



# HHS Public Access

Author manuscript

*Glob Public Health*. Author manuscript; available in PMC 2023 December 01.

Published in final edited form as:

*Glob Public Health*. 2022 December ; 17(12): 4043–4055. doi:10.1080/17441692.2019.1606265.

## **‘Sometimes it is not about men’: gendered and generational discourses of caregiving HIV transmission in a rural South African setting.**

**Sanyu A. Mojola,**  
Princeton University

**Nicole Angotti**  
American University

### **Abstract**

In this paper, we examine a prominent interpretation of HIV risk in a rural South African setting experiencing a severe HIV epidemic well into older ages: the discourse of caregiving HIV transmission. By caregiving transmission, we refer to HIV infection resulting from caring for family members who are living with HIV and may be sick with AIDS-related illnesses. We draw on individual life history and community focus group interviews with men and women ages 40-84, as well as interviews with health workers providing HIV counselling and testing services at local health facilities in their communities. We illustrate the social and strategic role caregiving HIV transmission discourse plays in re-signifying HIV as a sexless infection for older women, thereby promoting HIV testing as well as blameless acceptance of an HIV diagnosis. We further highlight the role of rural health workers who serve as medical epistemic bricoleurs, vernacularizing global HIV counselling and prevention messages by blending ideas of gender, generation, and local lived experiences and practices so that they resonate with community norms, values, and understandings. Our study highlights the gendered and generational complexities and challenges experienced by rural South Africans aging in a community over-burdened by an HIV epidemic and AIDS-related mortality.

### **Keywords**

Caregiving; HIV transmission; older women; rural South Africa

### **Introduction**

Local interpretations of HIV have long circulated alongside global biomedical explanations. In high prevalence African contexts, the magnitude of the HIV epidemic has given rise to culturally-familiar frameworks to make sense of its cause, severity, and onward transmission. These have included the role of money, both in scarcity and in excess (Weiss, 1993; Hunter 2002; Swidler & Watkins 2007; Mojola 2014), the departure from sexual

mores and the rise of moral decay (Posel, Kahn, & Walker, 2007; Schatz, Gilbert, & McDonald, 2013; Weiss, 1993), and the workings of witchcraft (Ashforth, 2002; Niehaus, 2012; Thomas, 2007), among other explanations. These discourses are often profoundly gendered, with young women's sexuality at the heart of social anxieties about the spread of HIV (Weiss 1993; Hunter 2010; Mojola, 2014).

In this paper, we examine a prominent gendered and generational interpretation of HIV risk that emerged from our research on HIV and aging in a rural South African setting experiencing a severe HIV epidemic well into older ages: the discourse of caregiving HIV transmission. By caregiving transmission, we refer to HIV infection resulting from caring for family members, often one's own children or grandchildren, who are living with HIV and may be sick with AIDS-related illnesses. Drawing on individual life history and community focus group interviews with men and women ages 40-84, as well as interviews with health workers providing HIV counselling and testing services at local health facilities in their communities, we analyse discourses of caregiving HIV transmission. We illustrate the role caregiving discourses play in re-signifying HIV as a sexless infection for older women, and more broadly, how these discourses advance a local way of contending with a global health threat.

### **An HIV Epidemic among Older Women**

The collective belief in caregiving HIV transmission was resonant throughout the community we studied in Mpumalanga Province in the rural northeast of South Africa —across the villages that have experienced a tremendous burden of AIDS-related deaths, in the homes of individuals grappling with their own (or others') HIV risk or infection, and in the health facilities where this counselling message was offered. Elevated AIDS-related mortality in the area began in 1997 and increased dramatically in the 2000s, contributing to high rates of illness and death, especially among middle-aged men (Gómez-Olivé et al., 2014; Houle, Clark, Gómez-Olivé, Kahn, & Tollman, 2014; Kabudula et al., 2017). By 2009, two-thirds of women aged over 60 were widows compared to 14% of same-aged men (Houle et al., 2018). While apartheid-era coerced male labor migration meant that, for several decades, women had been de facto heads of their households, the AIDS epidemic exacerbated the early and permanent onset of female headship as migrants returned home to 'convalesce and possibly die' (Clark, Collinson, Kahn, Drullinger, & Tollman, 2007, p.35; Hunter, 2010; Schatz, et al., 2013; Schatz, Madhavan, & Williams, 2011). As such, many older women had to manage an extraordinary burden of caring for the ill and dying, as well as orphaned children and grandchildren (Madhavan, 2004; Schatz, et al., 2013; Schatz and Ogunmefun, 2007).

Findings from a 2010-2011 population-based HIV prevalence and sexual behaviour survey (*Ha Nakekela*), however, point to a more complex picture of older women's role in the epidemic than previously documented (Gómez-Olivé et al., 2013). The *Ha Nakekela* survey is nested within the Agincourt Health and Socio-Demographic Surveillance Site (hereafter, AHDSS or 'Agincourt'), which is located in the Bushbuckridge sub-district of Ehlanzeni District, Mpumalanga Province and comprised of approximately 90,000 people in 27 villages at the time of the survey (Kahn et al., 2012). Gómez-Olivé et al. (2013) found that

nearly a third (27%) of women in their 50s, and 11% in their 60s and early 70s, were living with HIV. Testing services were not widely available until the early to mid-2000s (Snow, Madalane, & Poulsen, 2010), and antiretroviral treatment (ART) only became available in the two public hospitals in the area in 2004-2005, in some clinics in 2008, and more widely by 2011 (Mee et al., 2014). By 2010-2011, only half of women in their 50s, a third in their 60s, and a sixth in their 70s, had ever had an HIV test (Schatz, Houle, Mojola, Angotti, & Williams, 2019)<sup>1</sup>, and only a third of the Agincourt study population reported being on ART. This suggests that older women were not just surviving into older ages with HIV due to ART, but were also, likely, newly infected. While the HIV prevention and social marketing consensus emphasises sexual transmission as fueling the HIV epidemic (Boily et al., 2009; Gray et al., 2001; Stoneburner & Low-Beer, 2004), in the community, caregiving HIV transmission emerged as a privileged explanation for why (single or widowed) older women might be vulnerable to HIV.<sup>2</sup>

