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Antiretroviral therapy and aging as resources for managing and resisting HIV-related stigma in rural South Africa

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Abstract

The widespread roll-out of antiretroviral therapy (ART) in Africa has contributed to a large population of adults aging with HIV. However, little is known about how HIV-related stigma interacts with aging in the ART era. This study uses in-depth interviews with middle-aged and older South Africans living with HIV to explore stigma-related experiences and response strategies. Participants describe a persistence of stigma which requires the deployment of a range of common and age-based stigma management and resistance strategies. We find that participants *minimize* their exposure to stigma through selective disclosure of their HIV status; *neutralize* HIV-related stigma through comparisons to chronic illnesses common among older adults, and *deflect* stigma through asserting an ART-adherent identity and othering younger non-adherent adults. Overall, our study highlights the roles of ART and aging as resources for managing and resisting HIV-related stigma.

Keywords

HIV; ART; Stigma; Aging; South Africa

1. Introduction

When the Director of WHO's Special Programme on AIDS, Jonathan Mann, spoke at the Third International Conference on AIDS in 1987, he described the HIV pandemic as consisting of "three distinct, yet inter-twined global epidemics": an epidemic of HIV

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infection, an epidemic of deadly AIDS, and an epidemic of “social, cultural, economic and political reaction to AIDS” (Mann, 1988, p. 131). As the epidemic enters its fifth decade, sub-Saharan Africa has borne a disproportionate burden of infections and deaths (UNAIDS, 2019). South Africa, the focus of this study, has the world’s worst epidemic. An estimated 7.8 million South Africans live with HIV (UNAIDS, 2021), comprising a fifth (20.6%) of people aged 15–49 and nearly a fifth (17.2%) aged 50–64 (HSRC, 2018). At the epidemic peak, an estimated 2.8 million AIDS-related deaths occurred between 1997 and 2010 (Bradshaw et al., 2016). Since then, the wide-spread roll-out of antiretroviral therapy (ART) has led to dramatic reductions in HIV infections (Johnson et al., 2022) and AIDS mortality (Burger et al., 2022; Johnson et al., 2017) in South Africa, which currently hosts the world’s largest ART program (WHO, 2021). However, evidence on the course of Mann’s third epidemic is mixed or limited and questions remain as to whether and how HIV-related stigma has changed over time; and in particular, how experiences of and responses to stigma have been shaped by epidemic changes, aging, and the life-course.

This study draws on qualitative interviews with rural South African middle-aged and older adults who have been aging with HIV. We extend the literature by examining whether stigma has persisted as they have aged and across ART eras, from before ART was available to the present when treatment is widely available. We also explore whether strategies they use to manage stigma have shifted, especially since ART became available, and how other features of aging, such as biomedical events (e.g. the onset of chronic diseases) or changing life-course stages (e.g. becoming an elder in the community), might attenuate or exacerbate experiences of HIV-related stigma and shape strategies to manage and resist it.

2. Background

In this section we provide an overview of the literature on experiences of and responses to stigma, particularly stigma management and resistance strategies, in relation to epidemic changes over time, aging, and the life-course.

2.1. Declining stigma in the ART era?

From the beginning of the pandemic, negative social meanings have been attached to an HIV positive status, making it both a biomedical disease and a stigmatizing social condition (Link & Phelan, 2001; Parker & Aggleton, 2003). Its association with death, sexual immorality and personal irresponsibility, among other things (Campbell et al., 2006; Niehaus, 2007; Schatz et al., 2013), has resulted in a range of stigmatizing behaviors directed at people with HIV, from negative gossip and blame to eviction and physical violence (Skinner & Mfecane, 2004). Widespread ART availability across Africa in the mid-2000’s (Ford et al., 2011), led some to hope that this would eliminate HIV-related stigma (Gilbert, 2016; WHO, 2003). However, research examining the role of ART in normalizing the social experience of HIV has demonstrated the complexity of stigma processes. In particular, there are differing findings as to the extent that ART has reduced stigma by changing the social meanings of HIV as opposed to merely enabling those on treatment to conceal their status (by removing physical symptoms) and thus avoid stigma (Camlin et al., 2020; Chan et al., 2015; Lambert et al., 2018; Mall et al., 2013; Mojola et al., 2022; Treves-Kagan et al., 2015). Other research

suggests that stigma may have increased since the roll-out of ART (Kaler et al., 2016; Maughan-Brown, 2010; Roura et al., 2009). This complicated relationship between ART and stigma is likely to be especially salient among the growing numbers of Africans who are aging with HIV.

