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THE END OF AIDS? HIV AND THE NEW LANDSCAPE OF ILLNESS IN RURAL SOUTH AFRICA

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Abstract

The global HIV/AIDS scientific community has begun to hail the dawn of “the End of AIDS” with widespread anti-retroviral therapy (ART) and dramatic declines in AIDS-related mortality. Drawing on community focus groups and in-depth individual interviews conducted in rural South Africa, we examine the complex unfolding of the end of AIDS in a hard-hit setting. We find that while widespread ART has led to declines in AIDS-related deaths, stigma persists and is now freshly motivated. We argue that the shifting landscape of illness in the community has produced a new interpretive lens through which to view living with HIV and dying from AIDS. Most adults have one or more chronic illnesses, and ART-managed HIV is now considered a *preferred* diagnosis because it is seen as easier to manage, more responsive to medication, and less dangerous compared to diseases like cancer, hypertension and diabetes. Viewed through this comparative lens, dying from AIDS elicits stigmatizing individual blame. We find that blame persists despite community acknowledgement of structural barriers to ART adherence. Setting the ending of AIDS within its wider health context sheds light on the complexities of the epidemiological and health transitions underway in much of the developing world.

Keywords

HIV; AIDS; South Africa; Stigma; Chronic Disease

“sugar diabetes kills, high blood kills and HIV does not kill.”

“HIV is just a virus, [it] is not dangerous. We have dangerous diseases like cancer and sugar diabetes.”

“people are killing themselves because they are defaulting [ART] treatment.”

INTRODUCTION

The global HIV/AIDS scientific community has begun to hail the dawn of “the End of AIDS.” The End of AIDS is increasingly becoming the dominant frame through which the HIV/AIDS pandemic is now viewed, and is a new organizing principle for global programming efforts (see for example Havlir & Beyrer 2012; Granich et al 2017; Essex 2017). The 90–90–90 targets (90% tested, 90% on treatment, 90% virally suppressed) set to achieve the goal of ending AIDS by 2030 (UNAIDS 2014) reflect the significant global progress made over the last few decades—anti-retroviral therapy is increasingly widespread, more people living with HIV have undetectable viral loads, and AIDS-related mortality has dramatically declined (UNAIDS 2019). Against this backdrop, however, scholars have highlighted the limitations of this new framing. In a special symposium issue published in *Global Public Health* in 2018, a set of critical social science papers examined the “end of AIDS” project, and its new significations (Kenworthy et al. 2018a; 2018b). In particular, Kenworthy et al. (2018a) noted that global AIDS targets “ignore the ways that ending AIDS must be premised on ending fear, stigma, discrimination and the social, political and economic conditions that fuel infections” (p.959; see also Leclerc-Madladla 2018; Auerbach 2020). In this paper, we respond to the call to contribute to the body of knowledge examining “where, how and for whom AIDS may be ending” (Benton et al. 2017, p. 474), and address the scarcity of perspectives on the lived experience of the ending of AIDS highlighted in the symposium, especially in hard-hit African settings.

South Africa, where our study is based, is, possibly, the most important country in which to examine the end of AIDS. It has the world’s largest epidemic, with 7.9 million people living with HIV. Among those aged 15–49, an estimated 20.6% have HIV (HSRC 2018). Further, an estimated 2.7 million South Africans died from AIDS-related illnesses between 1997–2010 (Bradshaw et al. 2016). However, after a long delay, South Africa now also has the world’s largest ART program (UNAIDS 2018; see Youde 2005; Simelela et al 2015 for scholarship on the delay). ART roll-out efforts have contributed to dramatic declines in AIDS-related mortality in many parts of the country (Houle et al. 2014; Herbst et al. 2009), and progress on the 90–90–90 goals now stands at 90–68–87 (UNAIDS 2019). South Africa thus appears to be well on its way to ending AIDS-related mortality.

