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"I'm Getting Life from the Treatment": Perceptions of Life and Death Among Middle-Aged and Older Medication-Adherent Persons Living with HIV in Rural South Africa

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ABSTRACT

The widespread availability of health information and treatment for HIV in Southern Africa does not reach all populations. Few programs and materials are developed with middle-aged and older rural individuals living with HIV as the target audience, despite this being a growing population. This vacuum inevitably exacerbates the disjuncture between clinical and experiential knowledge. This study uses in-depth interviews from 2018 with middle-aged and older rural South Africans who self-report medication adherence to ART in order to explore experiences of living with HIV and beliefs about anti-retroviral treatment (ART). Participants revealed a general sense of vulnerability as a major motivation for HIV medication adherence. A majority of the participants believed that death was imminent if they defaulted on ART at any point in time. Although the availability of ART brought hope to many, HIV was still perceived as a death sentence, particularly if ART adherence was imperfect. The study findings suggest a need to examine the psychosocial component of community programs for middle-aged and older people living with HIV. For this growing population that experienced the full course of the epidemic, more research is needed on the burden of psychological and mental health issues emerging from the need for long-term HIV medication adherence.

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Introduction

AIDS-related morbidity and mortality persist (UNAIDS, 2020) but the availability of antiretroviral treatment (ART) for people living with HIV (PLWH) has resulted in reduced mortality, and increased life expectancy, globally (Centers for Disease Prevention and Control, 2018). In sub-Saharan Africa, where HIV is shifting from being an acute disease to a chronic one – due to the availability of ART – there is a growing proportion of middle-aged and older persons living with HIV (Bor et al., 2013; Mills et al., 2011).

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The policy and research foci of PLWH's life experiences on ART have centered on adolescents, pregnant women, and, generally, those of reproductive age (Eshun-Wilson et al., 2019; Murray et al., 2017; Oguntibeju, 2012; Omonaiye et al., 2018). Despite advances in HIV testing and treatment accessibility, knowledge on the beliefs and perceptions of middle-aged and older South Africans aging with HIV on ART remain limited (Denardo et al., 2022; Lucia et al., 2018)

In many low-income settings, being middle-aged or older is both a social and a biological identifier. Additionally, middle-aged and older adults are subject to different social expectations than younger people, particularly with regard to caregiving and providing for the family. Thus, middle-aged and older individuals have accumulated different personal experiences and have seen social change – as a cohort – while living in their communities (Barken, 2019; Riley et al., 1972; Riley, 1987). Age stratification theory predicts unequal experiences between age cohorts due to unique historical events or specific knowledge and attitudes acquired over time (Riley, 1987). This theory is manifested in contemporary South Africa, as middle-aged and older individuals learned to survive amid the HIV epidemic before ART was available, while experiencing HIV-related deaths of peers, spouses, and children (Zuch & Lurie, 2012). This differential exposure to the HIV epidemic has led to important age-related variation in sexual behavior, access to ART, and stigma surrounding infection and treatment (Brian et al., 2018; E. Schatz et al., 2021; Sarah et al., 2015). Middle-aged and older persons, therefore, continue to be responsible for providing care to and supporting grandchildren who have lost one or both parents to AIDS-related diseases (E. J. Schatz, 2007; E. Schatz & Ogunmefun, 2007).

South Africans continually witnessed improving health of individuals who initiated ART when they were ill – some even appearing near death – which contributed to substantive increases in trust in the effectiveness of ART. Seeing this "Lazarus effect," and that people survived on ART, encouraged PLWH to commit to daily ART regimens (Altice et al., 2001; Conroy et al., 2013). Today, South Africa has an HIV Test and Treat policy such that anyone who tests positive for HIV is started on ART regardless of CD4 count (UNAIDS, 2016).

The availability of ART has led to significant positive clinical outcomes, but PLWH still experience adverse mental health consequences related to living with HIV (Cianelli et al., 2020; Hansen et al., 2009; S. A. Mojola et al., 2020; Sikkema et al., 2003). The emotional weight of living with HIV may also be amplified in unique ways for middle-aged and older persons, due to their experiences of living through the entirety of the HIV epidemic (Kohler et al., 2017; Whyte, 2015). Given the prior experiences of PLWH – especially those who experienced the pre-ART years and are also dealing with age-related health challenges – it still may be hard to internalize the idea that one can live a healthy and long life on ART.

