Mark Brennan-Ing · Kristen E. Porter ·
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Janet Seeley *Editors*

Aging with HIV in Sub-Saharan Africa

Health and Psychosocial Perspectives

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Preface

In high-income countries like the United States, we have focused for some time on the aging of people with HIV. Currently, over half of the approximately 1 million people with HIV in the United States are aged 50 or older (CDC, 2019; High et al., 2012). While this is an astounding success story of HIV treatment, what is less well known is that the population of older people with HIV in sub-Saharan Africa is approaching four million—approximately four times as large as the entire population with HIV in the United States (Autenrieth et al., 2018). This volume is an attempt to bring greater attention to the often invisible yet burgeoning number of older people with HIV in this region, so that we can better understand their lives, their challenges, and the supports that are needed for them as they grow older.

The genesis of this volume goes back nearly a decade. In 2012, Stephen Karpiak and I were the research directors at AIDS Community Research Initiative of America (ACRIA) and were focusing our efforts on HIV and aging, including continued analysis and dissemination of the findings from the seminal ROAH (Research on Older Adults with HIV) study, based on the New York City population (Brennan et al., 2009). At that time, we met Joel Negin, who was in New York City on sabbatical. Joel was one of the few people working on HIV and aging in sub-Saharan Africa and was kind enough to meet with Steve and me to discuss the global implications of an aging epidemic. During the course of our conversations, we became curious about how older adults with HIV in Africa compared to those in our ROAH study in the United States, and the concept of ROAH Africa was born. The idea was to see how well our US ROAH survey would work in an African context. Soon thereafter Joel introduced us to Janet Seeley at the MRC/Uganda Virus Research Institute in Entebbe, Uganda. Janet had been working with Rachel Albone at HelpAge International, the organization that supported our initial study in Uganda.

Around this same time, I made acquaintance with my Australian colleagues Catherine MacPhail and Victor Minichiello when they invited me to Melbourne to give a presentation on HIV and aging at a public health conference. Catherine had been doing HIV research at the University of Witwatersrand in Johannesburg, South Africa, with Francois Venter. After our successful implementation of the ROAH Africa survey in Uganda, this connection afforded us the opportunity to expand our efforts in another country to see if our survey instrument was feasible in a broader African context. Catherine was able to include the ROAH survey in some of her ongoing research efforts, and ROAH South Africa was launched with funding from the University of New England Partnerships Career Development Grant.

While our initial aspiration of launching a large-scale ROAH survey across sub-Saharan Africa based on our pilot work in Uganda and South Africa was not realized, we recognized that we had some unique and significant data on older people with HIV in this region. At the International AIDS Conference in Durban, South Africa, in 2016, Janet, Catherine, Kristen Porter (who was doing a postdoc with me at ACRIA), and I met to talk about ways we could disseminate these data. We landed upon trying to do a special journal issue that would focus on findings from the two African pilot studies. Despite our attempts to put a special issue together, we ran into some obstacles. Fast-forward to the summer of 2019, when I met with editors at Springer who were very interested and supportive of a volume on HIV and aging in Africa, and thus this current volume was born.

Since those initial conversations with Joel Negin in New York, research on HIV and aging in sub-Saharan Africa has grown tremendously. For this volume, we wanted to expand beyond the pilot work we had done in South Africa and Uganda, and we reached out to scientists across Africa. Our goal was to include a wide variety of topics and to include research representing the different regions of the continent; the authors in this volume work in West, East, and Southern Africa. The chapters in this volume cover topics ranging from epidemiology to the impact of comorbid health conditions, mental health and cognitive functioning, perceptions of illness through the lens of the HIV epidemic, managing stigma, countering the myth that older adults are not sexually active and are not at risk for HIV, grandparenting and other caregiving from a population that also needs care, social support resources, HIV service provision, and policy recommendations written by both established and emerging scholars in HIV and aging.

It is our wish that the information in this volume serves as a resource for those working to support this population, as well as a source of inspiration to others who can add to our body of knowledge about the largest regional population of older adults with HIV on the planet. While these chapters address the myriad challenges facing older people with HIV in sub-Saharan Africa, they also highlight the resilience of a population that has managed to survive and often thrive into later life. It is to these older people with HIV that we dedicate this volume. We would also like to dedicate this book to Dr. Stephen Karpiak, whose passing at the time this volume was being completed has saddened many of us in the field of HIV and aging. He provided a tremendous impetus to advancing work on this topic in general, including the studies we report in this book. He will be missed.

October 2021
New York, NY, USA
Mark Brennan-Ing

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Chapter 1
The Epidemiology of HIV in the Older African Population

Francesc Xavier Gómez-Olivé

Contents

The HIV epidemic has been considered, since its commencement, a disease of young adults. While this might have been the case in the initial years, the demographics of the epidemic in Africa have seen a substantial change since the standard of universal access to antiretroviral therapy (ART) was introduced at the United Nations (UN) World Summit in 2005 and endorsed by the Group of 8 (G8) and the African Union (UNAIDS, 2006). ART has been linked to higher survival of people living with HIV and to the advent of the first generation of people with HIV over 50 years of age (Hontelez et al., 2012).

The Millennium Development Goals launched in 2000 and the Declaration of Commitment adopted in 2001 at the UN General Assembly Special Session on HIV/AIDS, with representatives of 189 countries, facilitated the development of monitoring systems and core indicators that would track the progress toward achieving the goal of reversing the epidemic of HIV by 2015 (UNAIDS, 2002, 2008). Since then, due to the indicators selected, the HIV pandemic became associated with the population aged 15–49 years and children mainly infected at birth or

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through breastfeeding. Adolescents were the main focus of programmes to prevent HIV transmission, while the population over 50 years old was ignored in both HIV prevention campaigns and reports of HIV infection or treatment. Before the introduction of ART, HIV literature mainly refer to older people as "affected" by the epidemic due to the extra burden of family responsibilities, such as caregiving for their dying children and orphan grandchildren (de Klerk, 2012; Schatz, 2007). Moreover, older people, especially women, suffered the stigma associated with being related to or taking care of someone with HIV (Ogunmefun et al., 2011). Older people were not seen as a group at risk of contracting HIV through sexual intercourse; it was generally assumed that older people were getting infected through caring for their sick children (Mojola & Angotti, 2019).

The progression of the HIV epidemic into older age groups became a cutting-edge issue around 2005, about 25 years into the HIV epidemic, after the limited introduction of ART (UNAIDS, 2006) in most African countries. Later, in the 2010s, the universal introduction of ART in all African countries had huge implications for the ageing of the HIV population, with an increased number of survivors resulting in higher prevalence of HIV among those over 50 years of age (Hontelez et al., 2012). The Joint United Nations Programme on HIV/AIDS (UNAIDS), in its 2006 annual global AIDS epidemic report (UNAIDS, 2006), acknowledged the increase in older adults with HIV worldwide, stating that reports should include older age groups and refer to adults as those "15 years and older" (UNAIDS, 2006). Even today, however, most reports keep the initial reference to those 15–49 years age for comparison with earlier ones. Moreover, with the exception of the Joint United Nations Programme on HIV/AIDS (UNAIDS) *HIV and Aging* report in 2013, few official reports describing the HIV epidemic in Africa have included the over-50 population or properly described how the HIV epidemic is ageing (UNAIDS, 2013).

To understand the ageing of the HIV epidemic, it is crucial to appreciate that sub-Saharan Africa, and more specifically the eastern and southern regions which have suffered the highest burden of the epidemic, now has the world's greatest scale-up of ART. South Africa, with 4.4 million people on ART, hosts the world's largest HIV treatment programme (Simbayi et al., 2019). The introduction of ART produced a 49% reduction of HIV-related mortality from 2010 to 2019 (UNAIDS, 2020). This increased survival has produced a rapid ageing of the epidemic that is expected to continue in the coming years (Hontelez et al., 2012). Those over 50 are becoming the first generation of older adults with HIV.

The HIV Epidemic in the Older African Population

The bias in HIV literature toward younger age groups has resulted in a dearth of information on the situation of the HIV epidemic in the older population (Kyobutungi et al., 2009). Some authors have tried to fill the gap with estimations of HIV prevalence (Negin & Cumming, 2010) and incidence in this older age group (Hontelez et al., 2012), using existing population data (Negin et al., 2012) or through self-reported infections (Kyobutungi et al., 2009). Very few research groups have directly studied the HIV epidemic in those over 50 (Gómez-Olivé et al., 2013; Wallrauch et al., 2010), and these studies have presented a geographical bias toward countries in eastern and southern Africa, where HIV prevalence is higher and the research capacity has developed further.