Beyond morbidity and mortality, however, an important feature of the lived experience of HIV and AIDS has been that of stigma (Parker & Aggleton 2003). Health-related stigma is a social process involving the blaming, negative othering, and devaluing of people who have or who are perceived to have a particular health condition or illness (Deacon 2006). A central component of HIV and AIDS-related stigma is the attachment of socially-constructed moralized meanings to the condition and the behaviors that are believed to be illness-causing (Link and Phelan 2001). As a consequence, individuals and groups who are linked to the

disease are viewed as morally responsible for their illness, and are feared vectors of a communicable disease that can lead to physical deterioration and death (Castro and Farmer 2005; Deacon 2006). As a result of the stigma associated with HIV and AIDS, South Africans living with the disease have experienced discrimination, social distancing, gossip, denial of healthcare, termination of employment, verbal abuse, and even violence (Skinner & Mfecane 2004).

HIV and AIDS-related stigma, as a social and relational process, is not static and has the potential to change over time as social contexts and the meanings attached to HIV change (Stadler 2003; Earnshaw & Kalichman 2013; Maughan-Brown 2010). While the scale-up of ART has resulted in a decoupling of HIV from AIDS-related bodily deterioration and imminent death, evidence of its impact on HIV-related stigma has been mixed. Some studies have argued that widespread ART has contributed to a reduction in HIV-related stigma (Chan et al. 2015; Wolfe et al. 2008), while others have suggested that the positive health effects of ART have allowed those on treatment to conceal their status and therefore avoid stigmatization and discrimination (Treves-Kagan et al. 2016; Tiruneh 2012; Mbonye et al. 2013). In the latter view, ART has transformed HIV from being a discredited stigma where HIV is visible and ‘marked’ to a ‘discreditable stigma’, where HIV is concealable and allows people with HIV to “pass” as HIV negative (Goffman 1963 as discussed in Treves-Kagan et al. 2016). However, anticipated fear of stigma and discrimination from an HIV positive status can also result in delayed or non-disclosure (Klopper et al. 2014), delay in testing and treatment uptake, and non-adherence (Treves-Kagan et al. 2016; Kalichman et al. 2019). Indeed clinics themselves can be spaces where HIV positive patients experience stigma for non-adherence or less than perfect adherence such as harsh scolding, threats and judgement from health workers (Bernays et al. 2017; Kenworthy 2017). In these ways, stigma and stigma-related discrimination can be significant barriers to HIV treatment (Katz et al. 2013; Sweeney and Vanable 2016; Heestermans et al. 2016), and can contribute to AIDS-related deaths. Overall, this body of literature leads us to ask: in an era of widespread ART, can declining AIDS-related deaths also lead to an end to HIV and AIDS-related stigma?

The ending of AIDS is also occurring in a rapidly shifting health context characterized by a widening cluster of illnesses. Complex epidemiological and health transitions are unfolding across Africa—a continued infectious disease burden among children, youth and adults, now compounded by COVID-19, is matched by a growing non-communicable disease (NCD) burden (World Health Organization 2014). This is further exacerbated by the vulnerability of people living with HIV to the early onset of NCDs (Deeks et al. 2013). South Africa is on the leading edge of these trends on the African continent (Mayosi et al. 2009; Westaway 2010; Mendenhall and Norris 2015). Indeed, as we will show, the growing burden of NCDs has provided local communities with a new lens through which to frame both the ART-enabled transformation of HIV into a chronic disease as well as AIDS-related deaths.

In this paper, we draw on a set of community focus groups and in-depth individual interviews conducted with adults aged 40 and above in several rural villages in Mpumalanga Province, South Africa to examine perceptions and experiences of the ending of AIDS in their community. We focus on this group because until recently, there has been a relative

neglect in the literature of older Africans with HIV. Yet, there is evidence of a growing population of people *aging* with HIV as ART extends life, as well as *acquiring* HIV at older ages (Vollmer et al. 2016; Gomez-Olive et al. 2020). Adults over 40 also have a longer vantage point on community change in the pre/post-ART era.