2.2. Shifting epidemic eras, aging and HIV-related stigma

Studies examining changes in HIV-related stigma over time have focused primarily on younger adult and general adult populations (Camlin et al., 2020; Chan et al., 2015; Maughan-Brown, 2010). Yet middle-aged and older Africans have had distinct experiences of the HIV epidemic. They have endured multiple epidemic eras (Conroy et al., 2013; Whyte, 2014), with early experiences as caregivers of dying partners and children and raising orphaned grandchildren (Schatz & Ogunmefun, 2007; Schatz & Seeley, 2015), giving way to experiences of gaining access to life-prolonging medication and living with and managing HIV themselves (Knight et al., 2020; Whyte, 2014). Importantly, ART has extended their lifespan, as they might otherwise have died (Vollmer et al., 2017). Now, middle-aged and older adults must navigate changing life stages along with managing HIV at older ages.

In addition, they have also been aging, with the attendant physiological changes such as increased vulnerability to chronic illnesses common to older age (Kennedy et al., 2014; Maharaj, 2013; Negin et al., 2012). In South Africa, there has been both a growing population of adults aging with HIV due to widespread ART access and averted death, as well as a dramatic rise in the prevalence of non-communicable diseases (Mayosi et al., 2009; Vollmer et al., 2017). This means that people with HIV are now aging into a life stage where having a chronic disease is more the norm than the exception. This may normalize HIV and reduce stigma for middle-aged and older adults.

However, they are also experiencing shifting familial and social expectations and norms, especially those relating to respectability and responsibility, as they age (Angotti et al., 2018; Mojola & Angotti, 2019). While young people with HIV, particularly women, experience stigma for their perceived sexual immorality (Campbell et al., 2007), stigmatizing messages have been directed at older adults with HIV, focusing on their loss of physical, moral and social power (Freeman, 2016). In this way, HIV-related stigma might intensify as people age. Overall, this study extends the literature by examining experiences of HIV-related stigma over time among middle aged and older people.

2.3. Stigma management and resistance strategies

Stigma management and resistance can take both structural and individual forms. At the structural level, the rejection of shame and blame through the collective enactment of stigma resistance has been an important political strategy to gain access to treatment and equal rights. In particular, the strategy of open status disclosure through sharing (auto)biographical narratives of people living with HIV has been used by activists to combat systemic stigma and inaction (Fassin, 2007; Tougaw, 1998). In South Africa, especially before widespread ART access and during the period of AIDS denialism, open disclosure was central to the work of activists such as Zackie Achmat, Andrew Mosane, and Prudence Mabele, as well

as their organization, the Treatment Action Campaign (TAC) (Green, 2017; Robins, 2006). Once ART was rolled out, collective patient activism and treatment testimonials helped to forge new shared understandings of an empowered and “responsibilized” HIV positive identity centering ART adherence, open disclosure of status, and a healthy lifestyle (Robins, 2006). However, with the end of AIDS denialism, increasing ART access, and government involvement, collective meanings attached to “responsible” treatment behaviors have shifted away from an activist orientation (Kagee et al., 2014; Mfecane, 2011). Indeed, Kagee et al. (2014, p. 107) argue that “treatment may be becoming more of a personal and individual act rather than a political act.”

However, individual strategies can be complex, require active management, and can have unintended consequences. For example, a common stigma management strategy is the concealment of a stigmatized status (Goffman, 1963); in this case, selective or non-disclosure of a positive HIV status. Yet this strategy can impede individuals from accessing health care and create challenges for treatment adherence (Kalichman et al., 2019; Rintamaki et al., 2019). People with HIV also pursue stigma resistance strategies such as voluntary self-disclosure (Goudge et al., 2009; Poindexter & Shippy, 2010), educating others about HIV (Buseh & Stevens, 2007; Zuch & Lurie, 2012), refusing to feel shame about their status and normalizing HIV (Spangler et al., 2018), and creating new positive identities (Campbell et al., 2011). While these approaches may increase experiences of stigma, they also offer opportunities for social support and can lead to greater treatment adherence and psychological resilience (Goudge et al., 2009; Spangler et al., 2018).

