.

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