## Materials and Methods

We draw on three sets of qualitative data collected within the AHDSS: 1) 60 life history interviews (LHIs) nested within the *Ha Nakekela* survey with individuals aged 40-80+, and stratified by gender (men, women) and HIV sero-status (30 living with HIV, 30 living without HIV); 2) nine community focus group interviews (FGIs) with 77 individuals, stratified by gender (women, men, mixed gender) and age group (40s, 50s, 60s+); and 3) eight key informant interviews (KIIs) with rural health workers (four HIV counsellors, one HIV counsellor supervisor, two nurses, and one administrator), all but one of whom were women. The health workers' work experience spanned from 3 years to upwards of 20 years and included prior HIV-related work in peer education, community awareness, coordination of prevention and clinical services, and home-based care (see Mojola, Williams, Angotti, & Gómez-Olivé, 2015 for further study details).

The LHIs and FGIs were conducted in XiTsonga/Shangaan, the local language, by local research assistants. The LHIs aimed to contextualize individuals' HIV risk and sero-status, and focused on their family lives, work and livelihood strategies, sexual and romantic relationships, general health and health care utilization, and HIV risk and protective strategies. The FGIs—which included semi-structured questions as well as vignettes depicting hypothetical scenarios involving similarly-aged men and women (Barter & Renold, 1999)—aimed to understand the larger normative environment in which rural Africans make decisions about their health as they age in an HIV-endemic setting.

One of the authors and a project collaborator conducted the KIIs in several health facilities in the Agincourt study site. The KIIs focused on experiences providing health care services

---

<sup>1</sup>For comparison, among younger women, 32% in their 20s, 44% in their 30s, and 34% in their 40s, were living with HIV (Gómez-Olivé et al., 2013), while 84% in their 20s, 82% in their 30s, and 65% in their 40s, had ever been tested (Schatz, et al., 2019).

<sup>2</sup>While risk of infection varies by type of exposure and the viral-load of infected blood, the average risk of HIV transmission through occupational exposure (the closest proxy for caregiving transmission) is estimated at 0.3% after a needle-stick or cut exposure, 0.1% through exposure of the eye, nose or mouth, and less than 0.1% after exposure of non-intact skin (Centers for Disease Control and Prevention, 2003). Our aim here is not to debate the plausibility of this mode of transmission. Rather, we aim to examine the cultural work and public health goals caregiving HIV transmission discourses accomplish by making HIV risk for older women appear sex-less.

to older adults, with a specific focus on HIV counselling, testing, and treatment. Our sample of health workers is relatively small. However, their cumulative work experience, the large number of clients and other health workers with whom they have interacted over the past decade or two, as well as our triangulation of data sources (LHI and FGI respondents identified health workers as a key source of caregiving transmission information), suggest to us that their perspectives were not unique.

Each author manually coded a subset of each data source using deductive coding to identify specific narratives around non-sexual HIV transmission and inductive coding to identify how caregiving HIV transmission discourses fit within the context of the entire transcript. We then discussed and identified salient themes emerging from the analyses. In the presentation of the data, we retained the vernacular English, but have inserted clarifying words in brackets and made minor edits to grammar to ease readability. Data are referenced by their source (LHI, FGI, or KII), respondent gender and age/age group (LHI and FGI only) or health worker category (KIIs only), and all names are pseudonyms. All respondents provided informed consent. The study received ethical approval from the authors' institutions, as well as the University of Witwatersrand Human Research Ethics Committee (H120415) and the Mpumalanga Provincial Government Department of Health in South Africa.

## Findings

### Non-sexual HIV transmission

When asked how and why older adults were at risk for HIV, or when making sense of their own or their relatives' and friends' HIV risk, caregiving HIV transmission was raised as a probable cause of infection. This finding emerged across Agincourt villages (FGIs), clinics (KIIs), and homes (LHIs). Within the context of discussions about sexual mores and HIV in the community, many focus group participants wanted to ensure that all concerned were aware that 'when it comes to HIV we have to understand that it does not come through sex only' (FGI, men 40s) or, in like fashion, that 'there are a lot of ways that you can be infected by HIV, not [only] because of sexual intercourse' (FGI, women 60s). The main non-sexual mode of transmission discussed, often at length, was caregiving HIV transmission.<sup>3</sup> In a typical response, Mary, a woman in her 50s, described it this way:

It happens like this, you find that you have children and they are HIV positive and they didn't tell you. And these children when they have HIV, they start to have [a] lot of diseases... And you as a mother, you have to take care of him/her. HIV doesn't transmit through sexual intercourse only, it also transmits when you are taking care of someone. You find that you are taking care of your child and s/he doesn't tell you s/he is HIV positive until you end up seeing it. Sometimes when s/he went to the clinic and they diagnose her/him with HIV, s/he don't tell you, so as a parent when your child is sick, is good to accompany him/her to the clinic and

---

<sup>3</sup>Other non-sexual modes of HIV transmission mentioned by respondents included sharing razors, needles, and nail clippers, and excessive blood exposure, such as during a car accident.

when they do the test, you will be there. This is how some women get HIV, they are taking care of their child (FGI, women 50s).

In another focus group, HIV risk from caregiving extended specifically to:

...old age people who are left staying with their grandchildren whose mothers are dead. They are able [have] to take care of those children. You find that, that child was born being HIV positive, her mother didn't protect her when giving birth. When busy taking care of her, it might happen that the child has a wound or something like part of her body is scratched or having a hole, then when that child bleed a grandmother will touch her without knowing that [s]he has to wear gloves or protect herself. In that way the grandmother becomes infected with HIV. At the end she will be sick too and die too (FGI, women 40s).