Individual strategies also change over time and over the HIV continuum of care in the ART era (Bonnington et al., 2017; Goudge et al., 2009). Unintentional disclosure through medication collection and use has been shown to be a new HIV-related stigma management challenge (Kalichman et al., 2019; Tiruneh, 2012). In addition, due to past health policies recommending treatment initiation for very low CD4 counts and continuing delayed ART initiation, there is a lingering association of ART with later stages of illness and dying (Curran et al., 2014; David, Schatz, Angotti, Myroniuk, & Mojola, 2021, May; Zuch & Lurie, 2012). The ART adherent are also stigmatized as hidden transmitters of infection (Kaler et al., 2016; Roura et al., 2009). However, people with HIV have also drawn on an ART-adherent identity to engage in a strategy of counter--stigmatization—that is, reframing and redirecting stigma—towards “the untested” (Campbell et al., 2011; Midtbø et al., 2012) and “the non--adherent.” This is reinforced in clinic settings where staff can stigmatize non-adherent or less than perfectly adherent patients (Bernays et al., 2017).

Counter-stigmatization aligns with biomedical discourses that have accompanied the global scale-up of ART and the transformation of HIV into a chronic disease (Mojola et al., 2022; Paparini & Rhodes, 2016; Viljoen et al., 2021). It further reflects the biopolitical claims and obligations of responsibilized health (or therapeutic) citizenship, which entail the right to access treatment (ART) and the responsibility to take treatment so as to ensure one’s own health as well as the health of others (Nguyen, 2005; Robins, 2006; Young et al., 2019). While these discourses encourage a positive, empowered self-concept for those who enact responsible behaviors, they also have the potential to create a new category of “problematic

persons” for those viewed as unwilling to be responsible citizens (Rose, 2007, p. 147), in this case the untested or non-adherent.

Aging may interact with these stigma management and resistance strategies. A premium on sexual respectability, especially for women as they age (Angotti et al., 2018; Mojola & Angotti, 2019), suggests that non-disclosure or selective disclosure may be an important stigma management strategy (Hlongwane & Madiba, 2020; Schafer et al., 2021). Counter-stigmatization may also be a key strategy. Older adults are rarely targeted for routine HIV testing, and have lower rates than younger adults (Johnson et al., 2015; Schatz et al., 2019; Schatz & Knight, 2018). However, once diagnosed and on treatment, older adults have high rates of treatment adherence (Sankar et al., 2011), and thus biomedical responsibility. As a result, counter-stigmatization may mesh well with social norms of responsibility for older adults. This paper thus examines strategies engaged in by middle-aged and older adults in the ART era, whether and why they vary with age, as well as the roles of the family and community.

3. Setting, data and methods

Our study is nested in the Agincourt Health and Socio-Demographic Surveillance System site (henceforth “Agincourt”), in Mpumalanga Province, South Africa. A former apartheid homeland area, Agincourt continues to be characterized by high unemployment, labor migration, and reliance on social grants to secure livelihoods (Collinson, 2010; Kahn et al., 2012; Twine et al., 2007). Agincourt also has a severe dual HIV/NCD epidemic among those aged 40 and over: 23% are living with HIV (Gómez-Olivé et al., 2018) and 69% are living with at least two chronic conditions (Chang et al., 2019). However, 64% of those with HIV are on ART (Manne-Goehler et al., 2017).

This paper is part of a larger study on aging in HIV-endemic settings, focusing on the transition from middle to older ages (see Mojola et al., 2015, 2022 for study details). We draw on in-depth interviews conducted in 2018 with 21 participants aged 45–83 who disclosed their HIV status in the interview (Table 1).

Respondents were randomly drawn from those who participated in an area survey conducted in 2011 (Gómez-Olivé et al., 2013). Interviews were audio-taped, lasted 1–2 hours on average, and were conducted in Shangaan/XiTsonga, the local language. The three interviewers were middle-aged local residents, who were gender matched with participants. Interviews were translated and transcribed by their respective inter-viewer and reviewed for clarity by the study team leaders (one of whom was the second author of this paper). Participant interviews were anonymized using pseudonyms. Research protocols were approved by the ethics committees of the authors’ institutions as well as the Mpumalanga Province Research and Ethics Committee. All participants provided signed informed consent.