This paper examines the ways in which ART adherence shapes, and in turn is shaped by, middle-aged and older South Africans' life experiences and mental health. The paper uses data from in-depth interviews with reportedly medication-adherent middle-aged and older persons living with HIV in rural South Africa. The findings add to our growing understanding of the unique and continuing challenges that middle-aged and older South Africans face in navigating an epidemic that they have known for a large portion of their lives. We also highlight opportunities for enhanced policies necessary to improve the psychosocial health of middle-aged and older individuals living with HIV.

Aging through the HIV pandemic

ART was introduced in South Africa in the early 2000s but only became accessible to the general public when free ART programs were expanded through public health clinics, nationally, between 2004 and 2006 (Paul et al., 2014; Simelela et al., 2015). Before this time, an HIV diagnosis was considered a death sentence, and PLWH were considered "already dead" (Conroy et al., 2013, p. 5; Niehaus, 2007; S. A. Mojola et al., 2020). HIV treatment policies during early-ART rollout also hindered early uptake of ART because PLWH were not eligible for ART unless their immune systems were compromised (Peter et al., 2012; Plazy et al., 2015). The World Health Organization's guidelines at the time recommended ART only if an individual's CD4 count fell below 200 cells/μl (WHO, World Health Organization, 2007). This delay in commencing ART inevitably led to mixed outcomes, where individuals who commenced ART late did not recover, while others began surviving with HIV. The former caused doubts about ART efficacy among PLWH, many of whom were also dealing with medication dosing and side effects, particularly in the early years of the multi-pill "cocktail" (Conroy et al., 2013). When ART was scaled up during the late 2000s (2007–2009) with documented experiences of PLWH dominated by fear, sorrow, and uncertainty about the future (Gilbert & Walker, 2010; Nkomo & Kufankomwe, 2020). So, while ART programs brought hope to many, PLWH who survived this initial ART-rollout era needed determination to adhere to ART as well as resilience to the challenges of living with HIV (Enid et al., 2019; S. A. Mojola et al., 2020).

Many middle-aged and older South Africans living with HIV today were young or prime-aged adults when the HIV epidemic hit their communities. Thus, for many, the entirety of their adult life, including their romantic and sexual relationships, marriage, and childrearing, occurred in the shadow of the epidemic (S. A. Mojola et al., 2017; Whyte, 2015). Middle-aged and older South Africans lost family members, including their spouses and children, and mourned close relatives and community members who died from AIDS-related diseases in the pre-and early-ART era (Conroy et al., 2013; E. J. Schatz, 2007). Their caregiving burden was also high due to assisting with, and caring for, fostered or orphaned grandchildren, whose parents were sick or died of AIDS-related illnesses (E. Schatz & Ogunmefun, 2007; Kuo & Operario, 2011; Kuo et al., 2014; S. A. Mojola & Angotti, 2019).

In addition to the caregiving experience, living through the early ART era meant that middle-aged and older PLWH may also have witnessed or endured various challenges and uncertainties of the early, more cumbersome, and less effective treatment (Alomepe et al., 2016; Nemakanga & Mndzebele, 2015; S. A. Mojola et al., 2020; Whyte, 2015). In the early-ART era, members of high HIV prevalence communities also witnessed HIV deaths of individuals who started ART when their CD4 count was very low or had poor compliance (Alberto et al., 2019; Motasim et al., 2006). Therefore, their understanding of ART compliance was driven by the experiences of seeing serious illnesses or deaths among people who were on ART (S. A. Mojola et al., 2020). Commencing ART at the time was associated with a host of challenges including the medication's daily burden, side effects, and risk of involuntary disclosure. And yet, choosing ART signified a decision to survive and continue caring for family members, even while living with HIV (Van Loggerenberg et al., 2015).

While ART significantly reduced AIDS-related mortality, living with HIV as a chronic disease when using ART meant the potential for anxiety about AIDS-related illness and death, and associated mental health outcomes (Ifeagwazi et al., 2018). Mental health is an important aspect of HIV management, as psychosocial problems can lead to poor ART adherence (Huynh et al., 2013). Limited access to social support tends to worsen mental health outcomes while also negatively influencing ART adherence (Asante, 2012; Huynh et al., 2013; Protopopescu et al., 2009). Furthermore, given the substantial losses of loved ones to AIDS, many middle-aged and older PLWH have less social support (Drenth et al., 2013). This vicious cycle of worsening mental health and poor adherence could lead to adverse physical health outcomes and diminished quality of life (J. C. Chukwuorji et al., 2019). Our study examined links among mental health, the experiences of living with HIV, and ideas about ART adherence among middle-aged and older persons.