The same lack of information is present in relation to HIV-related mortality in older populations, as some countries do not have a good death registration system. In Ethiopia, Reniers et al. (2009) used surveillance from burials to calculate the impact of the introduction of ART on AIDS mortality. In South Africa, where vital registration system is thorough enough, Pillay-van Wyck et al. (2019) calculated the changes in AIDS mortality from 1997 to 2012. Both countries have seen AIDS-related mortality cut in half since the introduction of ART.

HIV Prevalence and Incidence in the Older Population

In 2013, UNAIDS recognized older adults as representing an important proportion of the epidemic and published a special report on HIV and ageing (UNAIDS, 2013). A year later the *Gap Report* from UNAIDS added a chapter on the older population for the first time (UNAIDS, 2014c), highlighting the ageing process of the HIV epidemic all over Africa. Autenrieth et al. (2018) found that the number of people 50 and older living with HIV had doubled from 2000 to 2016 and estimated that 1 in 5 people living with HIV would be 50 years or older by 2020, with 64% of older adults with HIV living in sub-Saharan Africa. By 2040, it is estimated that 1 in 4 people living with HIV in sub-Saharan Africa will be 50 years or older (Hontelez et al., 2012).

Even as global reports of the HIV epidemic begin to recognize older adults, most nationally representative HIV surveys in sub-Saharan Africa are still mainly reporting on the population under 50 years of age. A remarkable example is the case of Kenya, where two surveys done in 2007 and 2012 included people up to 64 years old (Maina et al., 2014). These surveys show that in 2007 the HIV prevalence among people age 45–54 (7.8%) was higher than in the 15–24 age group (3.8%). In the second round in 2012, the prevalence of HIV in the 45–54 age group had increased to 9.1%, making it the age group with the highest HIV prevalence in Kenya (National AIDS and STI Control Programme, 2013).

In southern Africa, Botswana has also included people up to 64 years of age in their national reports, showing an increase of HIV in the older population from 2004 to 2013. This is especially notable in older men, where HIV prevalence has increased from 17% in 2004 to 28% in 2013 (Matlho et al., 2019). In the fifth national HIV survey of South Africa in 2017, the age group 50–64 had a prevalence of 17%, mainly affecting black women (Simbayi et al., 2019). Other studies in South Africa have shown HIV prevalence of more than 20% in people over 40 (Gómez-Olivé et al., 2013).

It is expected a certain increase in the prevalence of HIV in the older age groups due to both the survival of people with HIV after the universal introduction of ART and the demographic transition, with a higher proportion of the population reaching older ages. There is a third reason that has been considerably ignored, which is the high risk of new infections in older people due to unprotected sex, together with low awareness of the fact that people at older ages are still at risk of contracting HIV (Houle et al., 2020; Rosenberg et al., 2017). There is a worrying dearth of information on HIV incidence among older adults, and existing studies are mainly from South Africa (Gómez-Olivé et al., 2020; Hallett et al., 2010; Harling et al., 2015).

HIV Mortality in the Older Population

Since the beginning of the 1990s, the African continent has witnessed a huge increase of mortality due to the HIV/AIDS pandemic. UNAIDS estimated a worldwide peak of 1.7 million HIV-related deaths in 2004, with southern and eastern African regions the world's most affected areas (UNAIDS, 2019). Since then, these two African regions have experienced the highest ART uptake, leading to a 38% reduction in HIV-related mortality, the highest reduction in the world from 2010 to 2019. The western and central African regions have also seen a huge (25%) reduction of mortality (UNAIDS, 2020).

A study in South Africa (Pillay-van Wyk et al., 2019) confirms that the trend of increasing AIDS-related mortality since 1997 was halted with the introduction of ART in 2004 (Johnson, 2012). This event shaped the mortality curve in nearly all age groups, with a substantial reduction by 2012. Worryingly, this new trend did not benefit those over 60 years of age, increasing the gap between older and younger age groups in terms of gains achieved from the response to the HIV epidemic (Pillay-van Wyk et al., 2019).

Reporting AIDS deaths has been difficult, however, due to stigma and the lack of proper and generalized death registration systems in most African countries. In South Africa, where the death registration system covers more than 80% of all deaths, the main problem is misreporting because of lack of knowledge and unwillingness to disclose HIV as the cause of death, mainly due to stigma (Groenewald et al., 2005). After correcting for misclassification, the percentage of total deaths in South Africa associated with HIV/AIDS in 2006 moved from an initial estimation of 2.7% to a more accurate 47.5% (Birnbaum et al., 2011). In a similar study in South Africa, extending data to 2010, Bradshaw et al. (2016) estimated the total percentage of HIV-related deaths as 42% in 2006 with a decrease to 35% in 2010 while still assuming a high misclassification and misattribution of HIV deaths to other causes of death.

Many studies conducted at the beginning of the HIV epidemic or at the introduction of ART in Africa focused mainly or exclusively on young adults. But some studies, in South Africa, Uganda, and Kenya, incorporated HIV-related mortality among older Africans and showed a high toll of AIDS mortality (Bakanda et al., 2011; Gómez-Olivé et al., 2014; Negin et al., 2010). In the subdistrict of Bushbuckridge in Mpumalanga Province in South Africa, the Agincourt Health and Demographic Surveillance System has followed the rural population since 1992 (Kahn et al., 2012). In this subdistrict, data from 20 years of follow-up showed that in 2011 HIV/AIDS was one of the main causes of death for 50- to 64-year-olds and was an important cause of death even for those over 65 (Kabudula et al., 2014). HIV was the reason that the population in their 50s and 60s had a higher mortality rate than those in their 70s (Gómez-Olivé et al., 2014). A study analysing ART programmes in nine different sub-Saharan countries also showed that, despite the introduction of ART, excess mortality associated with HIV infection is higher among people 50 years and older than in younger age groups (Greig et al., 2012). In rural Kenya, it was observed that HIV was the main cause of death among people over 50 years of age (Negin et al., 2010).

Beliefs, Risk Behaviour, and Preventive Measures Among Older People

HIV prevention and treatment campaigns have been directed at young people mainly due to the belief that older people are not at risk of being infected (Mills et al., 2011). However, as we have already seen, all epidemiological findings and trends on HIV infection in older people indicate that both older men and women are at risk of being infected by HIV and that in some countries and regions older people are suffering the highest levels of prevalence, incidence, and even mortality. This all leads to the conclusion that it is crucial to include older people in HIV/AIDS prevention, awareness, and treatment campaigns.

For many years there was the general belief in Africa that older people are not sexually active and that the main way they acquired HIV was by taking care of people living with HIV. Unfortunately, older people also embraced the idea that they were at low risk of HIV infection, an idea that left them unprotected when engaging in sexual intercourse. A study in Malawi illustrates how older people see testing for HIV as stigmatizing and putting their own social status at risk. To accept being tested admits the possibility of being infected, which would show “lack of wisdom” (Johnson et al., 2021).

The myth that older people are not at risk of HIV infection has been challenged by various studies in several African countries. In Malawi, as early as 2012, Freeman and Anglewicz proved that people over 65 years of age are considerably sexually active (one quarter of women and three quarters of men reported having had sex in the past year, and 14% of men 65+ reported more than one sexual partner in the past 2 years) and have nearly double the HIV prevalence of younger age groups (Freeman & Anglewicz, 2012). In recent years in South Africa, it has also been shown that older people are sexually active and have sexual behaviours, such as low use of condoms, that put them at high risk of both acquiring and transmitting HIV (Houle et al., 2018; Rosenberg et al., 2017). These studies show HIV prevalence in those over 40 years of age increasing from 18% in 2011 to 22% in 2015, a high proportion of those in their 60s and 70s—especially men—reporting a sexual partner in the past 2 years, a relatively high proportion of older adults with casual partners, and low use of condoms in their last sexual intercourse (Rosenberg et al., 2017; Houle et al., 2018). A similar situation was observed in older people living with HIV in Uganda (Negin et al., 2016a), where people 50 years and older were still sexually active and reporting sexual behaviour that carries a high risk for HIV transmission. In Manicaland, Zimbabwe (Negin et al., 2016b), older people suffered an increase in HIV prevalence from 2006–2008 to 2009–2011, with one fifth of men 45 to 54 infected, double the prevalence of HIV among men aged 15 to 44. As in South Africa (Gómez-Olivé et al., 2020), older people in Manicaland are experiencing a relatively high number of new infections. In this context, it is not perilous to assume that the lack of information and the high sexual risk behaviour of older people may be the leading causes of the considerably high HIV incidence among the older populations in these two countries and, in general, in Africa.