Respondents were asked questions about their family life, romantic relationships, livelihoods, and general health, with specific questions about experiences living with HIV and ART access and experiences. Specific questions about HIV-related stigma were not

included in the interview schedule but emerged during interviews. The first author manually coded interview data, using both deductive codes informed by the stigma literature, as well as inductive codes emerging from analysis. All authors participated in the interpretation of the findings.

4. Findings

By 2018, our middle-aged and older participants had lived with HIV and been on ART for years, yet they described current experiences of HIV-related stigma. We identified three main strategies they pursued to minimize, neutralize, and deflect stigma, and also observed how ART and aging shaped their strategies to manage and resist stigma. These themes are explored in more detail in the sections below.

4.1. Persistent stigma in the ART era

Participants described ongoing experiences of and fears about HIV-related stigma in the ART era. For example, Katekani, 56, one of two wives, a mother of four, and diagnosed 14 years earlier as part of an antenatal exam, discussed experiencing stigma from her husband:

“I used that treatment until by the time my husband found it. He threw it away and said he didn’t want ARVs at his house. [Because he believes] It means I have been sleeping with other men at his house.”

The sign of an HIV-positive status had changed from the once visible bodily deterioration from AIDS to ART medication, and elicited stigma. As a result, adherence had been an ongoing challenge for Katekani as her home was not a safe place to take or store medication. She stopped medication but eventually restarted when she got sick. Her brother now collected her medication secretly. Secrecy and a lack of trust was evident throughout her discussion of how HIV was addressed at home, and she speculated that her husband may also be hiding his status and treatment. However, stigma concerns were not restricted to her home. By keeping treatment at her friend’s house, Katekani worried about her status becoming known:

“Now there is no confidentiality as I ha[ve] to take my treatment outside my house. People might find [out] and talk. You cannot know the future.”

Katekani wanted to take her ART “like anyone who is on treatment,” in the privacy of her own home, and anticipated community stigma as a result of her more visible medication taking.

Indeed, community talk and gossip were a recurrent form of stigma experienced by people living with HIV. For example, Magezi, 46, married father of four, stated:

“...the problem is that people talk a lot about people who are HIV positive. People can make you feel like you have already died. They take us as if we can die anytime. They don’t accept us. You see all those things.”

Magezi, who was diagnosed and started treatment in 2008 after his first wife died of AIDS, discussed receiving support from his current wife who also had HIV. He described both previous and ongoing personal experiences of stigmatizing community talk. His comments

highlighted how, even in the ART era, HIV was still seen as a deadly illness, and people with HIV could still be treated as “already dead.” The commonality of this stigmatizing rhetoric in Agincourt before widespread ART (Niehaus, 2007; Posel et al., 2007), suggests that it had removed the physical but not discursive connection between HIV and death. Magezi’s experiences demonstrate the persistence of community othering and treatment of people with HIV as liminal, despite ART.

Gloria, aged 71, twice widowed with no plans to remarry, was a mother of four. When asked if she goes with someone to collect treatment, she responded:

“I don’t invite anyone, and I don’t want to go with someone. This is my secret. People talk and I don’t want to hear my name spread all over the village.”

Gloria was also aware of community talk about people with HIV and especially feared her secret status becoming known through clinic visits; a fear discussed by several participants (see also Gilbert & Walker, 2010). Notably, it was the positive health effects of her ten-plus years on ART that allowed her to keep her secret. Vukosi, 68, widowed, re-married and father of four, was asked what advice he would give to someone who just found out that they have HIV. He similarly said:

“My advice can be of telling him/her that this is your own burden. You have to carry it alone and it is not acceptable to share it with other people. If you can talk about it, people will laugh at you. But you have to keep quiet. They will say he/she was active, that is why she/he got this illness it was because she/he was clever for women or men. You have to be careful and don’t tell anyone. This is your “ndofa-nayo.” (meaning you die with it. It is for life.) You have to know this alone ... This is a secret illness.”