HIV among middle-aged and older persons in South Africa

The ART experiences of middle-aged and older PLWH are likely to be different from those of younger individuals for three reasons (High et al., 2012). First, as outlined above, middle-aged and older persons survived their spouses' and children's illness and deaths, and spent years providing care to grandchildren (E. J. Schatz, 2007). Second, middle-aged and older PLWH are more likely than young people to be managing other chronic health conditions while navigating the general realities of aging that may make adherence and the experience of being on ART more complicated (Chang, Xavier Gómez-

Olivé, Payne, et al., 2019; Kuteesa et al., 2012; S. A. Mojola et al., 2020). Third, in South Africa, HIV programs and information are typically targeted toward younger groups (Levy-Dweck, 2005). HIV counselors, perhaps particularly in rural areas, often are not equipped with the skills needed to work adequately with middle-aged and older populations (Chang, Xavier Gómez-Olivé, Manne-Goehler, et al., 2019; Mwisongo et al., 2015). This vacuum exacerbates the disjuncture between clinical and experiential knowledge which matters for this population and their ideas about ART, given the peculiar nature of their experiences compared to other age groups of PLWH.

Methods

Setting

The data for this paper come from in-depth interviews (IDIs) that were part of the *Izindaba Za Badala/HIV after 40 study*, which seeks to understand the lives of middle-aged and older South Africans and their health decision-making in the context of a severe HIV epidemic (Sanyu A. S. A. Mojola & Angotti, 2019; S. A. Mojola et al., 2015). The project included middle-aged and older adult residents in the Agincourt Health and Socio-Demographic Surveillance System (also known as “Agincourt”), located in Mpumalanga Province, and managed by the MRC/Wits Rural Public Health and Health Transitions Research Unit at the University of Witwatersrand (see Kahn et al., 2012 for study site details). At this rural site, the prevalence of HIV among individuals aged 40 and above was 23% in 2015–16 (Gómez-Olivé et al., 2020). Data from 2011 showed that 59% of women and 14% of men aged 60+ were widowed, with the majority of HIV deaths occurring among younger age groups (Brian et al., 2018; Madhavan et al., 2009; S. A. Mojola et al., 2015). Apartheid’s legacy has resulted in high levels of unemployment, poor education, and endemic poverty, which has been further compounded by high labor migration levels mostly among young adults (Collinson, 2010; Tollman & Kahn, 2007). These conditions contributed to middle-aged and older persons assuming important roles in terms of household caregiving and their pensions providing financial support essential to household wellbeing (Case & Menendez, 2007; E. Schatz & Ogunmefun, 2007; E. Schatz et al., 2015). Households with multiple generations were common for middle-aged and older individuals, and, as of 2010, 70% of adults aged 50 and above lived in households with a minimum of three generations (Margaret et al., 2019).

Despite HIV Voluntary Testing and Counseling being available in Agincourt since 2002, the rollout of ART is more recent. ART became available at district hospitals from 2004 to 2005, at a private clinic on the study site in 2007, and more widely only in 2011 (Mee et al. 2014). During the past decade, however, there has been a constant increase in the availability and uptake of ART. This medication is provided by public health facilities at no cost, such that the primary cost PLWH incur are those associated with transportation to and from the facilities. While mortality from AIDS-related conditions dropped significantly, mostly due to increasing access and uptake of ART (Kabudula et al., 2014), the burden of other chronic conditions has become more evident. About 70% of individuals aged 40+ in the Agincourt site live with at least two chronic health conditions (cardiovascular conditions, depression, diabetes, etc.) (Chang, Xavier Gómez-Olivé, Manne-Goehler, et al., 2019). Our analysis occurs in a context of increasing access to ART, changing experiences of HIV-related morbidity and mortality due to ART uptake, and the increasing prevalence of chronic conditions.

This paper draws on IDIs conducted in 2018 with 20 middle-aged and older PLWH on ART (11 women and 9 men, aged 46 to 82 years old) who were part of a longitudinal study exploring experiences of aging during the HIV epidemic. The study began in 2013 and included nested individual life history interviews with 60 women and men living with and without HIV who had participated in a 2010–2011 community-based HIV/NCD prevalence and risk factors study (E. Schatz, 2012; S. A. Mojola et al., 2015). In 2018, follow-up in-depth interviews were conducted with 2013 life history interview participants who had discussed living with HIV. The interviews were conducted in the local language (XiTsonga/Shangaan) at the participants' residence by three trained local interviewers who were gender-matched with interviewees from the study community. The interviews were translated and transcribed by the respective interviewers and reviewed by the principal investigators (two authors on this paper) for clarity. ART adherence was determined by participant self-report. In 2018, the interviewers covered topics related to their experiences in the community while living with HIV, e.g., "Please tell me about your romantic relationships over the past 5 years" "How is your health in general?" "What was your experience being tested for HIV?" "How has HIV affected you, your family, and your partners, in recent years?" and "How do you feel now as you are on treatment?" Participants received a gift card to a local grocery store after the interview was completed as a token of appreciation; they did not know the gift was forthcoming.