It is important, then, to consider what older people believe about their risk of being infected and how that risk may change over time as they age. Some may think that the risk of infection just declines with age; some may see this change in relation to gender, with women less exposed as they age with a reduction of sexual intercourse, while men may still be highly exposed in their 40s and 50s due to migratory work, reducing their number of sexual partners only when they return back home (Mojola et al., 2015). In these different contexts, older people have their own beliefs about what is putting them at risk and what the best behaviours are to protect themselves against HIV (Angotti et al., 2018). As mentioned above, these views are different depending on the gender, although these beliefs may not always correspond to behaviour. When interviewed, some men say they expect to be sexually active until older ages, proposing that the correct behaviour to avoid infection would be regular condom use and having sexual partners close to their age, while women believe that fidelity and celibacy from a certain age is the way to behave (Angotti et al., 2018).

Older People, Care, and Stigma

Older People Taking Care of HIV-Infected Family Members

The traditional expectation is that when people get older, they will become dependent on their family members and their role as active and productive members of society will arrive at an end. However, the ageing of the African population has shifted this paradigm, and it is crucial to redefine "old age" and whether older people are "dependent" or "productive" (E. Schatz et al., 2015). With the introduction in some African countries of a noncontributory old-age pension, combined with high levels of unemployment and the HIV epidemic, the older members of families have shifted their role in the household and have become the carers instead of being cared for (Lekalakala-Mokgele, 2011). This change in social position from being dependent to providing for their families may have given older people a new status and some power gain in their social environment (Madhavan et al., 2017), while it has created a new and unexpected burden in the last years of life.

The impact of the HIV epidemic affected African older adults in all aspects of their life and at very different levels. As their children died from AIDS, the household structure changed, with more skipped-generation households missing young adults, and more older people, especially older women, left to look after “their own blood”, taking care of their infected children and grandchildren (Schatz, 2007) instead of being looked after as they would have expected to be (Madhavan et al., 2017; Schatz et al., 2015). At the same time, caring for their family members amid the stigma associated with this new responsibility isolated older people, who decreased participation in social activities (Lekalakala-Mokgele, 2011). Another important aspect of this new situation is the high economic cost that caring brings with it. Older people who typically have a low income must use it all to pay for health care for the sick, food, and school fees for the orphans living with them and expensive funerals for those who die. Many people in this situation had to depend on community members or incurred debts. Moreover, they suffered a serious loss of well-being and a high psychological burden given their family losses, the need to parent small children, and the economic burden (Lekalakala-Mokgele, 2011; Schatz & Ogunmefun, 2007; Tanyi et al., 2018). The impact has affected all sub-Saharan countries, including Cameroon (Tanyi et al., 2018), South Africa (Schatz & Ogunmefun, 2007; Schatz, 2007), and Zambia (Baylies, 2002). In Zambia, Baylies (2002) reported that 13% of all women had cared for a person living with AIDS and that these caregivers were mainly women over 40 years of age.

The introduction of ART and the longer survival of those infected have also made grandmothers the default caregivers of grandchildren living with HIV. As discussed by de Klerk (de Klerk, 2020) in her work in the northwest of Tanzania, grandmothers have become expert caregivers and monitors of HIV in their grandchildren. Monitoring consists of not only checking adherence to medication and physical body changes but also ensuring the social integration and general well-being of their grandchildren, guided by the grandmother’s and children’s positions in their families and society (de Klerk, 2020).

In another illustration of the support older people are giving due to the HIV epidemic, a study of 22 countries in sub-Saharan Africa analysed the effect of the HIV epidemic in the population 60 years and older using Demographic and Health Surveys. From 1991 to 2006, there was an increase in older people living alone, or living only with children 10 years and younger, and losing the financial and physical support that missing family members had provided (Kautz et al., 2010). So, in the worst years of the epidemic, older people not only had a new obligation to support their loved ones but also lacked anyone to care for them.

Who Takes Care of Older People Who Are HIV Positive?

As we have seen, older people, and especially older women, have been responsible for the well-being of their families in the years around the peak of the HIV epidemic and before the general availability of ART. While they were looking after their loved ones, older people had to face different health situations. First, their ageing process brought with it the advent of noncommunicable diseases such as hypertension, diabetes, depression, anxiety, and sleep disorders. Second, they had to strategize to avoid being infected by HIV, while they were at a higher risk than they were aware of. In relation to this, Angotti brings the concept of "taking care of yourself" as a way for older adults to be responsible and avoid new infections (Angotti et al., 2018). In this sense, older people in rural Mpumalanga, South Africa, celebrate ageing as an achievement after "good behaviour" at earlier ages to avoid HIV infection. At the same time, they believe that being healthy is a responsibility they carry given all the other responsibilities they still have to fulfil both in the family and in the community. Finally, older people living with HIV had to look after themselves in many ways, from testing for HIV to engaging with the health system to initiate and remain on ART. Older people living with HIV had to overcome both their own shame at being infected and the stigma that may be associated with being HIV positive. In rural northwest Cameroon, the HIV epidemic put older people in a very weak position as caregivers at old ages, instead of being looked after as older people. As in many other African regions, older people had to look after themselves while they were taking care of their sick children and were responsible for the growth of their grandchildren, at a huge cost to their own health, wealth, and general well-being (Tanyi et al., 2018).

The health and well-being of older people affected and infected by HIV is, therefore, of crucial interest. It is important to consider the needs of this population from different perspectives, including health care, improving health-care systems to respond to the needs of older age; social, family, and psychological issues, ensuring older receive the care they deserve in their local environment; and economic issues, supporting older people in their material and day-to-day needs (Gómez-Olivé et al., 2010; Nyirenda et al., 2013). In a very interesting life course approach, Loewenson et al. (2009) explore the singular impact that AIDS has had on African households and how differently the epidemic has affected people from birth to mature and old ages. The authors make important remarks on the special needs of the older population for health care, welfare, education about HIV/AIDS, and mental health support. In this context there are many questions that need response: who will look after the older people when they become frail and they cannot look after others (Payne et al., 2017)? Who will take care of them when they need to take different medications and their cognition starts to decline? Who is going to help them cope with the new problems that their now-adolescent orphan grandchildren will bring to their lives, like great-grandchildren, economic needs, educational needs, etc.? The African societies have a characteristic tradition of looking after their elders, but in the last decades this seems to have shifted, with no clear return to where it was before (Sinunu et al., 2009).

Stigma

History shows us that people suffering life-threatening diseases with no cure have suffered different types of stigmatization. Different times and cultures have stigmatized patients with leprosy, tuberculosis, and cancer. When the disease is sexually transmitted like syphilis and HIV/AIDS, the stigma associated with the disease is accompanied with the accusation of having "misbehaved." Although these two diseases have many differences—for example, HIV was initially associated with specific groups of people who were already stigmatized—it is interesting to observe the similarities between community reactions to syphilis at the beginning of the twentieth century and the reactions to those infected or affected by AIDS at the end of that century (Brandt, 1988). Looking at these similarities, it is expected that the introduction of ART, as the "magic bullet" that penicillin was, will be associated with a decrease of stigma, as has been seen in Uganda and South Africa (Mojola et al., 2020; Mugisha et al., 2018).

However, until the reduction of mortality due to ART has a serious impact on stigma, older people, especially older women, are suffering stigmatization from the society and community: directly, because some of them are living with HIV, or secondarily, because their family members are infected or they have looked after others who are infected (Ogunmefun et al., 2011). As a consequence of this stigma, older people may suffer isolation from their social networks or, because of shame or fear, they may isolate themselves from their friends, community, and family (Schafer et al., 2021). In some cases, older people say they have not suffered secondary stigma, but mainly because they have not disclosed the HIV status of those they care for (Ogunmefun et al., 2011). In Togo, a study showed that older people were afraid of disclosing HIV status, wanted to protect their own family members, or did not really know how to disclose to those close to them (Moore, 2013). Moreover, silence and concealing can be associated with both shame and caring, as shown in northwest Tanzania: older people caring for family members dying of AIDS were expected to conceal the disease from their community and not to discuss the disease with those they cared for. This was seen as a way to show compassionate care, protect the relationship with loved ones, and contribute to what is considered "good care" (de Klerk, 2012). On the other hand, in recent years more people are disclosing their status to family members or friends, producing positive effects like receiving community support and avoiding isolation (Schafer et al., 2021).