Discussions about caregiving HIV transmission were not only prominent in community focus group interviews, which reflect collective norms and understandings of HIV; they also were raised in a third of the individual life history interviews. When asked about how to avoid HIV infection, Liliana (age 47) responded:

I know that you have to use condoms when having sex. And when you see someone having a wound, if you want to help her you must use hand gloves. Don't touch her blood with your hands. (LHI, woman, age 47)

Mpumi (age 52) similarly replied:

Through sex with an HIV [positive] person or when you are caring for someone who is HIV positive without protecting yourself. (LHI, woman, age 52)

Stella (age 78) also thought caregiving would be how friends her same age would be at risk for HIV:

Yes, they do get infected by HIV, but I don't know if they get HIV through sex with old men. Usually I heard people say that if you are caring for a person who is HIV positive without protecting yourself you can be infected. When you care and you have a wound and she also has some fluids coming out you will be infected. It's what I heard for people of my age who are infected. (LHI, woman, age 78)

Individual accounts of caregiving HIV transmission were not just what people heard. In several instances, caregiving transmission is how they themselves understood their own HIV infection. When asked how she thinks she contracted HIV, Khensani (age 65) said she was unsure, though she had described a long-term relationship with an unfaithful partner who refused to use condoms with her. When prompted further, Khensani replied:

**Khensani:** I think I got infected from my sister's child that I was taking care of and she is dead. She was sick and unable to do anything.

**Interviewer:** You took care of her?

**Khensani:** Yes I was taking care of her without gloves. (LHI, woman, age 65)

While almost all of the life history interview accounts of caretaking risk were from women, two men also discussed their own caregiving risk. Lovedale (age 62), who was disabled and no longer having sex, thought a caregiver might transmit HIV to him. Simon (age 41), whose former girlfriend had another sexual relationship while she and Simon were still together, nonetheless thought he contracted HIV through providing care to his HIV-infected siblings:

**Interviewer:** Looking at your life do you think you ever might have been at risk for HIV?

**Simon:** Yes you can get infected from nursing your wounded and sick siblings. If you touch her/him you will get infected from the wounds.

**Interviewer:** At what point in your life do you think you became HIV positive?

**Simon:** In nursing my siblings, I think so. (LHI, man, age 41)

Simon might have thought he was infected through caregiving because his current partner, he mentioned, had tested HIV negative. Nonetheless, these men's accounts underscore the assessment of risk attached to the role of caregiving, one that was otherwise overwhelmingly feminized.

Respondents also noted the source of their information about caregiving HIV transmission: 'we get HIV information in the clinics when we go there' (FGI, men 60s). They were also clear about what they were advised. Mathabu (age 40) explained:

**Mathabu:** They educate us that we must protect ourselves during sex with condoms and when someone at home gives birth, we mustn't touch or wash the child because maybe we will get it [HIV].

**Interviewer:** What are they saying you use to protect yourself?

**Mathabu:** They said we must use gloves. Like when a person is sick, we mustn't use our hands, we must use gloves. (LHI, woman, age 40)

Caregiving HIV transmission discourses throughout the Agincourt community fit within a broader set of understandings of non-sexual causes of HIV. These include globally-recognized (and locally familiar) biomedical modes of transmission, such as from mother-to-child as well as through occupational risk. But they also, importantly, include socio-cultural causation centering on 'moral readings of behavior, linking AIDS to discourses of tradition, gender, and generational relationships' (Stadler, 2003, p.359; also see Niehaus & Jonsson, 2005; Posel, et al., 2007; Schatz, et al., 2013).

Against this backdrop, caregiving HIV transmission discourses served a number of social, and, at times, strategic purposes. As we describe next, caregiving discourses 1) solved a transmission puzzle by mapping onto gendered social roles and practices; 2) upheld sexual respectability and notions of respectable aging by re-signifying HIV for older women; and 3) advanced the HIV prevention goals of rural health workers.

## Making sense of caregiving HIV transmission discourses

**1. Solving a transmission puzzle**—The most common HIV transmission narrative featured an unfaithful husband, usually a labor migrant, who had concurrent sexual partners at his distant workplace and brought HIV home to his rural wife. Typical renditions of this narrative are reflected in the following two interviews with health workers. When asked how older adults are becoming infected with HIV, Meriam, a nurse at a local health facility, responded:

... Most of them their husband is working somewhere...and there they start another relationship and when they come back, they are HIV positive and give it to the woman [wife]. (KII, nurse 1)

An HIV counsellor, Eliza, from another facility, concurred:

We find the women who are married, the women is faithful, maybe she is Christian, and then afterwards she came for maybe she is not feeling well. She was excited to come to the clinic. Just for a regular check-up and she found out she is HIV positive. So, doing that counselling is very tough because the person is not easy for them to accept because she is married, she has been faithful but the husband is not faithful. But they didn't expect those results so doing counselling to those kinds of person is very difficult. (KII, counsellor 1)

While this narrative resonated with community members, it was less helpful in explaining how an older woman became infected with HIV when her husband died years ago. Indeed, the pace of AIDS-related deaths earlier in the epidemic, when testing services were limited and treatment was out of reach, could have reinforced a perception that an HIV diagnosis is the result of a recent infection. As such, caregiving helped solve a transmission puzzle. Thomas, a man in his 40s, explained:

You don't always get infected through sex. It may happen that the husband has long died. So perhaps they get infected through caring for their grandchildren while they have injuries on their hands and they are not aware. (FGI, mixed gender 40s)

Similarly, when asked how they might become infected with HIV, Ruth and Nxalati, two women aged over 60, reasoned:

**Ruth:** HIV affects young generation. For us, we have passed that stage and we are safe.

**Nxalati:** The person who will be infected by HIV and she is old it will be maybe if someone falls and she touches her blood by hands, then she gets infected but by sex, no, we are done on that. (FGI, women 60s+)

In these ways, non-sexual transmission was firmly established as a mode of infection for older women.