Analytic methods

Using Braun and Clarke's (2006) approach, the first two authors reviewed the first three transcripts to familiarize themselves with the data and inductively develop a coding scheme focusing on middle-aged and older persons' views on ART adherence and perceptions toward defaulting treatment. Applying the coding scheme developed through consensus, the first author deductively coded the rest of the transcripts using NVivo12 qualitative analysis software. When new themes emerged, the first two authors met to review, define, and codify the existing and new themes. The themes also were confirmed as valid and consistent within the scope of the larger project by the project's principal investigator and co-investigator (both authors of this paper) (Braun & Clarke, 2006). Further analysis and interpretation were conducted through discussion and consensus among the authors. Additionally, most of our extensive review of literature was done after themes were identified, reducing researcher bias, and employing the peer review process to support the integrity of the data analysis. To avoid the risk of overgeneralization in the thematic analysis, attention was focused on producing careful descriptions and detailed information on each theme and connecting these descriptions back to the participants' narratives. The data were then summarized into themes and sub-themes outlined in the Findings section below, with attention to the ways in which the findings are unique to middle-aged and older persons.

The study protocol was approved by the authors' institutional review boards, the University of Witwatersrand Human Research Ethics Committee, which oversees the site, and the Mpumalanga Province Research and Ethics Committee. All study participants provided written informed consent; all participant names listed below are pseudonyms.

Findings

Three main themes emerged from the interview data that both complement and contradict one another: HIV as a death sentence, the importance of ART availability and effectiveness, and ART noncompliance as a death sentence. Participants saw HIV as a death sentence *and* were thankful for living on ART; ART was viewed as a burden *but also* a source of hope; participants kept strict ART routines despite being weary of daily medication. These themes vividly describe the complexity and perceptions of middle-aged and older medication adherent PLWH toward their HIV diagnosis and living on ART.

HIV as a death sentence

The interviews revealed that when middle-aged/older people learned about their HIV diagnosis, they had concerns about the condition leading to death. Most of the participants reported these fears at some point in time while living with HIV. Minenhle, a 65-year-old woman whose husband died from an AIDS-related illness, recalled feeling that when she learned of her HIV diagnosis, she worried it meant she too was going to die.

> I was thinking about that I can die at any time. I have seen one of my neighbors who died of it. It was not nice as she suffered for a long time. She was coughing and after that her skin was peeling, with mouth changes. Later she died and left her children just like that.

> But now I accepted it. When I go to the clinic, I see many people who are collecting the same treatment like mine and I told myself that I'm not alone. Many people are on treatment.

She continued, saying, "Finding that I have this illness made me to think [worry] a lot. I told myself that this illness was not for human beings but for animals. Every day I thought I'm dead." Her comments highlight that an HIV diagnosis caused substantial stress for our study participants, which may have been compounded by witnessing others' AIDS-related illness and death.

Rethabile, age 58, whose husband also died from AIDS-related illness, described encouraging others to start ART with these words, "To someone who has just tested and found out he/she is HIV positive. Go for the treatment. Do not delay, as you can die at anytime." Her sense that death is imminent if ART is not started immediately highlights the severity with which HIV was and continues to be perceived, as well as anxieties about death that comes with an HIV diagnosis.

Uncertainty about health, and the overshadowing of death, impacted the ways that participants talked about HIV despite the availability of ART and their adherence to the medication. Bandile, a 49-year-old man who was on ART and whose partner was also living with HIV and on ART, shared the following concern, "If this illness [HIV] is still not curable, we are all going to die." John, 63, a male participant, expressed a similar notion, "I don't know what will finally happen. Maybe the medication will not be able to help me at the end and I die. You will not know." Both participants believed that death from HIV was highly likely and, perhaps consequently, were ART-compliant. Having access to and complying with ART, however, did not fully attenuate anxiety about death and uncertainty in this population. These persistent worries and fears about illness and death, as well as sadness and worry related to one's diagnosis, were part of the reality of living with HIV in this population.