SETTING, DATA AND METHODS

This study is nested within the Agincourt Health and Socio-Demographic Surveillance System (henceforth “Agincourt”), which is run by the University of Witwatersrand. The system, initiated in 1992, comprises 31 villages, and is located in Mpumalanga Province, in northeastern South Africa (see Kahn et al 2012 for system details). In 2018, we conducted 10 community focus group interviews (FGI) with participants recruited from key locations where residents typically gather, such as markets and pension points. The FGIs included a total of 84 people, and were stratified by gender (women/men/mixed gender), age group (40s, 50s, 60s-plus), and proximity to a health facility (6 FGIs in villages with a health facility, 4 FGIs in contiguous villages without a health facility). We also draw on in-depth individual interviews (IDIs) from HIV after 40/*Izindaba za Badala*, a larger longitudinal study on experiences of aging in the context of an HIV epidemic that began in 2013 which included 60 IDIs (see Mojola et al 2015 for study details). We focus on 21 IDIs conducted in 2018 with community residents aged 45–83 years who discussed living with HIV. FGI and IDI interviews were conducted in the local language (XiTsonga/Shangaan) by 5 resident interviewers; each FGI had a facilitator and a note-taker. All interviews were translated and transcribed by their respective interviewers, and were subsequently reviewed by the first two authors for clarity. All participants provided signed informed consent, and research protocols were approved by the authors’ institutions as well as the Mpumalanga Province Research and Ethics Committee.

FGI participants were asked about community norms and discourses about HIV and ART, barriers and incentives to HIV testing and ART uptake, and community experiences of HIV/AIDS and ART in the last 5 years (since mass ART rollout) and 15 years (since peak AIDS-related mortality). Participants were also presented with a series of vignettes (Barter and Renold 1999) featuring hypothetical people in their age group who: (i) might have HIV; (ii) were living with HIV and navigating the ART landscape; and (iii) think they might have high blood pressure (hypertension) or diabetes. Questions invited FGI participants to reflect on the motivations and experiences of these hypothetical individuals as they navigated healthcare. IDI respondents were asked about their family lives, livelihoods and general health status, including questions about living with HIV and co-morbidities, if relevant. All respondent names are pseudonyms.

The first author conducted manual coding, analysis and initial interpretation of the interview data for this paper. FGI analysis involved both inductive coding (Charmaz 2001) of themes that emerged in analysis, as well as deductive coding (Strauss and Corbin 1994), systematically analyzing responses to each question and vignette. Themes included continuities and changes in the treatment of people living with HIV; community perceptions of and experiences with ART; community support for people on ART; chronic disease experiences and how they compare with HIV; and general community challenges. These

themes were then explored deductively in IDIs to examine whether community perspectives revealed in FGIs were similar to, or different from, the lived experiences of individual respondents. All the authors participated in developing the interpretation and the paper's arguments.

RESULTS: The End of AIDS in Agincourt, South Africa?

1. Widespread ART access and declining AIDS-related mortality

Along with the rest of the country, Agincourt has experienced a severe AIDS epidemic. Elevated AIDS-related mortality began in 1998, dramatically increased in 2000, and peaked in 2004–2005 (Houle et al 2014). During that time, women's life expectancy at birth plummeted from 75 years in 1995 to its lowest point of 57 years in 2005; for men, it dropped from 68 years in 1993 to a low of 50 years in 2007 (Kabudula et al 2017). ART became available in district hospitals in 2004, and in a limited number of local health facilities in 2007, but was not widely available until after 2010 (Houle et al 2014; Mee et al 2014). Among those aged 40 and over, only 38% of the HIV-positive population reported ART use by 2010–2011 (our calculations); by 2017, however, 68% were on medication (Manne-Gohler et al 2017). While life expectancy at birth has since rebounded, now at 70 years for women and 61 years for men (Kabudula et al 2017), mortality rates remain higher than when surveillance began in 1994 (Houle et al 2014).