Vukosi had been diagnosed four years earlier but had only disclosed to his wife, at the encouragement of clinic nurses. Even though she was supportive, Vukosi, like Gloria, also collected treatment alone, not sending anyone to assist despite the fact that his knee pain caused him to sometimes miss scheduled collection dates. He also noted stigma linked to inappropriate sexual behavior, adding more motivation to conceal their status.

As these examples illustrate, the persistence of stigma led to a continued need among participants to carefully negotiate disclosures, and ART medication now both signaled their status and enabled them to hide it.

4.2. Stigma management and resistance strategies

While participants across age groups experienced persistent stigma, strategies to manage and resist stigma varied by age and life stage. Three primary discursive strategies that emerged through participant interviews were *minimizing* exposure to stigma through selective disclosure of their HIV status; *neutralizing* HIV-related stigma by normalizing it through comparisons to other chronic illnesses which most of their age-mates were now living with; and *deflecting* stigma through the othering of, especially younger, ART non-adherent adults. In practice, participants combined these strategies, but here we focus on highlighting each strategy.

4.2.1. Minimizing stigma through selective disclosure—While HIV was treated as a secret illness by some, nearly all participants disclosed to at least one person, with many employing selective disclosure to avoid or minimize exposure to stigma (Hlongwane & Madiba, 2020; Linda, 2013; Schatz et al., 2022). For example, Margaret, aged 46 and widowed with three children and a married boyfriend, said she had disclosed to family members, but when asked if she told her mother-in-law (with whom she was currently living), responded:

“I didn’t tell her. She is talkative ... I don’t like to tell her as when she is drunk, she will talk everywhere and say, “Makoti [my daughter-in-law] is ill. She has AIDS.” I won’t like that.”

For Margaret, who started treatment the prior year, disclosures had to be navigated with considerations not only of negative treatment in the home but also of possible community consequences. Likewise, Risuna, aged 49, widowed and a mother of two, disclosed to her sister and child, but when asked whether she told her neighbors, stated:

“I didn’t tell my neighbors as they are not my family members. I think if I can tell them, others don’t have secrets in their hearts and they can start talking about me and I won’t feel good about that ... It is a secret as if people can see that you are on treatment, they will start talking about you. After you won’t feel good about that and it might happen you stop taking the treatment.”

Risuna started HIV treatment in 2004, yet still anticipated stigma from her neighbors in 2018 and viewed her status as a secret outside of the home, concealing her medication with a “panado [paracetamol/acetaminophen] plastic bag.” She also highlighted the power of such stigma in contributing to non-adherence. This was a concern for Risuna who discussed life decisions (such as treatment adherence and not marrying again) as motivated by the positive health effects of ART and wanting to live longer to care for her children. Patricia, aged 51, and married with four children, described her own selective disclosure to fellow people living with HIV: *“Most of my friends are the ones we met at the clinic ... We are talking about our status and we are free as we are the same.”* She started treatment in 2009, and was happy to support the newly diagnosed, but only in private, saying:

“Myself I tell people that if they want to ask me about my illness, they must not ask me where there are many people or on the streets. But they must come to my house. I hate to be asked where there are many people. The reason is that other people might not answer me in a good way and I won’t feel good about that.”

The role of aging as a stigma management resource was apparent when participants described how they could minimize their risk of stigma by drawing on other common chronic illnesses as a cover. For example, Yvonne, 57, widowed and a mother of two, explained:

“You will hear them [people with HIV] saying my sugar is not good. You see! But inside the clinic our topic doesn’t include the illness of sugar. We talk reality as we are talking about the [ART] treatment. You will hear us telling each other on how we felt by taking the treatment on the first time. Others will say “hey, we wanted to die before taking the treatment.” Others will say “I’m what I am because of this

treatment.” You see! We did not talk about the illness of sugar. But here at home. (She laughed.) We change the topic ... People don’t want to be known. They are hiding their illnesses.”

Chronic illnesses, such as diabetes, also required regular clinic visits and daily medication; consequently, they provided an effective cover and enabled greater control over HIV disclosure decisions, especially in a context where most adults aged 40+ had two or more chronic illnesses (Chang et al., 2019).