Despite being ART adherent and having lived with HIV for 10 years, Lethabo, age 46, remained worried about his eventual demise from HIV. He expressed his uncertainty about the future and how he felt about living with the disease:

> We are scared. We don't know how life could be like. But we are saying, 'We shall see. Only God knows' ... 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.

Lethabo's statement reflects sentiments shared by most of our participants, highlighting the burden of anxiety and fear of death among those living with HIV in our study population. The comment also echoes the role of community experiences in shaping perceptions of death.

ART availability and effectiveness

While worry about death was prevalent among our respondents, for some, the increase in the availability of and access to ART over time, as well as its known effectiveness, have attenuated these worries and bolstered ART adherence. In addition, respondents' own experiences and witnessing improvements in health and appearance among those who initiate ART strengthened their beliefs in ART effectiveness.

Thato, age 57, who now requires less frequent clinic visits to collect ART due to having been adherent for some time, explained,

> My health has improved. In the past I had health problems. If I go to the clinic to collect my medication, they [now] give me [enough] medication that I will be able to use it for three months. It shows that there is an improvement. In the past I was supposed to go to the clinic after every two weeks. That is why I say it is working.

Thato's explanation linking his improved overall health to ART, and to a reduction in clinic visits, highlight his success with ART. His comments also reflect clinical practice in the region, where PLWH who achieve stable general health and low viral loads are viewed as ART adherent and thus are trusted to collect their medications less frequently.

Because of its ability to improve health and wellbeing, ART was viewed as a source of hope. Men, in particular, discussed how they were confident about living longer while on ART and felt they could have normal lives if they remain ART compliant. Kamogelo, a 57-year-old male participant, described this optimism when he said, "If I don't stop taking the medication, I can live another ten years." Other participants shared this opinion and expressed their hope for life while on ART. James, age 68, said, "The good thing is that I'm getting life from the treatment. I can still live longer while on treatment." Lethabo, a 46-year-old man, explained, "[ART] is helping us a lot. We see many people who are on treatment they are surviving. Others were not looking good [healthy] but as they used it, [and then] they recovered. If you take it in a good way, you will remain like that." Our participants therefore associated ART compliance with positive health outcomes and hope for longer life.

Women also expressed hope and the importance of adherence. When asked whether she can still achieve her future goals while living with HIV, Lesedi, a 51-year-old woman, who had been on ART since 2009 had the following response, "Yes. I can say the treatment makes us to be like anyone. As long as you stick on it, you will be fine. You can do whatever you feel you can do." Alice, a 49-year-old widow who had been on ART for 14 years and had lost her husband to AIDS-related illness, expressed her belief that there is hope as long as ART is available, "I think if I don't stop taking the treatment … and if our government cannot stop supplying and issuing us with the treatment from the hospital … and also people take and use that treatment, we can survive." A number of these respondents began ART in the early years, when one had to be sick to access it. Thus, for them, devotion to ART was integral to survival and longevity.

The anticipation of death without ART

Despite the burden of taking ART drugs daily, participants kept a strict routine. They worried that if they did not, there would be dire implications – these beliefs were based on their experiences as middle-aged and older persons who saw many non-compliant kin die, in the past as well as those who are now are not adherent. Many had set reminders to take their medication at specific times during the day. They considered daily ART medication a necessary, but not necessarily desired, new way of life.

Karabo, a 57-year-old widow whose husband died from AIDS-related health conditions around 2015, was living with one of her grandchildren at the time of the interview. She expressed her displeasure in taking ART daily:

> Taking treatment for everyday is not a good life. We are not born like that, and our parents didn't do like that in the past. They were getting older and older until they were not able to walk because of old age. But they didn't take treatment. But with us, things have changed now.

She continued:

> You can get tired of eating a sweet for every day. But with this treatment even if you are tired or not, they say you have to take it, ba. [*Ba is a term Mozambicans living in the area used to mean "you are sticking to what you are saying." There was laughter as the woman was looking happy when she talks about treatment.*] If you can say you don't want to take the treatment, you will go to heaven.

Despite her frustration, Karabo felt that there was no other option; she laughed as she explained that you have to be diligent in taking ART or you will die from HIV rather than old age.