**Gendered social roles and HIV vulnerability.:** Caregiving discourses were compelling precisely because they mapped onto gendered social roles and practices in rural South Africa. In rural areas, women typically perform both the hard labor of subsistence

agriculture, such as collecting firewood, harvesting crops, and pounding maize, as well as domestic tasks like cooking over open fires, hand-washing clothes, raising children, and taking care of sick family members (Schatz & Ogunmefun, 2007). The legacy of apartheid left an indelible mark on the country's health infrastructure, leaving former homeland areas like Agincourt with limited, under-resourced, and under-staffed health facilities (Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009; Kahn, et al., 2012). The AIDS epidemic further stretched this system, resulting in significant task-shifting, with nurses doing the work of doctors, and the work of hospitals outsourced to community volunteers and family members (namely older women), who did the bulk of caregiving at home (Callaghan, Ford, & Schneider; Akintola, 2008; Campbell, Nair, Maimane, & Sibiyi, 2008; Schatz, et al., 2011).

In practical terms, caring for sick loved ones means bathing them, treating wounds, and cleaning soiled clothing and bedding (Chimwaza & Watkins, 2004), among other indignities that pave the path to an AIDS-related death. Importantly for discourses of caregiving transmission, the rigor of domestic labor leaves the body vulnerable to cuts and wounds, through which—as the community saw it and health workers explained—HIV could be contracted. In this way, caregiving discourses resonated with modes of transmission through occupational risk faced by health workers, a point to which we will return.

**2. Upholding sexual respectability**—In addition to solving a transmission puzzle, caregiving HIV transmission discourses also highlighted the importance of sexual respectability for older womanhood. It was assumed, indeed even expected, that men engaged in (concurrent) sexual relationships with younger partners well into older ages, especially as their wives aged and grew tired of sex (Mojola, et al., 2015). Women, on the other hand, were expected to have sex only with their husbands; if he had died, they were expected to abstain (Angotti, Mojola, Schatz, Williams, & Gómez-Olivé, 2018). These underlying community norms were revealed in several focus group interviews, and exemplified by the exchange below among Busi, Jane, and Rholani, three women aged over 60. When presented with a vignette about how a woman their same age became infected with HIV, they replied:

**Busi:** She might get it through bathing people or she was raped.

**Jane:** Maybe if she has a husband. Her husband got it from young girls and infected her. Maybe she doesn't take care of herself. There are people who are old having 60 years still having sex. You can see that this old woman was not supposed to have sex. You ask yourself what she feels.

**Rholani:** If she is still looking for men she has to get it [HIV] (FGI, women 60s+)

Sexual acquisition of HIV, outside of a union, came with social sanctions: it meant that a woman was not 'taking care' (Angotti, et al., 2018) or 'behaving well' (Sennott and Mojola, 2017). Women voiced a common refrain, below captured by Busi, that:



... those who don't behave well while they are old they can be infected. We are seeing others who are old and they don't have respect. They don't behave well. (FGI, women 60s)

Later in the interview, Rholani clarified what 'behaving well' entailed for respectable older women:

... you will be safe when you behave well. If you are older and tired you stay out of sex. You will be safe from many things. (FGI, women 60s)

Thus, if an older woman contracted HIV, the only 'respectable' reasons were from an unfaithful husband or through caring for her sick children, both of which rendered her blameless. In a life history interview, Lindiwe (age 46), who was married, shared that she was infected with HIV by her husband, who had other sexual relationships during a period of separation. When asked what the biggest challenges were for people her age, Lindiwe responded:

People still think that you get HIV through sex only. So people are scared to disclose their [HIV] status because they think people will say they have many [sexual] partners. (LHI, woman 46)

Paulina, a health facility administrator, discussed the shame associated with an HIV diagnosis for older women:

It's a shame you know to see an older person sick [with HIV]. You start to ask yourself, how did they get it [HIV] to start with? Was it because of rape, because the man was cheating with a young person, or what's going on? ... if you start to have signs that there is a sexual-related illness, then that is a very big problem...Because in that means that in you there is that problem. Yah, it's regarded as a sickness of shame, how do you speak about it and how do you start seeking help?...But for youngsters, it's not a shame per se, but you also want to be included, you don't want to be excluded, as part of the society, as part of the group. You feel like I'll be isolated, I'll be discriminated against, there is stigma, but it's not necessarily a shame. Because you know when you do it [sex], you know these are the consequences. But for the poor old woman who was not even aware that there would be consequences for what I am doing, because at face you never thought like there are risks. So it becomes a shame to ask yourself how did it happen, how could it happen to me at my age, how do I translate that or communicate that to my children, and how do I prevent that happening to my children? (KII, administrator)

**Re-signifying HIV for older women.:** The prominence of sex in HIV prevention messages, dating back to the widely-recognized ABC (abstain, be faithful, use condoms) prevention campaigns, has occurred against a near silence around older adults' HIV vulnerability (Hosegood and Timaeus, 2006). Older adults are assumed to have 'aged out' of sexual risk (Mutevedzi and Newell, 2011; Negin and Cumming, 2010). This assumption aligns with community discourses of sexless HIV acquisition among older women who are widows or otherwise single at older ages. Sex can be "considered incompatible with 'the beautiful

image of old age' represented by the 'elder', a figure that showed restraint and control in all areas of life" (Van der Geest, 2001, as cited in Freeman & Coast, 2014, p.2 ). The caregiving HIV transmission discourse effectively dissociates sex from the transmission reality for older women, for whom sex is largely stigmatized (Heidari, 2016). Indeed, the importance of maintaining sexual respectability made the caregiving discourse particularly compelling, and illuminates why Enelo, a focus group participant in her 50s, succinctly declared, 'sometimes it is not about men' (FGI, women 50s).

Expanding the modes of HIV transmission to include caregiving to family members created a respectable avenue for older women to contract HIV. It made it possible, as Fanisa, a focus group participant in her 50s, intoned, to 'not judge her of [for] having [being] 55 years [old]' (FGI, women 50s). Helen, an HIV counsellor supervisor, also noted:

The thing is when they hear that they are HIV positive because they used to know that if you are HIV positive it means that you used to sleep around. So we used to encourage them; we were telling them that you don't [only] get HIV because of sex. It's not the only way. So now they understand that maybe one of my child was sick and I didn't know I used to wash him without gloves...So now they know it's not about sex. The stigma was all about maybe if they say I'm HIV positive it means that I was sleeping around. So now it is normal. (KII, counsellor supervisor)

By re-signifying HIV as a sexless infection, HIV was no longer about illicit sex, or about men. Rather, it was about caring for others, a central role in older women's lives.