These higher levels of disclosure may be one of the positive consequences of the reduction of stigma, but it may also be that the disclosure itself is helping to fight stigma. It is, therefore, crucial to have ways to measure what elements will help reduce stigma and improve the lives of older people infected or affected by HIV/AIDS. A study by the Tanzania Stigma-Indicators Field Test Group notes the importance of having specific indicators to objectively measure stigma, focusing on four domains: (1) fear of transmission and avoidance of contact with people living with HIV; (2) values and attitudes including aspects like shame, blame, and judgement, which are difficult to measure; (3) previous experience of having suffered stigma and/or discrimination; and (4) disclosure of HIV status (Nyblade et al., 2005).

Getting Older with HIV

There is clear evidence that the HIV epidemic is ageing as the world is ageing (Hontelez et al., 2012). In 2016, although it still has a young population, Africa was home to nearly 4 million of the estimated 5.7 million people over 50 living with HIV or 70% of all older people with HIV worldwide (Autenrieth et al., 2018). In many sub-Saharan African countries, the HIV prevalence among those 45–59 years of age is higher than the country's average all-age prevalence (Vollmer et al., 2017), and countries such as Malawi, Zambia, and Zimbabwe have seen the HIV prevalence among those over 50 exceeding that of the 15–49 age group (Harris et al., 2018).

Despite such statistics, older people have been left behind in efforts to tackle the HIV epidemic. Older people infected with HIV still face many challenges to placing themselves in a strong position to prevent new infections and receive antiretroviral treatment in time to save their lives. These challenges can be divided into three categories: social/behavioural (low-risk perception, low testing levels, low support), structural (lack of awareness on the part of health providers and health systems, low access to treatment, increasing poverty), and biological (weak response to ART, increased risk of other chronic conditions) (Harris et al., 2018; UNAIDS, 2014c).

As the HIV epidemic is ageing mainly due to the introduction of ART, it is expected that this new HIV old-age generation will present with other health conditions associated with age (hypertension, diabetes, cancer, dementia, etc.), creating a double epidemic of HIV and noncommunicable diseases that requires a well-prepared response from the existing health-care systems in sub-Saharan Africa (Rabkin et al., 2012). In such countries as South Africa, Malawi, Kenya, and Eswatini (former Swaziland), policy makers have developed integrated chronic care systems that aim to support patients with multimorbidity (Matanje Mwagomba et al., 2018). Although attractive, these initiatives still need further development and extension in Africa in general.

The above-mentioned double epidemic has been observed in the older population in settings like South Africa, where HIV is highly prevalent and where the coexistence with cardiometabolic conditions calls for a quick health systems response (Clark et al., 2015). In rural South Africa, two thirds of the population 40 years and older are already presenting multiple chronic conditions (Chang et al., 2019). There is, however, a potential benefit for older people receiving ART and presenting with multimorbidity, as seen in rural South Africa. In Agincourt subdistrict, it has been observed that users of ART services in primary health-care systems have higher chances of being checked for chronic conditions, being more aware of their condition, and receiving preventive advice for their chronic conditions (Manne-Goehler et al., 2017).

Still, it is important to pay attention to some of the worries of older people in relation to multimorbidity and its consequences. In South Africa, older people seem to be more worried about chronic noncommunicable diseases than about HIV, because the latter, they say, can be controlled with ART, while the other conditions—especially hypertension and diabetes—are seen as more difficult to control, causing many deaths in this older age group (Sanyu A. Mojola et al., 2020).

Awareness and Testing

In 2014 UNAIDS established a very ambitious plan: first to reduce HIV transmission by 2020 and then to end the HIV epidemic by 2030 (UNAIDS, 2014b). This new target moved beyond the objectives of the Declaration of 2011 to have an incremental response to HIV by 2015: the aim was that, by 2020, 90% of all people living with HIV would know their HIV status, 90% of those who knew they had HIV would receive ART, and 90% of those on ART would have viral suppression (UNAIDS, 2014a), representing 76% viral suppression overall. By 2030 the aim was to increase these percentages to 95%, achieving 86% viral suppression among people living with HIV (UNAIDS, 2014b). However, progression to reach the 2020 target has been very unequal in the African continent. In the eastern and southern regions, only seven countries have achieved the target, and three are close. In these regions countries like South Africa will have to make a dedicated effort to achieve the fast-track objectives, which would bring a huge reduction in both incidence and prevalence of HIV (Abuelezam et al., 2019). Meanwhile, the central and western regions are still far from achieving the target. Worryingly, these targets were mainly for those under 50, and most results in the UNAIDS, 2020 report still focus on those under 50, with no specific information about those over 50 (UNAIDS, 2020), making it nearly impossible to measure the treatment cascade progression in older age groups. To achieve these targets in the older population, it is necessary to reverse the present situation in which they are ignored.

These ambitious targets are linked to different stages. First is the implementation of strategies to increase HIV testing and therefore awareness. Second requires the involvement of those who learn they have HIV, so they approach health facilities and are included in ART treatment programmes. Finally, it is crucial to establish systems to increase retention of people living with HIV in the ART programmes to achieve the target of people with viral suppression.

What does all this mean for the older population? Older age can affect these three targets in different ways. First, older people do not feel at risk of HIV infection and therefore do not see the need for testing for HIV. In this context, those who get infected at older ages are considered irresponsible, not adhering to the normal behaviour expected in old age (Johnson et al., 2021). In addition, age-related mental problems can affect the levels of testing. In South Africa, the level of awareness of

HIV status was found to be 24% higher among those with higher cognitive scores (Rosenberg et al., 2020), highlighting the importance of considering ageing and cognition when organizing campaigns to increase HIV testing and awareness to achieve the first 90 among older population.

To achieve the second and third 90s, it is necessary to have the Primary Health Care (PHC) system fully involved in the health and well-being of the older population. The African PHC strategy was introduced in 1978 with the goal of achieving health for all (World Health Organization, 2008). But the system was not organized around the treatment of the main health problems of the older population, most of them requiring chronic care, and even nursing and medical studies are not fully covering gerontology as the new demographic situation requires (Lekalakala-Mokgele, 2011). In this context, it is very difficult for older people living with HIV to receive a holistic care approach to their health, and the situation complicates their inclusion in an ART programme and the continuous follow-up required to increase adherence and reduce viral load. Although there have been some initiatives in different African countries to treat HIV and noncommunicable diseases in an integrated chronic care disease management system, as discussed above, its full implementation has not been achieved (Matanje Mwagomba et al., 2018).

Conclusion

The HIV epidemic is ageing in Africa, creating the first generation of older people living with HIV. In the next 20 years, the percentage of older people living with HIV may triple on the continent. This new situation may have serious implications for the health of those 50 years and older who also suffer from age-related diseases like dementia, cognitive impairment, frailty, and noncommunicable diseases. In this context, where older people are experiencing high levels of multimorbidity, it is crucial that health and social systems prepare holistic and integrated care for older patients. Moreover, policy makers should provide new guidelines to promote HIV testing, treatment, and follow-up among older people presenting in Primary Health Care facilities seeking treatment for their noncommunicable chronic conditions. Finally, it should not be ignored that older people are suffering different levels of stigma in relation to HIV and that support programmes should be organized.