Further discussions with participants revealed that this strict compliance with daily treatment was due to a sense of heightened vulnerability to death if one defaulted on treatment, even in minor ways. There was consensus that ART adherence was viewed as something people living with HIV must be resolute with or risk dying at any time. Mary, age 46, who has been on ART for seven years, believed that defaulting on ART was akin to 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 stupid. I read more books and I understand what life is. Reading books makes me wise. That's why I have more information than those who are educated. I mean the HIV information. I don't think I can default the whole of my life. This stranger [HIV] in my body can be happy if I can do like that. So, with those who are defaulting I called them stupid as they are. This is like committing suicide.

Rose, a 46-year-old widow, emphasized her desire to stay ART adherent in order to avoid death, “I won’t stop using the treatment. I don’t want to die. I will die as death is there, but I don’t want to die of HIV.”

Many participants believed that they had only two choices: adhere and survive or default and die. They saw no margin for error in missing a day of treatment. This dichotomy perhaps emerges from the cumulative experience of loss over time, such that having lived through the pre-and early-ART era, there is a sense that there is no room for a continuum of adherence. When Thandi (age 57), who recently lost her older son to AIDS-related illness, was asked whether she had defaulted on her ART regimen before, her response was unequivocal:

> I never did that, and I will not do that. Many people who defaulted don’t survive. Once you default, to survive is by chance. That is why others are disabled, others have blindness, and they don’t see any longer. That is why I can only stop when they can say there is no more treatment on this earth.

Most of the participants, therefore, saw ART compliance as a compulsory practice learned over time. This sense of commitment could be inferred from Rose’s remarks when asked about advising others living with HIV:

> I can advise the one who doesn’t want to take treatment. I can tell him or her that treatment is a must. I can also disclose my status to that particular person. I can refer her/him to people who are dying as we are attending funerals of the young ones mostly. It is clear that they didn’t take treatment, or they stopped.

The experiences of grief, loss, and sorrow in communities where many young individuals, including loved ones and relatives, die from AIDS-related illnesses are reflected in Thandi and Rose’s comments. These experiences, which recall losses in the pre-and early-ART era, provide a warning for the necessity of complete compliance; thus, middle-aged and older persons living with HIV interpret complete ART adherence as essential.

Amahle, an 82-year-old woman whose daughter is also HIV positive, expressed a similar opinion, “People must not stop the treatment, even if you feel you don’t have any pain you don’t have to stop. If you stop, you will go [die].” Minenhle, a 65-year-old widow had the same view toward defaulting ART, laughing as she explained, “I would say they must not stop taking the treatment … It is because if you don’t take it you will sleep [die].”

Participants also noted that both community experiences and health information from the clinics greatly contributed to this notion of “comply or die.” Karabo (57), who had expressed her frustrations with the daily ART regimen, cited her experiences in the community as a reason to remain vigilant,

> It is because I’m living. If it was not about the treatment, I should have been dead. Long time ago. Even if you collect them from the clinic and don’t take them *swa wena swo chipa* [you die]. There are those who are collecting the treatment but don’t use it, many,

> they are dying. The reason is that the virus will overcome you and you will die. Many people are collecting the treatment and if they start to feel better, they stop taking. By that time more illnesses will come to your body and by this, you die.

Amahle, age 82, held similar views, but they were derived from the instructions she received at the clinic,

> They told us that if you stop taking, you die. That is why I'm also telling other people that they must not stop taking as if they can do like that, they will die. I got that information from the clinic. We were told not to skip the time that we have been taught about. The time that you used to take the treatment. They are saying if you skip and take the treatment in other times, you give a chance to the virus.

As shown, participants had significant concerns about death following non-compliance to ART. Their understanding of the benefits of compliance had been shaped by their own experiences, witnessing others at home and in the community, and reinforced by clinic messaging as the HIV epidemic ravaged the region over the last two decades. ART drugs were therefore symbolic of survival, while also serving as reminders for lost loved ones who might have continued to be a part of these individuals' lives if access and compliance had been achievable. Hence, a perceived need for flawlessness with ART compliance was pervasive in this middle-aged/older population living with HIV.

Discussion

This study explored the experiences of living and aging on ART among middle-aged and older PLWH in rural South Africa. Our findings suggest that, even though the availability and effectiveness of ART had influenced compliance positively, study participants still view HIV as a death sentence. Additionally, despite the burden of having to take daily treatment, the fear of death motivates these middle-aged and older PLWH to stick with ART. While adherence is a positive outcome, anxiety related to the need for perfect ART adherence, as expressed by our respondents, could exacerbate depression, emotional distress, poor self-esteem, and loss of hope (Braunstein, 2004; Cianelli et al., 2020; Ifeagwazi et al., 2018).