**3. Advancing rural health worker goals**—The individual life history and focus group interviews identified health workers as the primary source of information about caregiving HIV transmission risk. The interviews with health workers show how these discourses enabled them to advance HIV prevention goals. Given the perception, described earlier, that older women felt 'safe' because they 'have passed that stage [of sex]', counselling messages invoking caregiving HIV transmission were a way for health workers to encourage older women to test. It allowed them to say, as Eliza, an HIV counsellor remarked, 'it's [HIV] not for young people only.' Eliza felt that it was important to 'explain all the way[s], the mode[s] of transmission.' Thus, when counselling women over the age of 50, 'I [Eliza] tell them HIV is a sexual transmitted infection but even blood contact, by taking care of a sick person' (KII, counsellor 1). Katekani, another HIV counsellor, elaborated:

...we give them health talk in the morning, we encourage them, even [if] you are old or young, it is good to do an HIV test. Because even though some are not active sexually, because they are old. But when coming to their child or grandchildren, when they are sick, they can bathe them, making all things for them, maybe he or she had wound or cut, then she help him or her, when their cuts come together or some blood can get to a wound, it [HIV] can be [transmitted]. If he or she is HIV positive, then the old one can be infected in [by] some of them. So we encourage them that even if they are not sexually active, but they can get [HIV], they can do an HIV test, in order to know their HIV status. (KII, counsellor 2)

Women had indeed absorbed these messages, as reflected in the words of Rholani, a focus group participant (quoted earlier):

Our children are sick and we touch them when they are sick without using gloves. So you can get it, it is important to know my [HIV] status. (FGI, women 60+)

Caregiving messages also enabled women to make sense of, and accept, their own HIV diagnosis. Khombiso, a widow whose husband died from an AIDS-related illness, explained:

It was painful and I was worried because I was asking myself where did I get it [HIV]? It gave me problems because I never slept with anyone except my husband. But they told me that may[be] we got it through taking care of someone without using gloves, we can find it through blood, we don't get it through sex only but there are other ways. Another thing is that my husband was working in different places as a soldier; it might happen I got it from him or through blood when someone is injured. (LHI, woman, age 44)

Being able to consider non-sexual modes of HIV acquisition allowed Khombiso to avoid having to confront the possibility that her husband's extra-marital relationships were the cause of her own infection. The caregiving narrative also allowed her, and women like her, to avoid blaming themselves for their HIV acquisition. Indeed, conveying the message that 'they didn't do something wrong' (KII, counsellor 3) was an important goal for health workers, regardless of gender. An HIV counsellor supervisor, Helen (quoted above), further noted:

So you have to make him or her understand that maybe it's not his [/her] fault. It's just a disease like high blood [pressure] or diabetes, something like that. So convincing a person is not easy. (KII, counsellor supervisor)

The task was easier, however, when the reason was caregiving.

**Health workers as medical epistemic bricoleurs.:** In high HIV prevalence settings like Agincourt, health workers are on the frontlines of the global HIV and AIDS response. They are also, presumably, equipped with knowledge of occupational exposure to HIV, namely through needle stick injuries and through splashes of infected blood into mucus membranes of the body, like one's eyes and mouth (National Department of Health, 2010). Moreover, health workers are also aware of the importance of HIV testing—for individuals, their partners, and for mitigating the community impact of the epidemic (National Department of Health, 2010). Above all else, they are also part of the community. As such, they are acutely attuned to community norms and practices and, in turn, the messages that would and would not work to encourage older women to know their HIV status and initiate treatment.

In everyday practice, rural health workers craft prevention messages by drawing on a bricolage (or creative mix) of global, national, and locally-relevant medical epistemologies (or knowledges) about HIV prevention. Thus, as medical epistemic bricoleurs, they absorb HIV counselling and testing guidelines from their own ministries of health, with great influence from the global AIDS community, and translate them 'in the vernacular' (Merry, 2006, p. 39; Angotti, 2010, 2012; Heimer, 2007). In so doing, they make prevention messages resonate with existing cultural knowledge, norms, values, and understandings. The caregiving HIV transmission discourse can thus be interpreted as a product of this 'epistemological bricolage' (Freeman, 2007). The discourse draws on older women as

proxies for nurses experiencing occupational exposure to HIV, which gells with the social roles that they occupy in their daily lives as caretakers for orphans, the infirm, and the dying. It also maps onto emic ideals of respectable sexless aging by rendering an HIV diagnosis for an older woman at once blameless and normal.

Thus, here was a discourse that advanced HIV prevention goals for older women by plugging into a local way of seeing, blending ideas of gender, generation, and local lived experiences and practices. By aligning counselling messages with community ideas about respectable aging that fit the social realities of older women's lives, caregiving HIV transmission was also strategic: it provided rural health workers with a dignified rationale for encouraging older women to test, and accept, without shame, an HIV diagnosis.

## Discussion

The caregiving HIV transmission discourse served a number of social and strategic purposes throughout Agincourt, an HIV-endemic setting experiencing a growing number of older women living with HIV. To begin, it helped the community make sense of HIV acquisition among a particular population – single/widowed older women living with HIV – who belied the standard narrative of unfaithful husbands and cheated-on wives. It also allowed older women living with HIV to maintain sexual respectability by making sense of their diagnosis through the lens of ordinary and respectable social roles of caregiving, particularly if their husband was long deceased. Finally, it represented a strategic narrative to encourage older women to test. By de-emphasising sex and invoking care for others, it removed blame from women who tested HIV positive and enabled them, and the community, to accept their status. Rural health workers were critical actors in disseminating this narrative. As medical epistemic bricoleurs, they transposed HIV prevention goals into familiar frameworks and socially achievable outcomes.