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Chapter 2
Comorbid Conditions Occurring in Older Adults on Antiretroviral Therapy in Botswana: A Retrospective Cross-Sectional Cohort Study of Patient Data

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Contents

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Introduction

As patients develop growing numbers of medical conditions, their risk of disability, frailty, and physical incapacitation rises. Comorbidity—defined here as the presence of one or more additional illnesses co-occurring with a primary disease—is increasingly regarded as the norm rather than the exception in primary care throughout the world (McPhail, 2016; Held et al., 2016; Hien et al., 2014). Yet health systems in many countries remain configured and focused on specific disease treatments rather than comprehensive interventions that are mindful that chronic illnesses may coexist (Wittenberg, 2015; Barnett et al., 2012). While complex co-occurrence of diseases is not seen exclusively among older individuals, it becomes more common with increasing age, introducing additional sources of risk and competing demands for care (Sico et al., 2015; Durand et al., 2011; Schouten et al., 2014). A review by McPhail (2016), examining multimorbidity and resource utilisation in health settings around the world, highlighted some of the systemic challenges faced by people with advanced age, frailty, and disadvantageous socioeconomic circumstances. The author noted the importance of prioritising interventions and health services delivery that can mitigate the burden of multimorbidity in safe and cost-effective way.

The global success of antiretroviral therapy (ART) has enabled people living with HIV to survive long enough to experience an increased risk and exacerbation of certain chronic illnesses and age-associated diseases (Mahy et al., 2014; UNAIDS, 2014; High et al., 2012). Co-occurring illnesses are also a common feature in HIV long-term manifestation; therefore, it is critical to comprehensively explore and understand the management of multiple chronic diseases in the ageing HIV population. While the rates of AIDS-defining cancers such as non-Hodgkin's lymphoma and Kaposi's sarcoma dramatically declined with the advent of highly active antiretroviral therapy (HAART), the post-HAART era seems to have ushered in the rise of non-AIDS-defining cancers, such as lung, liver, kidney, and anal cancer, as well as Hodgkin's lymphoma (Work Group for the HIV and Aging Consensus Project, 2012; Hasse et al., 2014; Deeken et al., 2012). Studies point to an emerging common thread, implicating HIV as a significant factor in the development of non-AIDS disorders (comorbid conditions occurring in people with HIV on HAART) in adults ageing with the disease (John, 2016). These conditions may include cognitive decline; diseases of the heart, liver, and kidney; and communicable diseases such as tuberculosis (Akgun et al., 2013; Oursler et al., 2006; Alford & Vera, 2018; Ripamonti & Clerici, 2020). These broad complex types of diseases do not simply exist in parallel, but can interact, one exacerbating the other, likely increasing mortality rates despite viraemic control (Young et al., 2009). For example, diabetes is associated with increased risk of developing active TB, and the presence of diabetes in TB patients is associated with poorer outcomes (Zhu & Wang, 2006; Viswanathan et al., 2012; Qiu et al., 2017; Pealing et al., 2015). Another example is the potential for some antiretroviral regimens to increase the risk of diabetes and other cardiovascular risk factors, particularly lipid abnormalities (Dau & Holodniy, 2008; de Gaetano Donati et al., 2010; Mashinya et al., 2015).

Given the ageing of the HIV cohort and the increased multifaceted disease burden in sub-Saharan Africa, recognising age as a major factor in understanding the associations between HIV and related comorbidities (Dagadu & Patterson, 2015) is of paramount public health importance (Matlho et al., 2017; Aikins et al., 2010). While limited, some studies in sub-Saharan Africa have examined the relationships between HIV, age, and noncommunicable diseases. A cross-sectional study of the population-based survey in the Bushbuckridge subdistrict, Mpumalanga Province, in South Africa observed that older people living with HIV were more prone to multimorbidity than their counterparts without HIV (Chang et al., 2019). Phaswana-Mafuya et al. (2013) noted the need for targeted comprehensive health promotion and interventions addressing risk factors for noncommunicable diseases, in a study examining the sociodemographic predictors of such risk factors among older adults in South Africa. Negin et al. (2012), on the other hand, did not find any significant association between HIV and chronic conditions, such as depression, asthma, hypertension, stroke, and other cardiovascular diseases, among those aged 50 and above. Other studies of this emerging HIV cohort have pointed to challenges that include complications due to ART often affecting the adherence to treatment; the need to manage multiple diseases and infections (Zhao & Goetz, 2011; Chawla et al., 2018; Gebo, 2008; Diallo et al., 2017); and decreased metabolic function (Deer & Volpi, 2015; Ramnath et al., 2018), hepatic function (Kim et al., 2015), and nephrotic function (Boswell & Rossouw, 2017).

In Botswana, however, adults over the age of 50 living with HIV have, over the years, been largely underrepresented in HIV research (Republic of Botswana Ministry of Heath et al., 2012). In fact, there are currently no health interventions that provide or promote clinically meaningful care aimed specifically at older adults in Botswana, even though increased multimorbidity has been a problem within the older population in general (Mengesha, 2007). This country with high HIV prevalence, where ART coverage rates over 90% have been achieved, provides a unique opportunity to examine the complex relationship of HIV infection and ageing and comorbidities (Farahani et al., 2014; Republic of Botswana Ministry of Heath et al., 2012).

Although research is limited, some studies have examined the interactions between HIV and specific diseases in Botswana. For instance, a study by Moyo et al. (2013) noted that HIV-infected adults in Botswana, including those on ART regimens such as efavirenz regimen and protease inhibitors, had an elevated risk of developing diabetes mellitus. Cancer-related mortality has also been reported to be disproportionately higher in people with HIV, with cancer incidence in some cases as high as three to five times that of their counterparts without HIV (Suneja et al., 2013). A study by Dryden-Peterson et al. (2015), which sought to explain cancer trends in Botswana since the onset of the ART programme, observed that despite the age-specific risk of cancer decreasing due to the expansion of HIV treatment, a growing and ageing population accounted for constant high numbers of new cancer cases in the HIV population.

While Botswana is tackling the changing patterns of HIV infection and associated mortality with great efficiency, it continues to emphasise specific demographics (i.e. pregnant mothers, younger people, and people of reproductive age) in its management of the HIV epidemic, often excluding older adults as a subgroup of interest. In light of the increasing population of older people living with HIV in Botswana and the projected rise in associated noncommunicable diseases, however, a long-term strategy aimed at optimising holistic and comprehensive treatment and care for older people with HIV is crucial. Gauging and understanding the potential health implications of the co-occurrence of acute and chronic illness in this cohort is an essential part of this strategy, because as more people grow older and stay alive, the chronic care and management challenges will also grow. Our research looked at the prevalence of comorbidities among older adults living with HIV in Botswana with the intent to inform programme development as well as to better understand the important and practical issues that need to be addressed in this at-risk population.

Research objectives:

- To describe the patient disease characteristics among patients aged 35 years and older on first-line treatment and to determine any gender-related differences.
- To ascertain the prevalence of comorbidities within the population sample and determine any within-gender age-related differences in prevalence.
- To determine whether there are age-specific associations between disease characteristics and number of comorbidities.
- To determine whether there are any gender-related differences in prevalence of comorbidities among adults aged 50 years and older.
- To determine whether there are associations between patient characteristics and number of comorbidities after controlling for confounding factors.

Method

Settings

The data were drawn from patient files from Infectious Disease Care Clinics (IDCCs) in and near Gaborone, the capital city of Botswana. The contributing IDCCs in this study included one large metropolitan referral hospital, Princess Marina Hospital in Gaborone; one urban clinic, Bontleng Clinic in Gaborone; and two semiurban facilities, Athlone Hospital Lobatse and Phuthadikobo Clinic in Molepolole. These specialised clinics are dedicated to the care of adult and paediatric outpatients with HIV and AIDS. They are equipped with a fully operational laboratory capable of performing tests to detect the presence of HIV antibodies in the blood or oral fluid, otherwise known as enzyme-linked immunosorbent assay (ELISA); toxicity-monitoring chemical analyses; complete blood counts; HIV-1 DNA polymerase chain reaction (PCR) analysis; plasma HIV-1 RNA quantification; and CD4 cell counts. Nurses with additional HIV specialist training provide the bulk of ongoing clinical care. An on-site HIV physician provides complementary care on consultation basis, with diagnostic support from the hospital's laboratory and radiology services. Patient data on HIV disease stage, comorbidities, prescribed drugs, and laboratory test results are recorded at each clinic visit. The information is then stored in paper-based files linked through unique patient identifier numbers.