Across our FGIs, residents acknowledged the reduction in AIDS-related death since ART became more widely available. As succinctly noted by a man in his 40s, “there is a change because the number of people dying of HIV has reduced” (M3, M40s). Another man added:

M4: The introduction of ARV [ART] has help[ed] a lot of people, because we [are] no longer having [a] lot of people dying of AIDS. People are getting ARVs at clinics unlike before whereby ARVs were not available at clinics (M40s).

A woman in a 60s-plus FGI noted a generational shift, saying, “most of our children died because of HIV and there was no treatment then, but as we know about ART, people survive” (W7, W60s-plus). Indeed, ART meant that HIV was no longer a death sentence, as a woman in her 40s noted “people know that HIV does not kill people. As long as they accept and they take their treatment, they will live longer” (W1, W40s). The participant went on to note the difference made by the South African government's shift to universal testing and treatment in 2017 (WHO 2017; Schatz and Knight 2018):

Facilitator: How do people feel since ART has been introduced?

W1: The community feels good since there is ART because in the past after they tested they wait for their CD4 count to suppress so that they could start with the ART. Nowadays when people test positive, they are given treatment [the] same day. (W40s)

Along with community experience of reduced AIDS-related deaths as a result of expanded ART access, participants also discussed the consequences of these shifts, which we turn to next.

2. Declining HIV-related stigma?

FGI participants described how ART has led to a decline in HIV-related stigma, leading to significant improvements in how people living with HIV were being treated in the community. For example, in discussing community changes since the introduction of ART, a participant remarked:

W10: ...there is a change in our community ... people living with HIV, they are getting support from the community even [from] their family members... More people died some years ago because of stigma and were not getting support from people who are close to their heart even in the community but now things have changed. They are getting support, like me if I can go to the shop I make sure that I buy apples because I'm living with someone who is HIV positive. (WM50s)

While this statement may reflect messages emanating from HIV-related interventions in Mpumalanga Province (Khoza 2012; KYR 2010), it also resonates with the lived experiences of IDI participants. For example Laban in his mid-40s, was asked:

I: Where do you receive the most support in treating your HIV?

Laban: Here at home. My parents are also supportive. My mother is the one is most supportive than them all...Everyone at home is supportive as they know my status.

Participants reported disclosing to one or more family members, being lovingly taken care of, and openly building treatment regimes into daily household routines. For some, this openness extended into the community. Hannah, in her mid-40s, noted:

I go with my treatment everywhere and I don't hide it. I take it where people are there. I remember there was death at my sister's house and I was supposed to go and sleep there. I took it and many people were there. I was not scared to take it.

However, other respondents experienced community stigma. For example, when asked "what makes you to be scared?", Hlangnani, also in his mid-40s said:

It is because we know that everyone who is living will die. But 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.

This led many to keep their HIV diagnosis secret. Moses, in his late 60s, felt that "this is your own burden" and "a secret illness" because "if you can talk about it, people will laugh at you." Mary, in her late 40s, also felt it was a secret and hid her medication noting that she "put it in the panado [Panadol, a pain killer] plastic bag [so] people will think I'm taking panados meanwhile they are my ARVs." She felt that "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."

Overall, these experiences reflect both continuities and change in HIV/AIDS-related stigma in Agincourt (Zuch and Lurie 2012). Family members' willingness to support ART adherence perhaps suggests a greater acceptance of HIV-positive status (see also Schatz et al. 2019), and a reduction in secondary stigma attached to those taking care of sick family

members compared to an earlier study in Agincourt (Ogunmefun et al. 2011). However, stigmatizing community talk, making people feel they “have already died” reflects earlier community research by Niehaus (2007) who illustrated how people living with HIV/AIDS were considered and treated as “corpses that live” or “dead before dying” (p. 847). Thus, a key reason community respondents perceived HIV-related stigma to have declined, was likely because ART has made HIV invisible by reducing external AIDS symptomatology and making people look “fresh” (see also Kaler, Angotti and Ramaiya 2016; Treves-Kagan et al 2016). In a typical response, a man noted in an FGI, “It is good, why, because now you cannot see that this person have HIV and this one doesn’t have, if a person follows instructions” (M2, M50s). Another group respondent remarked, “now even if you meet them you can’t recognize them” (M5, M50s). Thus, it was not necessarily that stigma had declined; but rather, if people with HIV could not be identified, they could not be stigmatized.