Even though this article focuses primarily on the perception of death as a consequence of HIV status and ART noncompliance, interviews with participants also revealed elements of other psychosocial issues affecting the lives of middle-aged and older individuals living with HIV. The prevalence of mental health conditions among individuals living with HIV in South Africa is significantly higher than that of the general population and the introduction of ART did not reduce this prevalence (Hiv Clinicians Society, 2013). Further, among middle-aged and older populations, these symptoms may be compounded due to experiences of losing spouses and children beginning in the pre-and early-ART era. Nonetheless, HIV programs seldom target interventions for middle-aged and older populations (Lucia et al., 2018). For middle-aged and older persons, social support may be lacking due to the loss of loved ones over time, further compounding mental health issues and increasing the risk of poor quality of life (Cianelli et al., 2020; Doris et al., 2015; J. C. Chukwuorji et al., 2019; Protopopescu et al., 2009; S. Mojola et al., 2022; Tostes et al., 2004; Weldesenbet et al., 2020).

Life stages influence the type of psychosocial challenges experienced by those living with HIV. While younger PLWH also face a host of psychosocial issues including depressive moods, anger, stress, and anxieties following an HIV diagnosis (Galano et al., 2016), worries about family, marriage, and fertility are key issues linked with living with HIV among this population (Smith & Mbakwem, 2007; Yeatman, 2009). As predicted by age stratification theory, middle-aged and older persons living with HIV would face psychosocial challenges that are both compounded by their life experiences and are influenced by their life stage, such that they are likely to be worried about health issues linked with aging as well as HIV. In contrast to younger individuals, middle-aged and older persons, who are further along in the life course, may be particularly vulnerable to anxieties about death given broader worries about wellbeing, as general health deteriorates with age (Cianelli et al., 2020). Additionally, middle-aged and older individuals witnessed many HIV deaths in their personal and community circles during the pre-and early-ART era, influencing the way they perceive and talk about living with HIV in the community (Conroy et al., 2013). ART compliance is, therefore, likely to be credited for survival among middle-aged and older individuals who experienced severe illness before meeting the eligibility requirement to commence HIV treatment in the early-ART era. This heightened level of devotion to ART may be less prevalent in younger individuals, who primarily know ART as something that is provided when you test positive for HIV, not something that is only accessed when you are “sick enough” (Galano et al., 2016). Thus, middle-aged and older individuals’ ART compliance may be driven by these experiences and appreciation for the effectiveness of ART in ways not seen in younger populations.

In this study, most participants initially viewed their HIV diagnosis as a death sentence. The widescale roll-out of ART, however, attenuated those concerns. Similar to study findings from other sub-Saharan African contexts, positive changes to health since commencing ART played an important role in our participants’ view of life with HIV (Conroy et al., 2013; S. A. Mojola et al., 2020). While ART was seen as a source of hope, the medication was experienced as a burden and a new way of life. Participants kept a strict daily routine for ART because they feared death as a consequence of even intermittent noncompliance. This concern was reinforced by family and community experiences, as well as the information received from health facilities.

Middle-aged and older PLWH are vulnerable to poor mental health outcomes when perceptions of death persist as they navigate the hurdles of living with HIV and maintaining ART adherence (Cahill & Valadéz, 2013). Past traumatic social experiences, particularly those related to HIV, such as the death of a spouse and children and a subsequent loss of social and financial support, likely augment their anxieties associated with death (Vail et al., 2019). Indeed, other studies have found that these traumatic experiences could dampen positive coping strategies such as seeking social support (Hansen et al., 2013; Rosenfeld et al., 2018; Vail et al., 2019). With an HIV diagnosis being a traumatic experience for middle-aged and older adults who may be facing multiple health conditions and declining resources, fear of death could alter perceptions about recovery and discourage PLWH from seeking care (Mello et al., 2010; Onu et al., 2017). In order to fully understand the mental health consequences of traumatic experiences and fear of death from non-compliance, similar work is needed among middle-aged and older persons living with a recent HIV diagnosis, as well as those living with HIV who are non-adherent.