Data

We conducted a retrospective cross-sectional study to examine comorbidities (TB, diabetes, dyslipidaemia, asthma, hypertension, and cancer, as well as cervical dysplasia or cancer in women) present in older people living with HIV in Botswana. The data were drawn from the existing database of HIV patients attending IDCCs in the greater Gaborone region, described above. The data comprised file reviews from patient cohorts from treatment years 2002, 2005, 2010, and 2012, from a database being developed by the Ministry of Health Botswana. The data analysed in this study consist of randomly selected blocks of consecutive HIV patients' records within each treatment year. We randomly selected a total of 100 consecutive patient records within each IDCC, yielding a total of 1600 records from the participating hospital and three clinics. From these records, we then extracted data for patients aged 35 years and above who were currently or last known to be on first-line ART, yielding a total of 346 patient files. Identifiable information was anonymised at the point of data extraction. All data were tabulated and stored in an encrypted Microsoft Excel document. Patients' characteristics, including demographics, baseline CD4, current CD4, viral load, date of drug initiation, starting regimen, current regimen, line of treatment, and comorbidities, were captured. Comorbidities included in the data set were TB, diabetes, dyslipidaemia, asthma, hypertension, and cancer. Other independent variables were CD4 cell counts (<500 and ≥ 500 cell/mm^3) and ART regimen: nevirapine (NVP) or efavirenz (EFV) first-line combination-based regimens; Atripla or Truvada + NVP; lamivudine (3TC) + stavudine (D4T) + EFV/NVP; Combivir (CBV) + EFV/NVP; or another regimen.

Comorbidity Definitions

HIV was listed as the primary diagnosis, and the presence of a confirmed comorbidity listed on the patient clinical record was regarded as a secondary diagnosis. Comorbidities in this study were defined according to the criteria in the Botswana clinical guidelines (Ministry of Health, 2015). Only comorbidity diagnoses that were confirmed by clinicians and listed on the patient clinical record were considered.

- Tuberculosis: Established by medical history, physical examination, chest x-ray, and/or skin test and confirmed by other laboratory tests that establish the presence of *Mycobacterium tuberculosis*.
- Hypertension: Raised blood pressure—systolic blood pressure ≥140 and/or diastolic blood pressure ≥90 mmHg or currently on medication for raised blood pressure.
- Diabetes mellitus: Elevated blood glucose greater than 11.1 mmol/L with the presence of any of these common symptoms of diabetes—excessive thirst, increased drinking of water, frequent urination, dehydration, weight loss, excessive tiredness, nausea, abdominal pain, heavy breathing with the smell of acetone in the breath, drowsiness, and diabetes coma. Also considered was a fasting blood glucose greater 7.0 mmol/L, taken after fasting for at least 8 h, on two or more occasions in the absence of symptoms.
- Dyslipidaemia: Elevated plasma cholesterol, triglycerides, or both or a low HDL cholesterol level that contributes to the development of atherosclerosis.
- Asthma: Recurrent episodes of wheezing, breathlessness, chest tightness, and coughing as confirmed by the attending clinician.
- Cervical dysplasia or cancer: Based on Pap smear screening and appropriate classification followed by an endoscopy confirmation.
- Cancer: All other clinical confirmed cancer diagnoses.

Analysis

Data was analysed using IBM SPSS software version 24.0 and Stata version 16.0. All *p* values were two sided, and *p* values <0.05 were considered statistically significant. Disease count was used to measure the prevalence of multimorbidity, defined here as the presence of HIV and at least one of the listed chronic conditions above. To understand the disease characteristics of the study population, contingency tables were used to ascertain proportions and any significant differences between genders. Pearson's chi-square test was used to test for significance, with Fisher's exact test used where expected cell count was under five. The same process was used to determine age-group-specific associations between HIV disease characteristics and number of comorbidities.

Analyses to ascertain the prevalence of comorbidities within the population sample were stratified by age group (35–49 vs. ≥50) and by gender. The tables function in SPSS allowed for comparison of column proportions for the number of comorbidities by age group and by gender among older adults. This function reports the *p* value for significant differences only, so nonsignificant *p* values are not reported in these sections of the tables.

To ascertain significant differences in the prevalence of specific comorbidities between age groups within genders, contingency tables were used with Pearson's chi-square test. Where the expected cell count was less than five, Fisher's exact test was used. Prevalence of comorbidities was calculated together with their 95%

confidence intervals (CIs). Due to the small sample size for many proportions, the Jeffreys interval was used in the calculation of all confidence intervals, as it is recommended for use with small samples (40 or below; Brown et al., 2001). The same process was used to compare prevalence of comorbidities among older adults by gender.

To determine the association between patient characteristics and having one or more comorbidities, logistic regression models were used to estimate odds ratios (ORs). Univariable logistic regression was used first to measure the association between the number of comorbidities and patient characteristics. Due to the small number of variables, all were included in a full multivariable model then iteratively removed through backward stepwise selection to reach a final model. Crude odds ratios (cORs) were calculated with 95% CIs for univariable logistic regression analyses, and adjusted odds ratios (aORs) were calculated with 95% CIs for the multivariable logistic regression analysis.

Four variables under investigation (CD4 count, viral load count, ART starting regimen, and cancer diagnosis) had missing data. The number of cases missing data ranged from 1 to 42. For the above analyses, listwise deletion was used with results reflective of the available data.

Ethics

The Human Research Development Committee at the Ministry of Health (MoH) Botswana approved this study (Reference No: HPDME: 13/18/1 Vol. X [300]). The study therefore was treated in accordance with the ethical guidelines and requirements of human research ethics as stipulated by MoH Botswana. The study did not involve any contact with patients. It was based on hospital records, so permission for individual consent was waived. Nevertheless, the sample population was treated anonymously, and it was impossible to identify individuals.

Results

Patient Characteristics and Descriptive Analysis

There was a total sample size of 346 patients aged 35 years and older on their first line of treatment, as of 2017 (Table 2.1). Stratified by gender and age independently, as indicated in Table 2.1, the study sample emerged roughly evenly distributed: 48.0% male and 52.0% female, 53.8% younger adults (35–49 years), and 46.2% older adults (≥50 years). There were no significant differences in the distribution of age groups by gender, but while men were evenly split between age groups (49.4% aged 35–49 vs. 50.6% aged ≥50), there was a slightly higher proportion of women

Table 2.1 Characteristics of study population ≥35 years as of 2017 selected from Infectious Disease Care Clinics in and near Gaborone, Botswana, last known to be on first-line ART

Variable	Total *N* (%)	Men *n* (%)	Women *n* (%)	*p* value between genders
	346 (100)	166 (48.0)	180 (52.0)	
Age category				.209
35–49	186 (53.8)	82 (49.4)	104 (57.8)	
≥50	160 (46.2)	84 (50.6)	76 (42.2)	
(50–64)	126 (36.4)	64 (38.6)	62 (34.4)	
(≥65)	34 (9.8)	20 (12.0)	14 (7.8)	
Current CD4 range (*n* = 313)				**.005**
<500 copies	149 (47.6)	81 (56.2)	68 (40.2)	
≥500 copies	164 (52.4)	63 (43.8)	101 (59.8)	
Viral load range (*n* = 304)				.706[a]
Below detectable limit	297 (97.7)	134 (97.1)	163 (98.2)	
Detectable	7 (2.3)	4 (2.9)	3 (1.8)	
Treatment initiation (year)				**.034**
2005 or earlier	116 (33.5)	67 (40.4)	49 (27.2)	
2006–2010	197 (56.9)	84 (50.6)	113 (62.8)	
2011 or later	33 (9.5)	15 (9.0)	18 (10.0)	
ART first-line regimen (*n* = 345)				**<.001** [a]
EFV-based	226 (65.5)	147 (89.1)	79 (43.9)	
NVP-based	111 (32.2)	16 (9.7)	95 (52.8)	
Others	8 (2.3)	2 (1.2)	6 (3.3)	

[a] Fisher's exact test was used to accommodate small expected cell counts

aged 35–49 in the sample (57.8%) compared to those aged ≥50 (42.2%). A significantly higher percentage of men had a current CD4 count below 500 (56.3%) compared to women (40.2%), $p = .005$. Nearly all of the patients had an undetectable viral load. While the majority of the study sample's first-line ART treatment was an EFV-based regimen (65.5%), there was a clear difference in ART starting regimen in terms of gender. Men were significantly more likely to have an EFV-based regimen (89.1%) as their first-line treatment than were women (43.9%), $p < 0.001$.