3. Declining AIDS-related stigma? Structural barriers vs individual choices

Widespread ART availability also produced tensions and contradictions within the community regarding the causes of an AIDS-related death. On the one hand, respondents acknowledged structural barriers to “following instructions”, a recurring phrase, which included adhering to ART, as illustrated below in excerpts from different FGIs:

M40s:[the] most important [community] challenge that I observed is that now is difficult for older people to collect their medication at [clinic] because of distance.” (M2).

W50s: To add on what W5 said about unemployment and not having enough food in the house. We are surprised because not every HIV positive people are given energy booster (soft porridge maize meal). I don’t know why others get it while some were not meanwhile the treatment that they get is the same. (W1)

M50s: You see what you are saying that a person have to start by eating when he is taking the medication. I am not working and there is no one at home to give me something to eat. Why they don’t give us the pension for six month [he means the disability grant]? They said they are no longer giving the pension because people stop taking the medication, because they wanted to get the pension. They are giving us the medication, what are we going to eat? You give us soft porridge. It was our mistake. (M1)

Despite these frank discussions of poverty, lack of food and transport, FGI respondents nonetheless attributed AIDS-related death to individual ignorance and poor choices as illustrated in the excerpts below:

M40s: Ok when we can compare back then and now this disease, it was a dangerous disease but now we can see that it’s just like any other disease and when I compare back then and now, it’s that people these days are ignorant. They don’t want to take medication and if you don’t take medication you will die and really people are dying if they don’t take medication. (M1)

W50s: According to me I think the government has done [a] good thing to implement the treatment so that people could take it. It is up to me to choose what I like. There are people in our community, they know that there [is] treatment but they say that “what is the treatment for” and sometimes they stop taking their treatment and others die because of that. There are people who want to live longer and they adhere on treatment. (W4)

M50s: “people are killing themselves because they are defaulting treatment” (M2)

These perspectives did not just exist among FGI respondents. For example, an IDI with Khalani, in her mid-40s, explicitly rejected structural barriers as a reason for non-adherence, describing how people:

“have the demon of defaulting and I don’t know why. Other people will tell you that they are defaulting because the government has stopped giving them pension. Others are saying they were supposed to get free food parcels from the government... But that is not a reason of defaulting.”

Khalani went on to suggest that people should instead try to grow their own food and be self-sufficient noting, “You can do something that you find yourself l[i]ving[.]”

In trying to make sense of these contradictions, we find that the attribution of an AIDS-related death to personal failure and irresponsibility was, in part, the result of a shifting landscape of illness characterized by the increasing prevalence of other life-threatening chronic illnesses.

4. A New Landscape of Illness and a New Interpretive Frame

Our data show that the current formation of views about HIV/AIDS did not occur in isolation; rather, they emerged in tandem with a new landscape of illness, in which ART-managed HIV was now one of many other chronic diseases prevalent in the community (see also Mendenhall & Norris 2015; Knight et al 2018). In Agincourt, half the population (54%) are living with at least one serious chronic condition (HIV, diabetes or hypertension) (Clark et al 2015). Among those aged 40 and over, 69% are living with at least two chronic conditions (Chang et al 2019). In a context where most adults had personal experience with chronic illness, community members considered HIV to be the easiest chronic condition to manage. When asked to compare living with NCDs and HIV, two FGI women noted:

W2: HIV is the disease that [we] should not be scared of. People should be proud if they are HIV positive than if they have high blood and sugar diabetes because they [those with NCDs] could die at any time. There is life with HIV than sugar diabetes...