Our sense that caregiving HIV transmission was, at least in part, a strategic discourse, was supported by instances in our data where it was apparent that not everyone subscribed to this particular non-sexual transmission narrative. In at least one key informant interview and one focus group interview, respondents – both men—discussed the possibility that, even if a husband had died a long time ago, a woman could have still contracted HIV from him because of the long latency of the virus. Furthermore, given the community opprobrium directed at sexually active (single or widowed) older women, it could be that older women did not want to disclose to health workers (or local interviewers, for that matter) that they were having sex (Houle et al., 2016; Nnko, Boerma, Urassa, Mwaluko, & Zaba, 2004).

Nonetheless, what is striking, is the cultural and pro-social work that caregiving HIV transmission discourses accomplished—for health workers advancing public health goals as well as for older women, having buried a husband and possibly also a child, and having to come to terms with an HIV diagnosis later in life. It was a discourse that was greatly attuned to gendered and generational relations in the community, to caregiving practices in the absence of strong health infrastructure, and to the pressures that health workers might face to routinely encourage HIV testing in settings like Agincourt, experiencing a severe HIV epidemic.

While caregiving HIV transmission was an effective and resonant emic message, re-signifying HIV as a sexless infection for older women comes with clear costs. Ignoring older women's sexuality beyond reproduction eliminates them from messages of sexual risk. Indeed, in one instance, an HIV counsellor noted that when a woman said she was not having sex, she did not provide her with information about condoms. Survey findings, however, clearly illustrate that older women are having sex. In Agincourt, nearly three-quarters (73%) of women aged 40-59 and 18% over the age of 60 reported having had sex in the past two years. Yet, at last sex, only 15% of those aged 40-59 and none over age 60 reported using a condom (Houle, et al., 2018; see also Rosenberg et al., 2017). The caregiving discourse also reproduces a patriarchal double-standard: it reinforces expectations of celibacy for older women in a community where so many are now widows (or otherwise single) and presumably available for new partnerships, while preserving sexual freedom for older men for whom extramarital relationships with younger partners is a continued norm. Our analysis of caregiving HIV transmission discourses sheds light on the gendered and generational complexities and challenges experienced by rural South Africans aging in a community burdened by HIV and AIDS-related mortality.

## Acknowledgements

Authors are listed in reverse alphabetical order; each author contributed equally to the manuscript. This article is part of a special issue on 'African Voices in Global Health: Knowledge, Creativity, and Accountability' edited by Mandisa Mbali and Jessica Rucell. We are indebted to all the respondents who participated in this study. We also thank the 'HIV after 40' (*Izindaba za Badala*) research and field teams, as well as the people of Agincourt, for their long involvement with the AHDSS study. We gratefully acknowledge Jill Williams for her significant contributions to the design, data collection, and intellectual underpinnings of the project, and Laurie Hawkins, Moira Nolan, Allison O'Rourke, and Miriam Counterman for their research assistance. We also thank Vusumuzi G. Dlamini, F. Xavier Gómez-Olivé, Jane Menken, and the anonymous reviewers for their helpful comments, and Erin Ice for her editorial assistance. We are grateful for funding support from: the National Institute on Aging –HIV after 40 in rural South Africa: Aging in the Context of an HIV epidemic [R01 AG049634] (PI Sanyu Mojola); the National Institutes of Health - Partnership for Social Science AIDS Research in South Africa's Era of ART Rollout [R24 AG032112-05] (PI Jane Menken); the University of Colorado Innovative Seed Grant (PI Sanyu Mojola) and the William and Flora Hewlett Foundation African Population Research and Training Program [2009-4060] (PI Jane Menken). The MRC/Wits Agincourt Unit is supported by the South African Medical Research Council and the University of the Witwatersrand, as well as the Wellcome Trust, UK (grants 058893/Z/99/A, 069683/Z/02/Z, and 085477/B/08/Z – PI Stephen Tollman). We further acknowledge support for services and resources provided by the District of Columbia Center for AIDS Research, an NIH-funded program (A117970) and the Center on Health, Risk, and Society (CHRS) at American University. The content of this paper is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

## References

- Akintola O (2008). Defying all odds: Coping with the challenges of volunteer caregiving for patients with AIDS in South Africa. *Journal of Advanced Nursing*, 63(4), 357–365. doi: 10.1111/j.1365-2648.2008.04704.x [PubMed: 18727763]
- Angotti N (2010). Working outside of the box: How HIV counselors in Sub-Saharan Africa adapt Western HIV testing norms. *Social Science & Medicine*, 71, 986–993. doi: 10.1016/j.socscimed.2010.05.020 [PubMed: 20619944]
- Angotti N (2012). Testing differences: The implementation of Western HIV testing norms in sub-Saharan Africa. *Culture, Health & Sexuality*, 14(4), 365–378. doi:10.1080/13691058.2011.644810
- Angotti N, Mojola SA, Schatz E, Williams JR, & Gómez-Olivé FX (2018). 'Taking care' in the age of AIDS: Older rural South Africans' strategies for surviving the HIV epidemic. *Culture, Health & Sexuality*, 20(3), 262–275. doi:10.1080/13691058.2017.1340670
- Ashforth A (2002). An epidemic of witchcraft? The implications of AIDS for the post-apartheid state. *African Studies*, 61(1), 121–143. doi:10.1080/00020180220140109