Burden of Comorbidity Within Age Group and Gender

A significantly higher proportion of patients aged 35–49 reported no comorbidities (70.4%) compared to those aged 50 years or older (52.5%), $p = .001$ (Table 2.2). This finding was consistent among both men and women. Older women had a significantly higher prevalence (39.5%) of one comorbidity than their younger counterparts (25.0%), $p = .038$. Among men, the proportion of the population with one comorbidity was fairly evenly distributed between the two age groups, but a

Table 2.2 Comorbidities present within the study population, stratified by age and gender of patient

	Total			Men			Women		
Age (years)	35–49	≥50	*p*	35–49	≥50	*p*	35–49	≥50	*p*
n (%)	186 (53.8)	160 (46.2)		82 (49.4)	84 (50.6)		104 (57.8)	76 (42.2)	
0 comorbidities	131 (70.4)	84 (52.5)	.001	58 (70.7)	47 (56.0)	.048	73 (70.2)	37 (48.7)	.003
1 comorbidity	45 (24.2)	53 (33.1) [b]		19 (23.2)	23 (27.4)[a]		26 (25.0)	30 (39.5)	0.038
2+ comorbidities	10 (5.4)	23 (14.4)	.004	5 (6.1)	14 (16.8)	.032	5 (4.8)	9 (11.8) [b]	
	Prevalence (95% CI)	**Prevalence (95% CI)**		**Prevalence (95% CI)**	**Prevalence (95% CI)**		**Prevalence (95% CI)**	**Prevalence (95% CI)**	
TB	15.6 (10.9, 21.3)	20.0 (14.4, 26.7)	.283	25.6 (17.1, 35.7)	22.6 (14.7, 32.4)	.652	7.7 (3.7, 14.0)	17.1 (9.9, 26.7)	**.052**
Hypertension	11.8 (7.9, 17.0)	25.0 (18.8, 32.1)	**.001**	6.1 (2.4, 12.8)	16.7 (9.9, 25.7)	**.032**	16.4 (10.2, 24.3)	34.2 (24.3, 45.3)	**.005**
Diabetes	1.1 (0.2, 3.4)	5.0 (2.4, 9.2)	**.049** [a]	0	7.1 (3.0, 14.1)	**.014** [a]	1.9 (0.4, 6.0)	2.6 (0.5, 8.2)	.750 [a]
Dyslipidaemia	0	2.5 (0.8, 5.8)	.045 [a]	0	3.6 (1.0, 9.2)	.084 [a]	0	1.3 [a] (0.1, 6.0)	.422
Asthma	0	2.5 (0.8, 5.8)	.045 [a]	0	3.6 (1.0, 9.2)	.084 [a]	0	1.3 [a] (0.1, 6.0)	. 422
Cancer (*n* = 327)	4.9 (2.5, 8.8)	6.9 (3.6, 11.9)	.454	3.8 (1.1, 9.8)	8.1 (3.5, 15.9)	.257	5.8 (2.5, 11.6)	5.6 (1.9, 12.8)	.957
Cervical cancer	3.5 (1.3, 8.9)	2.7 (0.5, 8.3)	.504 [a]				3.5 (1.3, 8.9)	2.7 (0.5, 8.3)	.504 [a]

[a] No significant difference found between age groups

[b] Fisher's exact test was used to accommodate small expected cell counts

significantly higher proportion of older men (16.8%) had two or more comorbidities compared to younger men (6.1%), $p = .032$.

Patients 50 years or older had a significantly higher prevalence of hypertension (25.0%) compared to those aged 35–49 (11.8%), $p = .001$. Older women had a significantly higher prevalence of hypertension (34.2%) than younger women (16.4%), $p = .005$, as did older men (16.7%) compared to younger men (6.1%), $p = .032$. Several conditions showed gender-specific age differences. While there was no significant difference in the prevalence of TB between older and younger men, older women had a significantly higher prevalence (17.1%) than younger women (7.7%), $p = .052$. Men, on the other hand, showed significant differences in age for diabetes; there were no cases reported among younger men, compared to 7.1% of older men ($p = .014$). There were no cases of dyslipidaemia or asthma among adults aged 35–49, resulting in a significant association between these two comorbidities and age ($p = .045$). This association appears to be more within men in the sample than women, though the differences within genders are not significant. There were no significant differences between age groups for the prevalence of cancer or cervical cancer.

Age-Group-Specific Associations Between Disease Characteristics and Multimorbidity

Patient disease characteristics (viral load, CD4 count, ART regimen, and length of exposure) were stratified by age group to determine the association between the characteristics and multimorbidity (Table 2.3). For both the younger and older adult groups, no significant associations were evident between these disease characteristics and the presence of a comorbidity. A comparison of patients with one comorbidity and those with more than one (not shown) had similar results.

Comorbidities Relative to Gender Among the Older Cohort (≥50 Years)

Table 2.4 shows the prevalence of comorbidities (TB, hypertension, diabetes, dyslipidaemia, asthma, and cancer) within the cohort of participants aged 50 years and older stratified by gender. One third of this older cohort was diagnosed with one comorbidity, while 14.4% presented with two or more. Among older women, 39.5% had one comorbidity, compared to 27.4% of men, while 16.8% of men had more than one comorbidity, compared to 11.8% of women, but the differences were not statistically significant.

In men and women, TB and hypertension were the most common problems, with hypertension significantly more prevalent among older women (34.2%) than among

Table 2.3 The association between patients' disease characteristics and multimorbidity, stratified by age

Age group (years)	Variable	0 comorbidities (%)	≥1 comorbidity (%)	*p* value
35–49[a] (younger adults)	Current CD4 range			.762
	<500 copies	49 (40.2)	23 (42.6)	
	≥500 copies	73 (59.8)	31 (57.4)	
	Viral load range			.936
	Below detectable limit	117 (98.3)	53 (98.2)	
	Detectable	2 (1.7)	1 (1.8)	
	Treatment initiation (year)			.858
	2005 or earlier	24 (18.3)	11 (20.0)	
	2006–2010	89 (67.9)	38 (69.1)	
	2011 or later	18 (13.7)	6 (10.9)	
	ART first-line regimen			.231
	EFV-based	66 (50.4)	34 (61.8)	
	NVP-based	62 (47.3)	21 (38.2)	
	Others	3 (2.3)	0 (0.0)	
≥50[b] (older adults)	Current CD4 range			0.974
	<500 copies	40 (56.3)	37 (56.1)	
	≥500 copies	31 (43.6)	29 (43.9)	
	Viral load range			.332
	Below detectable limit	64 (95.5)	63 (98.4)	
	Detectable	3 (4.5)	1 (1.6)	
	Treatment initiation (year)			.443
	2005 or earlier	42 (50.0)	39 (51.3)	
	2006–2010	39 (46.4)	31 (40.8)	
	2011 or later	3 (3.6)	6 (7.9)	
	ART first-line regimen			.546
	EFV-based	64 (77.1)	62 (81.6)	
	NVP-based	17 (20.5)	11 (14.5)	
	Others	2 (2.4)	3 (3.9)	

[a] $n = 186$, 0 comorbidities = 131, ≥1 comorbidity = 55

[b] $n = 160$, 0 comorbidities = 84, ≥1 comorbidity = 76

their male counterparts (16.7%), $p = .010$. The opposite was true for TB, with 22.6% of men TB positive compared to 17.1% of women, a difference that was not significant.