The role of aging in intensifying stigma was evident in how respectability drove the use of selective disclosure, especially among our oldest women respondents, who disclosed to fewer people. Gloria, 71, who earlier discussed keeping her status a secret, had only disclosed to one neighbor, who also had HIV, and her daughter, who had since died of cancer. Tintswalo, aged 76, had been living with HIV for almost 20 years, yet had only disclosed to her sister and a friend who were directly helping her. She discussed the concern of women her age having daughters-in-law finding out about their status. Masingita, 83, a widowed mother of four and traditional healer, was particularly concerned about how clinic procedures for disseminating ART could reveal her status to younger adults, explaining:

“Another thing is that they must not mix us with the young ones [at the clinic]. Let me say my son-in-law came to collect his treatment, I also went there for my treatment. Do you think there will be a respect when he sees that I’m on treatment also? But they must have privacy. Adults to adults and the young ones together. That’s why I say they must give treatment door-to-door.”

Masingita had been very ill when diagnosed more than five years ago. ART had since eliminated all her debilitating and status revealing symptoms which was why she said she could not stop treatment. Yet regular treatment collection at the clinic threatened to undermine her selective disclosure decisions and expose her to negative reactions and loss of elder respect. Her comments reflected community expectations for women to “behave well,” “take care of themselves” and maintain sexual respectability as they aged (Sennott & Mojola, 2017; Angotti et al., 2018).

In sum, selective disclosure allowed aging adults in the ART era to minimize their experience of stigma through both active disclosure to carefully chosen others, as well as active non-disclosure through different forms of concealment enabled by ART and the communal burden of chronic illness among older adults. Further, community expectations for older adults intersected with HIV-related stigma to contribute to relatively more use of this strategy among the oldest women participants.

4.2.2. Neutralizing stigma through comparison to other chronic illnesses

—The large chronic disease burden was also an important aging-related resource for neutralizing stigma. Respondents’ discussions of living with HIV while on ART frequently involved comparisons to other chronic illnesses such as diabetes and high blood pressure. For example, Risuna, 49, noted: “*I don’t see any problem with this illness. To me it is like if you have high blood pressure or the illness of sugar.*” Not only had ART made HIV “just an illness,” it was often viewed as more effective and simpler than treatment for other

chronic illnesses such as diabetes and high blood pressure. For example, Tintswalo, 76, who separated from her (now deceased) husband, described her co-morbid experience by saying:

“It is not easy my child. Particularly with the high blood. I have to choose what I eat. I don’t eat fatty foods or cold drinks. With the HIV I don’t have any problem but high blood is a problem now.” Unlike ART, treatment for high blood pressure required dietary changes in addition to medication adherence. Patricia, 51, who only had HIV, when disclosing to her children, thus neutralized her illness, saying: *“the treatment makes us to be like anyone. As long as you stick on it, you will be fine. ... This treatment is more powerful than the sugar and high blood treatment. Why? I said with HIV, you control it.”* By highlighting to her children how ART made people “like anyone” and how ART-managed HIV was relatively more controllable, she was able to neutralize their HIV-related stigma. Her children had previously not wanted to touch her or eat her food for fear of contagion, but now supported her.

Overall, while the oldest adults in the sample were more likely to have multiple chronic illnesses and to discuss the greater challenges of having high blood pressure and diabetes compared to HIV, it was middle-aged adults (45–59) who most often drew on neutralizing comparisons to other illnesses. This could be because they openly disclosed to more people and thus were more exposed to stigma, and therefore needed more discursive tools for managing and resisting stigma.

4.2.3. Deflecting stigma through a responsible, adherent identity—Identity work that centered on ART adherence allowed participants to resist and deflect HIV-related stigma. Treatment adherence was characterized as an individual “choice” and a responsibility to oneself and one’s family, which as an adult with children, was especially important. As Rhulani, 46, mother of five, separated from her husband and newly repartnered, put it: *“I have got the right to receive it and it is my responsibility to take it.”* When asked about treatment, Emmanuel, 63, a father of several children, and currently in a new romantic relationship, said:

“... You give up on your own. Is not the choice of the people who are working at the clinic or whose whom are testing people, [it] is your own choice ... What you dedicate yourself with. You give up here on earth. Myself I don’t give up. I have children.”