- Barter C, & Renold E (1999). The use of vignettes in qualitative research. *Social Research Update*, 25(9), 1–6.
- Boily M-C, Baggaley RF, Wang L, Masse B, White RG, Hayes RJ, & Alary M (2009). Heterosexual risk of HIV-1 infection per sexual act: Systematic review and meta-analysis of observational studies. *The Lancet*, 9, 118–129. doi: 10.1016/S1473-3099(09)70021-0 [PubMed: 19179227]
- Callaghan M, Ford N, & Schneider H (2010). A systematic review of task-shifting for HIV treatment and care in Africa. *Human Resources for Health*, 8(1), 8. 10.1186/1478-4491-8-8 [PubMed: 20356363]
- Campbell C, Nair Y, Maimane S, & Sibiya Z (2008). Supporting people with AIDS and their carers in rural South Africa: Possibilities and challenges. *Health & Place*, 14(3), 507–518. doi: 10.1016/j.healthplace.2007.10.002 [PubMed: 18023238]
- Centers for Disease Control and Prevention. (2003). Exposure to blood: What healthcare personnel need to know. Retrieved from: [https://www.cdc.gov/HAI/pdfs/bbp/Exp\\_to\\_Blood.pdf](https://www.cdc.gov/HAI/pdfs/bbp/Exp_to_Blood.pdf)
- Chimwaza AF, & Watkins SC (2004). Giving care to people with symptoms of AIDS in rural sub-Saharan Africa. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, 16(7), 795–807. doi: 10.1080/09540120412331290211
- Clark SJ, Collinson MA, Kahn K, Drullinger K, & Tollman SM (2007). Returning home to die: Circular labour migration and mortality in South Africa. *Scandinavian Journal of Public Health*, 35(69 suppl), 35–44. doi: 10.1080/14034950701355619
- Coovadia H, Jewkes R, Barron P, Sanders D, & McIntyre D (2009). The health and health system of South Africa: Historical roots of current public health challenges. *The Lancet*, 374(9692), 817–834. doi: 10.1016/S0140-6736(09)60951-X
- Freeman EK, & Coast E (2014). Sex in older age in rural Malawi. *Ageing and Society*, 34(07), 1118–1141. doi: 10.1017/S0144686X12001481
- Freeman R (2007). Epistemological bricolage: How practitioners make sense of learning. *Administration & Society*, 39(4), 476–496. doi: 10.1177/0095399707301857
- Gómez-Olivé FX, Angotti N, Houle B, Klipstein-Grobusch K, Kabudula C, Menken J, ... Clark SJ. (2013). Prevalence of HIV among those 15 and older in rural South Africa. *AIDS Care*, 25(9), 1122–1128. doi: 10.1080/09540121.2012.750710 [PubMed: 23311396]
- Gómez-Olivé FX, Thorogood M, Bocquier P, Mee P, Kahn K, Berkman L, & Tollman S (2014). Social conditions and disability related to the mortality of older people in rural South Africa. *International Journal of Epidemiology*, 43(5), 1531–1541. doi: 10.1093/ije/dyu093 [PubMed: 24836326]
- Gray RH, Wawer MJ, Brookmeyer R, Sewankambo NK, Serwadda D, Wabwire-Mangen F, ... Quinn TC. (2001). Probability of HIV-1 transmission per coital act in monogamous, heterosexual, HIV-1-discordant couples in Rakai, Uganda. *The Lancet*, 357(9263), 1149–1153. doi: 10.1016/S0140-6736(00)04331-2
- Heidari S (2016). Sexuality and older people: A neglected issue. *Reproductive Health Matters*, 24(48), 1–5. doi:10.1016/j.rhm.2016.11.011
- Heimer CA (2007). Old inequalities, new disease: HIV/AIDS in Sub-Saharan Africa. *American Review of Sociology*, 33, 551–577. doi: 10.1146/annurev.soc.31.041304.122203
- Hosegood V, & Timaeus IM (2006). HIV/AIDS and older people in South Africa. In Cohen B & Menken J (Eds.), *Aging in Sub-Saharan Africa: Recommendations for furthering research* (Chapter 8, pp. 250–275). Washington, DC: National Academies Press.
- Houle B, Angotti N, Clark SJ, Williams J, Gómez-Olivé FX, Menken J, ... Tollman SM. (2016). Let's talk about sex, maybe: Interviewers, respondents, and sexual behavior reporting in rural South Africa. *Field Methods*, 28(2), 112–132. doi: 10.1177/1525822X15595343 [PubMed: 28190977]
- Houle B, Clark SJ, Gómez-Olivé FX, Kahn K, & Tollman SM (2014). The unfolding counter-transition in rural South Africa: Mortality and cause of death, 1994–2009. *PloS One*, 9(6), e100420. doi: 10.1371/journal.pone.0100420 [PubMed: 24959714]
- Houle B, Mojola SA, Angotti N, Schatz E, Gómez-Olivé FX, Clark SJ, ... Menken J. (2018). Sexual behavior and HIV risk across the life course in rural South Africa: Trends and comparisons. *AIDS Care*, 30(11), 1435–1443. doi:10.1080/09540121.2018.1468008 [PubMed: 29701073]