W1:... those who are diabetic could die anytime if they forgot to take their treatment. ...With HIV even if I forgot to take it at the time given or a day I won’t die because of that. (W40s)

HIV medication was thus seen as far more forgiving than diabetes medication, needing less vigilance. In response to the same question, same-aged men similarly noted:

M1: According to my understanding, sugar diabetes kills, high blood kills and HIV does not kill. People just kill themselves. Why I say so, most people don't adhere to the treatment but with cancer it does not matter whether you take treatment or not. You eventually die. High blood [hypertension] you can die any time but HIV does not kill.

Facilitator: Any other view?

M2: We agree with the last speaker. (M40s)

Concurring with this perspective, IDI participant Moses, in his late 50s, felt "You have to follow instructions...[HIV] is not killing...There is diseases that kill even if you are following the instructions." Indeed, "HIV is just a virus, [it] is not dangerous. We have dangerous diseases like cancer and sugar diabetes. (W10, WM 50s). The lack of danger from HIV was linked to its controllability, as Miriam, in her early 50s, reflected:

This illness [HIV] is good. (*She laughed.*)... It is controllable... you cannot control the illness of sugar [diabetes] or high blood [hypertension]. But with HIV you can... This treatment is more powerful than the sugar and high blood [hypertension] treatment.

For those with HIV and hypertension, it was hypertension which "troubles me a lot." (see also Hing et al 2019). They took more pills per day compared to HIV, and complained of dizziness, headaches and increased frequency of urination as they struggled to manage their blood pressure. Melda, in her late 50s, felt HIV and hypertension were "fighting in one body", however:

I don't complain when it comes to HIV. What worries me most now is that I have the illness of high blood [hypertension]. High blood is not good my sister. Having this illness you can suffer for your whole life. But with this one (*HIV*), as long as you follow the rules of taking treatment, you don't have problems... I can tell you that even if I can die now, I would not die of HIV but maybe with high blood as it becomes stronger than HIV to me.

These perspectives led respondents to talk about HIV as a disease of "choice" compared to other illnesses, noting, "if you can choose, I can choose HIV because I can control it." (M4, M50s). Responding to a vignette about "Makhi Mpumi," a recent widow who had tested HIV-positive and was on ART, FGI participants reflected:

W9: Now there is diabetes...and cancer and these illness it's too much dangerous. And if I can choose between HIV, diabetes and cancer, I'm going to choose HIV because it's not killing anyone, but high blood, diabetes and cancer, you won't survive if you have one of them, they will kill you now...

M6: I heard what they are saying and it's true...(WM50s)

In sum, the changing landscape of illness in the era of ART in Agincourt has led community members to now see HIV as controllable, relatively easy to manage with medication, and the preferred illness compared to the more dangerous and unstable diseases that could result in death *even if* someone "followed instructions." It was through this lens, that dying of AIDS

was subject to individual blame. HIV was not killing anyone. People who died of AIDS were those who “just kill themselves.”

DISCUSSION AND CONCLUSION

This study portrays a complex unfolding of the “End of AIDS” in a rural South African setting. Community members are witnessing a dramatic ending of AIDS-related deaths as a result of widespread access to ART. However, HIV/AIDS-related stigma has endured, and is now newly motivated. We argue that this is driven by a shifting landscape of illness that has produced a high community burden of dual infectious and chronic disease epidemics. This has changed the interpretive lens through which the community views living with HIV and dying from AIDS, providing fresh fuel for AIDS-related blame.

Our study complements and builds upon previous literature on a shift in HIV/AIDS-related stigma in the era of ART. Like previous research, we find both a perceived reduction in HIV-related stigma, alongside evidence that this perception is driven, at least in part, by the concealability of HIV as a result of ART (Treves-Kagan et al 2016). We also find evidence that stigma attached to non-adherent HIV-positive patients in clinics (Bernays et al. 2017; Kalichman et al 2019), extends out into the community, as reflected by moralized community discourses blaming AIDS-related deaths on non-adherence to ART. These perspectives have also been reflected in other African settings such as Malawi and Lesotho, where individuals who do not seek ART or “default” are seen to be choosing death and are thus subject to blame (Ashforth & Watkins 2015; Kenworthy 2017).