Findings from other studies suggest that anxiety about death is a common experience for many PLWH and could be mitigated when social support systems are functional (Cianelli et al., 2020; J. C. Chukwuorji et al., 2019; Wouters et al., 2016). Middle-aged and older PLWH in South Africa often have limited social support due to the loss of family in the pre-and early-ART years of the epidemic (E. Schatz & Seeley, 2015; Knodel et al., 2003). Additionally, as individuals age, the experience of loss increases whilst they confront the reality of their own mortality. As expressed by our respondents, dealing with uncertainties about life with HIV makes this experience even harder. Reflecting on their experiences with HIV, both as caregivers in the early 2000s and now as PLWH, and possibly other health conditions, the negative mental health effects of death anxieties in this population could impact quality of life significantly. Policymakers and HIV intervention program planners must develop targeted approaches that incorporate enhanced age-based health information that reflect the unique experiences and needs of middle-aged and older populations living with HIV. More research is needed to understand how stages of illness or age affect the severity of anxiety about death among individuals living with HIV.

Policy implications

At the national level, policymakers should prioritize mental as well as physical health when planning HIV intervention programs for middle-aged and older individuals. Public health campaigns promoting discussions around mental health are needed, including ones that recognize the growing population of middle-aged and older PLWH and that speak directly to this population. Health facility staff in rural areas should be trained, encouraged, and given resources to include mental health discussions with middle-aged and older persons when they receive an HIV diagnosis, as well as for PLWH during routine medication pick-up visits. HIV messaging should emphasize the benefits of achieving undetectable viral load while living with HIV rather than the risks of death as a result of non-adherence. While these are broad national goals, there are tangible processes at lower levels of jurisdiction, such as provinces, where meaningful stakeholder engagement (including physicians, nurses, community health workers, and people living with HIV) could impact primary care pertaining to ART and mental health (Wilkinson et al., 2022). For example, the Mpumalanga Department of Health could sponsor sessions with these key stakeholders to identify the most thoughtful ways to approach a conversation about living with HIV, ART use, and mental health during routine primary care visits. Guidelines could be developed to facilitate such conversations in primary care across the province, thereby also providing a template for other health jurisdictions to adapt to their specific contexts. Mass information dissemination on HIV-related mental health wellbeing should be considered. Text campaigns from cellphone carriers may be effective in raising awareness among middle-aged and older PLWH, as well as other members of the community who could be persuaded to understand and provide necessary social support (Gurman et al., 2012; Kiplagat et al., 2021).

Peer mentorship and peer group support systems might also be bolstered at the community level and should engage middle-aged and older people, allowing interested middle-aged and older PLWH to connect with others, share experiences, and enhance social support (Muhindo et al., 2021).

Limitations

All our participants reported being ART adherent (sample selection bias) and therefore the findings may not represent other middle-aged and older individuals living with HIV who are non-adherent to ART. However, non-adherence may amplify the types of negative responses outlined above in the absence of “hope” associated with ART compliance. Alternatively, non-compliant individuals may not believe in the effectiveness of ART so may feel they are better off without it. Additional research is therefore needed, especially among non-adherent middle-aged and older individuals, to assess the external validity of our findings. Respondents may have also reported good ART adherence due to social desirability bias and the desire to appear as responsible, treatment-adhering patients. Nonetheless, given the context and age of participants in this study, we believe these findings are important for health policy interventions in the region, but their transferability is limited to similar contexts.

Conclusion

Our study findings suggest a need for greater health information and counseling for middle-aged and older PLWH regarding ART adherence and its influence on health. Interventions and policies must be tailored to take into account the unique experiences and needs of middle-aged and older PLWH, particularly their life stage and health status, as well as their accumulated experiences of living through the pre-and early-ART eras. This article provides a unique contextual view of psychosocial challenges faced by middle-aged and older persons living with HIV, highlighting unique experiences and how these experiences shape the way ART compliance is perceived by this group. We also explored literature on how younger populations in South Africa, without the same cumulative loss or health profiles related to aging, may differ in the ways they internalize the messages about HIV as a death sentence and ART compliance as needing to be absolute. Despite these differences, we believe that there are important areas for policy reform that will incorporate the experiences of middle-aged and older people into ART distribution and adherence programs. As the HIV epidemic ages and there are increasing numbers of middle-aged and older persons living with HIV, but also more whose reproductive lives began after the availability of ART changing their experience of HIV (S. A. Mojola et al., 2021), it is critical to continue to document the experiences of middle-aged and older persons and develop policies that are reflective of their needs.

Key points

- Middle-aged and older individuals living with HIV (PLWH) face unique mental health challenges;
- The experiences of middle-aged and older PLWH make them more vulnerable to negative mental health outcomes;
- Fear of death among middle-aged and older PLWH could diminish quality of life;
- There is a need for expanded health information opportunities for middle-aged and older PLWH; and
- HIV intervention programs must be tailored toward the needs of specific age groups.

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