- Hunter M (2002). The materiality of everyday sex: Thinking beyond 'prostitution'. *African studies*, 61(1), 99–120. doi: 10.1080/00020180220140091
- Hunter M (2010). *Love in the time of AIDS: Inequality, gender, and rights in South Africa*. Bloomington: Indiana University Press.
- Kabudula CW, Houle B, Collinson MA, Kahn K, Gómez-Olivé FX, Clark SJ, & Tollman S (2017). Progression of the epidemiological transition in a rural South African setting: Findings from population surveillance in Agincourt, 1993–2013. *BMC Public Health*, 17(1), 424. doi: 10.1186/s12889-017-4312-x. [PubMed: 28486934]
- Kahn K, Collinson MA, Gómez-Olivé FX, Mokoena O, Twine R, Mee P, ... Khosa A. (2012). Profile: Agincourt health and socio-demographic surveillance system. *International Journal of Epidemiology*, 41(4), 988–1001. doi: 10.1093/ije/dys115. [PubMed: 22933647]
- Madhavan S (2004). Fosterage patterns in the age of AIDS: Continuity and change. *Social Science & Medicine*, 58(7), 1443–1454. doi: S0277-9536(03)00341-1. [PubMed: 14759688]
- Mee P, Collinson MA, Madhavan S, Root ED, Tollman SM, Byass P, & Kahn K (2014). Evidence for localised HIV related micro-epidemics associated with the decentralised provision of antiretroviral treatment in rural South Africa: A spatio-temporal analysis of changing mortality patterns (2007–2010). *Journal of Global Health*, 4(1). doi: 10.7189/jogh.04.010403.
- Merry SE (2006). Transnational human rights and local activism: Mapping the middle. *American Anthropologist*, 108(1), 38–51. doi: 10.1525/aa.2006.108.1.38
- Mojola SA (2014). *Love, money, and HIV: Becoming a modern African woman in the age of AIDS*. University of California Press.
- Mojola SA, Williams J, Angotti N, & Gómez-Olivé FX (2015). HIV after 40 in rural South Africa: A life course approach to HIV vulnerability among middle aged and older adults. *Social Science & Medicine*, 143, 204–212. doi: 10.1016/j.socscimed.2015.08.023. [PubMed: 26364007]
- Mutevedzi PC, & Newell M-L (2011). A missing piece in the puzzle: HIV in mature adults in sub-Saharan Africa. *Future Virology*, 6(6), 755–767. doi: 10.2217/fvl.11.43. [PubMed: 22427781]
- National Department of Health. (2010). *National HIV Counselling and Testing Policy Guidelines*. Private Bag X828, Pretoria, 0001.
- Negin J, & Cumming RG (2010). HIV infection in older adults in sub-Saharan Africa: Extrapolating prevalence from existing data. *Bulletin of the World Health Organization*, 88(11), 847–853. doi: 10.2471/BLT.10.076349. [PubMed: 21076566]
- Niehaus I (2012). Witchcraft and the South African Bantustans: Evidence from Bushbuckridge. *South African Historical Journal*, 64(1), 41–58. doi: 10.1080/02582473.2012.640829.
- Niehaus I, & Jonsson G (2005). Dr. Wouter Basson, Americans, and Wild Beasts: Men's conspiracy theories of HIV/AIDS in the South African lowveld. *Medical Anthropology*, 24(2), 179–208. doi:10.1080/01459740590933911 [PubMed: 16019570]
- Nnko S, Boerma JT, Urassa M, Mwaluko G, & Zaba B (2004). Secretive females or swaggering males?: An assessment of the quality of sexual partnership reporting in rural Tanzania. *Social Science & Medicine*, 59(2), 299–310. doi: 10.1016/j.socscimed.2003.10.031. [PubMed: 15110421]
- Posel D, Kahn K, & Walker L (2007). Living with death in a time of AIDS: A rural South African case study. *Scandinavian Journal of Public Health*, 35(69 suppl), 138–146. doi: 10.1080/14034950701356443.
- Rosenberg MS, Gómez-Olivé FX, Rohr JK, Houle BC, Kabudula CW, Wagner RG, ... Tollman SM. (2017). Sexual Behaviors and HIV Status: A population-based study among older adults in rural South Africa. *Journal of Acquired Immune Deficiency Syndromes* (1999), 74(1), e9–e17. doi: 10.1097/QAI.0000000000001173. [PubMed: 27926667]
- Schatz E, Gilbert L, & McDonald C (2013). 'If the doctors see that they don't know how to cure the disease, they say it's AIDS': How older women in rural South Africa make sense of the HIV/AIDS epidemic. *African Journal of AIDS Research*, 12(2), 95–104. doi: 10.2989/16085906.2013.851719. [PubMed: 25871379]
- Schatz E, Houle B, Mojola SA, Angotti N, & Williams J (2019). How to "live a good life": Aging and HIV testing in rural South Africa. *Journal of Aging and Health*, 31(4):709–732. doi:10.1177/0898264317751945. [PubMed: 29318924]

- Schatz E, Madhavan S, & Williams J (2011). Female-headed households contending with AIDS-related hardship in rural South Africa. *Health & Place*, 17(2), 598–605. doi:10.1016/j.healthplace.2010.12.017 [PubMed: 21292533]
- Schatz E, & Ogunmefun C (2007). Caring and contributing: The role of older women in rural South African multi-generational households in the HIV/AIDS era. *World Development*, 35(8), 1390–1403. doi: 10.1016/j.healthplace.2010.12.017.
- Sennott C, & Mojola S (2017). ‘Behaving well’: the transition to respectable womanhood in rural South Africa. *Culture, Health & Sexuality*, 1–15. doi:10.1080/13691058.2016.1262062
- Snow R, Madalane M, & Poulsen M (2010). Are men testing? Sex differentials in HIV testing in Mpumalanga Province, South Africa. *AIDS Care*, 22(9), 1060–1065. doi: 10.1080/09540120903193641. [PubMed: 20824559]
- Stadler J (2003). Rumor, gossip and blame: Implications for HIV/AIDS prevention in the South African lowveld. *AIDS Education and Prevention*, 15(4: Special issue), 357–368. doi: 10.1521/aeap.15.5.357.23823 [PubMed: 14516020]
- Stoneburner RL, & Low-Beer D (2004). Population-level HIV declines and behavioral risk avoidance in Uganda. *Science*, 304(5671), 714–718. doi: 10.1126/science.1093166 [PubMed: 15118157]
- Swidler A, & Watkins SC (2007). Ties of dependence: AIDS and transactional sex in rural Malawi. *Studies in Family Planning*, 38(3), 147–162. doi:10.1111/j.1728-4465.2007.00127.x. [PubMed: 17933289]
- Thomas F (2007). ‘Our families are killing us’: HIV/AIDS, witchcraft and social tensions in the Caprivi Region, Namibia. *Anthropology & Medicine*, 14(3), 279–291. doi: 10.1080/13648470701612679. [PubMed: 27268743]
- Van der Geest S (2001). “No strength”: Sex and old age in a rural town in Ghana. *Social Science & Medicine*, 53(10), 1383–1396. doi: 10.1016/S0277-9536(01)00222-2. [PubMed: 11676408]
- Weiss B (1993). ‘Buying her grave’: Money, movement and AIDS in north-west Tanzania. *Africa*, 63(1), 19–35. doi: 10.2307/1161296.