Emmanuel, who had been on ART for several years, struggled with adherence in the beginning; now like Rhulani, he discussed personal responsibility in taking treatment after the clinic had done their part. He added, similarly to others, that his motivation for adherence was his children.

Personal responsibility was also reflected in participants’ descriptions of how they navigated everyday challenges with adherence. Joy, 57, a widowed mother of seven, discussed missing a scheduled medication collection date at the clinic because she had attended an out-of-town funeral and how the nurses were “angry” because of the danger of missed medication. Asked how she felt about the nurses’ reaction, Joy, who had been on treatment since 2005, replied:

“I didn’t have a problem as I knew I made a mistake. I asked for forgiveness and I said that will never happen again and really it doesn’t happen. I make sure that I go in time.”

Joy’s acceptance of blame for missing her appointment is a poignant example of the personal responsibility of adherence taken on by nearly all of the participants. In this vein, Yvonne, 57, discussed taking treatment as paying back a debt and reasoned that it was “negligent” people who died of HIV noting:

“I won’t stop until I die. I know that after death, I would be done with my debt of taking the treatment. I would be not owing by then ... If it was not because of the treatment, I would be not alive. Those who were negligent are gone and we have seen them dying with our own eyes. So, I don’t want to be negligent. Really, they are gone. (There was pause.) Ha ... I can’t stop taking the treatment, I can’t. I will get tired, but I can’t.”

Rhulani, 46, also described adherence as a choice with even stronger language, describing people who stop treatment as “committing suicide”:

“I can’t play like that. I mean stop taking the treatment. I won’t do that. I’m not educated but I’m not a stupid ... So, with those who are defaulting I called them stupid as they are. This is like committing suicide. They forgot that there is life while on treatment. What if next year the government introduce the cure? Where would you be? I will take the treatment until it get tired or until it stops working in my body.”

In this way, Yvonne and Rhulani, along with other participants, deflected stigma to others by framing themselves as responsible and resilient ART adherents, while framing the non-adherent as “negligent” and “stupid.” Being ART adherent for participants meant both choosing to live and choosing to be moral, responsible community members.

Analysis also revealed the role of age in cementing an identity as a responsible ART adherent, especially among middle-aged (45–59) participants, who drew on their status as people with family responsibilities, and deflected stigma onto non-adherent youth. When asked how common it was for people to stop treatment in her village, Yvonne answered:

“This is common. Very common. Particularly the young ones. They want to enjoy nice time and forget about their lives.”

Yvonne not only attributed non-adherence primarily to young people, but also attributed their motives as not wanting to take on the responsibility required for ART adherence. Talking about her own son, Harriet, aged 57, said he had not gone to the clinic despite having HIV, and losing weight, energy and appetite. In making sense of his refusal, she said, “*maybe it was because he didn’t have responsibility ... if he was having children like me, children who are depending on him, maybe he would be on treatment.*” Thus, the responsibility of children was seen as binding people to the responsibility of medication. At the time Harriet started treatment in 2006 she was separated from her husband and had two children to care for: “*That’s why with me ..., I will take the [ART] treatment until I die.*”

Patricia, 51, was particularly frustrated by a younger woman she was advising, despite her medication challenges:

“Ah ... ! That one was a trouble. (There was laughter.) ... Sometimes she was not taking the treatment. She has been on treatment for years, but she is not responding well to it as she sometimes stops taking it. I was getting tired of her as she used to come and complain to me. I became angry with her and told her that myself I was not taught to stop the treatment by the hospital. It’s up to her to choose life than death. I also told her that if she becomes ill, she must not send her children to me as she decided not taking the treatment. I also told her to stop calling me. I know what the problem was as sometimes she could skip taking the treatment for a week. That’s why by the time she will go back to it, she will have side effects.”

For Patricia, non-adherence and poor treatment response was the young woman’s fault and choice; she was neglecting her obligation as a mother and choosing death. Thus, Patricia emphasized the personal and family responsibility attached to being ART adherent that she felt the young woman was not taking as seriously as she did.

In sum, both middle-aged and older adult participants managed HIV-related stigma through establishing an identity of a responsible, ART-adherent adult with family responsibilities. Middle-aged respondents were more likely to draw on this identity to deflect stigma, especially to younger non-adherent adults, by re-directing the HIV-related stigma of irresponsibility and moralized blame towards those they characterized as young, selfish, and irresponsible. Expectations for older age meshed with those of treatment adherence, while stereotypes about youth aligned with stereotypes of non-adherents. In this way, aging served as an important resource to resist stigma.