We extend the literature by setting these stigmatizing discourses in the context of a rising chronic illness burden and illustrate new ways in which HIV resists normalization (Moyer and Hardon 2014). Here, it is considered less dangerous, easier to control with medication and, indeed, a *preferred* diagnosis to other common chronic illnesses like diabetes and hypertension. We further show how in a setting where almost 70% of adults over 40 are living and aging with two or more conditions (Chang et al 2019), a new health landscape provides fresh motivation for holding people with HIV responsible for their own death. This wider illness context may also have reduced the salience of structural and social determinants of ART access and adherence (Kagee et al 2011; Moyer & Igonya 2018; Knight et al 2018). While food and clinic access affected everyone living with a chronic illness, what uniquely distinguished HIV, was that it was no longer dangerous, if one followed instructions. Thus, people who died of AIDS were simply choosing not to take their medication, thereby “killing themselves.” This reflects a neoliberal discourse well-documented in studies of health and illness (Paparini & Rhodes 2016). The “biomedical responsabilization” of neoliberal subjects living with HIV (Thomann 2018) now extends beyond sex to strictly following bio-medical instructions to self-manage their chronic illness. In this view, death from HIV/AIDS is not a reflection of social-structural failures, but rather a reflection of personal irresponsibility, making an individual subject to blame.

African communities have had evolving experiences and interpretations of the HIV/AIDS pandemic (see for example Watkins 2004; Conroy et al 2013; Whyte 2014). Our study also reflects changes in the community’s ethos in Agincourt. Posel and colleagues (2007)

conducted focus group interviews in Agincourt in 2003–2004, before widespread access to ART. Then, an AIDS “death was understood and explained through an avowedly social lens – a “bad” death being first and foremost a symptom of a cultural and moral condition” (p. 141). The widespread availability of ART at the time of our study in 2018, that was seen to enable people to prevent this ‘bad death’, may have further contributed to AIDS-related blame. The individualization of an AIDS death also exists in tension with an emic communal ethic evident when we interviewed Agincourt community members in 2013 (Angotti et al. 2018). This ethic was expressed in strategies to prevent HIV transmission and AIDS-related death by “*ku ti hlalisa*,” taking care of not only oneself but also others in the community, understanding that “a community lives and dies together” (p. 270), and that responsibility is therefore shared (ibid). This ethic was less salient in our follow-up interviews in 2018, just 5 years later when ART was more widely available and other managed chronic health conditions were highly prevalent. This, too, is part of the complex legacy of the ending of AIDS in Agincourt.

In reflecting on experiences studying the US South, Sangaramoorthy (2018) argued, “HIV chronicity, then, does very little to substantiate the logic of the ‘end of AIDS’; rather, it reinforces the unending possibility of suffering, poverty, and illness.” (p.985). Indeed, as most Agincourt residents aged 40 and over are living and aging with one or more chronic diseases, the “End of AIDS” will not result in Agincourt residents emerging into a disease-free era. Rather, the projected timetable for the “End of AIDS” by 2030 coincides with the time when, as Bain and colleagues (2017) argue, “NCDs are set to overtake HIV and other infectious diseases as the top killers in low-income countries.” (p. 2). Further, COVID-19, an infectious disease which preys on people with chronic diseases, may be particularly devastating in settings such as Agincourt.

AIDS-related deaths are ending, but they are leaving in their wake neoliberal ways of being and blaming, as well as a burgeoning chronically ill population whose many illnesses are not on the global health funding agenda for the developing world. As the global HIV/AIDS community heads towards the end of AIDS, our findings lend support to calls to renew efforts to reach, test, and link to care, those who have been left behind (Auerbach 2020) and engage in efforts to eliminate structural barriers to ART access and adherence (Kagee et al 2011). More broadly, it is time for a more comprehensive global health mandate, fully integrating HIV/AIDS infrastructures with existing (or newly created) chronic disease healthcare for middle aged and older adults (Mwagomba et al 2018; Schatz et al 2018). This will best ensure a continued flow of resources and support to rural African communities grappling with the new landscape of illness in the decades to come.

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