5. Discussion

Social identities are relational and discursive social processes. What living with HIV means “is repeatedly being renegotiated in relation to a range of other people ... in their lives and in relation to institutional and cultural discourses” (Burrows & Wright, 2004, p. 83). In this paper, we extend the literature by illustrating how the management and resistance of HIV-related stigma are ongoing, active processes both over the life-course and over a shifting disease epidemic context. We find evidence for the persistence of HIV-related stigma in the era of ART as well as the need to engage in stigma management and resistance strategies among nearly all our participants, which we identified as minimizing, neutralizing and deflecting HIV-related stigma. We also highlight the aging-related resources available to middle-aged and older adults to manage stigma in a context of widespread ART availability and a large community chronic disease burden.

In particular, we find that older South African adults engaged in selective disclosure to trusted others as well as concealment to minimize their exposure to stigma. These findings are corroborated by recent studies (Hlongwane & Madiba, 2020; Schatz et al., 2022). We extend the literature by highlighting variation across middle and older ages. Notably, we find that our oldest respondents appeared to disclose to relatively fewer people. This is concerning given that more restrictive disclosure could place this already vulnerable

population at risk for greater social isolation and lower levels of emotional and instrumental support (Kautz et al., 2010; Harris et al., 2018).

Living in a high chronic disease prevalence context also served as a resource for aging adults. Navigating the voluntary or involuntary disclosure of a stigmatized health condition like HIV was easier to do when most same-age peers were also managing chronic conditions, such as hypertension and diabetes, that required daily medication and clinic visits. Participants were able to draw on the cover of other diseases to conceal their HIV status and thus minimize potential stigma (Rintamaki et al., 2019; Treves-Kagan et al., 2015) and draw on comparisons of HIV to other illnesses (Makoae et al., 2008; Zuch & Lurie, 2012; Mkwanazi et al., 2015) to neutralize stigma. We find that particularly middle-age respondents drew on this stigma neutralizing strategy. This may be due to their wider disclosure and therefore potentially greater exposure to stigma.

Finally, respondents resisted stigma through deflecting it to others (Campbell et al., 2011; Midtbø et al., 2012). We find that especially middle-aged participants deflected to non-adherent younger others, while simultaneously positioning themselves as responsible, resilient and as conscientious parents choosing to live for their children. Through the moralized meanings of ART adherence, meanings which also mapped onto older age-related family responsibilities (Angotti et al., 2018), participants had access to a new legitimizing social identity - being ART adherent - with which to resist stigma. As such, participants were likely drawing from larger community discourses in clinics (Bernays et al., 2017), support groups, and educational campaigns. For example, the South African National AIDS Council launched a national HIV testing and counseling campaign in 2010 with the theme “I am responsible, we are responsible, South Africa is taking responsibility” (SANAC, 2010), which espoused responsabilized HIV citizenship (Robins, 2006). We extend the literature by illustrating problematic ways this citizenship mapped onto aging and respectability norms. While moralized messages resonated in ways that encouraged adherence, they were deployed, in practice, towards blaming and stigmatizing younger adults.

Overall, our findings suggest that individual identities and life-course stage interact with multi-level contexts such as the state, the socio-epidemiological context, the community, and the family to produce distinct forms of HIV-related stigma, and distinct strategies to manage and resist it. We focused on variation across life stage and epidemic eras, showing how aging and widespread ART availability served as resources from which middle-aged and older adults could draw to manage and resist persistent HIV-related stigma. Our findings underscore the importance of policy makers crafting public health strategies attendant to age and life-course based concerns in both the dissemination of ART, as well as in messaging to encourage ART uptake and adherence, in order to reduce community stigma and enable adults with HIV to feel fully supported across the life-course.

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Table 1

Participant demographics.

| Age groups | Women | Men |
|------------|-------|-----|
| 45–49 | 3 | 3 |
| 50–59 | 5 | 2 |
| 60–69 | 0 | 3 |
| 70–83 | 3 | 2 |
| Total | 11 | 10 |

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