Table 2.4 Prevalence of comorbidities among people ≥50 years in the sample population, stratified by gender

	Total		Men		Women		
	N	Prevalence (95% CI)	*n*	Prevalence (95% CI)	*n*	Prevalence (95% CI)	*p* value
	160		84		76		
1 comorbidity [b]	53	33.1 (26.2, 40.6)	23	27.4 (18.7, 37.6)	30	39.5 (29.0, 50.7)	
>1 comorbidity [b]	23	14.4 (9.6, 20.4)	14	16.7 (9.9, 25.7)	9	11.8 (6.0, 20.5)	
Confirmed TB	32	20.0 (14.4, 26.7)	19	22.6 (14.7, 32.4)	13	17.1 (9.9, 26.7)	.384
Confirmed hypertension	40	25.0 (18.8, 32.1)	14	16.7 (9.9, 25.7)	26	34.2 (24.3, 45.3)	**.010**
Confirmed diabetes	8	5.0 (2.4, 9.2)	6	7.1 (3.0, 14.1)	2	2.6 (0.5, 8.2)	.282[a]
Confirmed dyslipidaemia	4	2.5 (0.8, 5.8)	3	3.6 (1.0, 9.2)	1	1.3 (0.1, 6.0)	.622 [a]
Confirmed asthma	4	2.5 (0.8, 5.8)	3	3.6 (1.0, 9.2)	1	1.3 (0.1, 6.0)	. 622 [a]
Confirmed cancer	10	6.9 (3.6, 11.9)	6	8.1 (3.5, 15.9)	4	5.6 (1.9, 12.8)	.746 [a]

Cervical cancer was not included because a comparison cannot be made between genders

[a] Fisher's exact test was used to accommodate small expected cell counts

[b] No significant difference found between genders

Univariable and Multivariable Analyses on Patient Characteristics and Number of Comorbidities

Univariable logistic regression (Table 2.5) showed that older adults were more likely to have one or more comorbidities (multimorbidity) than younger adults (cOR 2.16, 95% CI [1.39, 3.35]). People on NVP-based first-line regimens were found to be significantly less likely than those on EFV-based regimens to have multimorbidity (cOR 0.55 [0.34, 0.89]). Gender, current CD4 range, viral load range, and treatment initiation year were not significantly associated with having multimorbidity.

In the final multivariable model, only age was found to be significantly associated with having multimorbidity. Adults aged 50 years and older are nearly two times more likely to have multimorbidity compared to adults aged 35–49 (aOR 1.84, 95% CI [1.16, 2.95]).

Table 2.5 Univariable and multivariable logistic regression analysis for association between patient characteristics and having at least one comorbidity

Variables	cOR (95% CI)	*p* value	aOR (95% CI)	*p* value
Gender		0.682		
Male	1.00			
Female	1.1 (0.71, 1.69)			
Age group		0.001		.010
35–49	1.00		1.00	
≥50	2.16 (1.39, 3.35)		1.84 (1.16, 2.95)	
Current CD4 range		0.503		
<500 copies	1.17 (0.74, 1.84)			
≥500 copies	1.00			
Viral load range		0.577		
Below detectable limit	1.00			
Detectable	0.62 (0.12, 3.27)			
Treatment initiation (year)				
2005 or before	1.33 (0.60, 2.94)	0.489		
2006–2010	0.94 (0.48, 2.03)	0.882		
2011 or after	1.00			
ART first-line regimen				
EFV-based	1.00		1.00	
NVP-based	0.55 (0.34, 0.89)	0.016	0.67 (0.40, 1.12)	.125
Other	0.81 (0.19, 3.48)	0.780	0.77 (0.18, 3.37)	.730

Discussion

The rise in prevalence and increased risk of noncommunicable diseases such as diabetes, dyslipidaemia, and cardiovascular diseases has previously been reported in the general HIV population in Botswana and other countries in sub-Saharan Africa (Reid et al., 2012; Narayan et al., 2014; Rankgoane-Pono et al., 2018). Our study, however, was the first of its kind to examine HIV and comorbidities in the context of ageing in Botswana. The results pointed to a growing presence of comorbidities in older people living with HIV compared with their younger counterparts, thus supplementing and adding to the existing literature, globally, that people ageing with the infection exhibit particular vulnerability to multiple health problems (Abraham et al., 2015; Ando & Yanagisawa, 2015; Durand et al., 2011; Edelman et al., 2013; Goodkin et al., 2017; Smit et al., 2015).

Our study underlined age as an important distinction, with the older cohorts having higher odds of developing comorbidities than their younger counterparts. This observation was consistent with the general takeaway from several prior studies that reported a higher presence of multiple morbidities in older individuals with HIV compared to younger people (Karlamangla et al., 2007; Cardoso et al., 2013; Goulet et al., 2007; Held et al., 2016; Mata-Marín et al., 2019). Older people with HIV have also been observed in several studies to have more chronic conditions than older people without HIV (Obimakinde et al., 2020; Calvo-Sánchez et al., 2013). They are also more at risk of geriatric syndromes such as osteoporosis, fractures, and frailty (Piggott et al., 2016; Yang et al., 2019), as well as stroke, which has been associated with cognitive problems such as Alzheimer's disease and vascular dementia in the immune-compromised older population (Reinhardt & Cohen, 2015).

It is clear from this study that gender has some role in comorbidity predisposition, with older women, specifically, more likely to be affected by hypertension than older men. This observation aligns with research in other parts of sub-Saharan Africa that reported higher rates of morbidity in women living with HIV in Zimbabwe and South Africa, respectively (Negin et al., 2012; Magodoro et al., 2016). While our study did not find a strong association between the presence of comorbidities and patient disease characteristics, the use of some HIV medication, prolonged exposure to ART treatment, lower CD4 count, and high viral load have in the literature been linked to some disposition to comorbidities (Wing, 2017; Onen et al., 2010; Ruzicka et al., 2018). Furthermore, while there was no significant association between the first-line HIV treatment the patients received and the existence of comorbidities, gender did seem to play a role in the type of first-line HIV treatment the patients received. Of the two types of NNRTI (non-nucleotide reverse transcriptase inhibitor)-based combination regimens commonly prescribed in this cohort, men were much more likely to be on EFV-based regimens than women. From 2002 to 2012 in Botswana, EFV was recommended for use only in men and in women who were not of reproductive age because of contraindications to pregnancy (Karim et al., 2011; Vitoria, 2005). In addition, EFV was a preferred NNRTI in the presence of TB, which was more common in men than in women in this cohort (van Leth et al., 2005; AIDSinfo, 2016; Vitoria, 2005; Steele et al., 2011; NACA, 2015).

There were several limitations to our study, starting with the fact that this was a retrospective study based on electronic and paper medical records, thereby open to multiple possibilities of information bias due to recording errors, incomplete information, and misinterpretation of data. The study was also exclusively focused on patients who were on first-line treatment, predominantly an NNRTI, thereby likely excluding patients on alternative treatments who may have experienced failure or resistance to the first-line treatment. Omitting such complex patients in the study may have underestimated the overall morbidity and mortality of this cohort. Furthermore, the data were mainly from urban clinical dwellings, as the ability to diagnose comorbidities in nonurban settings was limited. Another clear limitation of our study was that it exclusively focused on the HIV-positive cohort without making any demographically matched comparison to an HIV-negative cohort, even though the older population is known to experience a similar disposition to comorbidities even without HIV (Held et al., 2016; Handschin et al., 2015; Valderas et al., 2009). Comparison with older adults without HIV would have likely offered useful information in understanding the situation even better (Zhu & Wang, 2006; Viswanathan et al., 2012; Qiu et al., 2017; Pealing et al., 2015). In addition, the study did not comprehensively capture other known comorbidities, including hepatic and metabolic complications that are often exacerbated by HIV infection, immunodeficiency, metabolic syndrome, and other adverse effects of combination ART (Cahill & Valadez, 2013; Kaplan-Lewis et al., 2017; Coffman et al., 2017; Pelchen-Matthews et al., 2018). Such complications can result in increased hospitalisation and death (Brothers et al., 2014; Greene et al., 2015; Kooij et al., 2015; Prieto-Alhambra et al., 2014; Rasmussen et al., 2015).

While clinical care in Botswana remains largely fragmented, with HIV patients still often isolated as a group and treated within specialised HIV clinics that tend to focus largely on managing and administering HIV treatment without particular vested interest in coexisting morbidities, there has been some research development on the complexities associated with this greying HIV epidemic. Botswana is, in fact, 1 of only 14 countries in the world that had, by 2019, achieved the 90-90-90 minimum target of viral suppression in people living with HIV (UNAIDS, 2020). Success of such magnitude has inversely shined a spotlight not only on the nonexistent geriatric care, but on other challenges linked to the prolonged HIV epidemic, such as the multifaceted nature of longevity with HIV and the demands associated with it. Such challenges were not always apparent in a setting such as Botswana, where HIV had markedly reduced life expectancy and with it the geriatric care concern. Some recent studies that examined the relationships between HIV and noncommunicable diseases in Botswana have singled out HIV as a key complicating factor in the management of such diseases (Haacker et al., 2019). Reports of a rising manifestation of various noncommunicable diseases and cancer-related incidents in people living with HIV have been highlighted (Suneja et al., 2013; Dryden-Peterson et al., 2015; Haacker et al., 2019). Studies such as the one by Zetola et al. (2016) have investigated the link between HIV, TB, and cervical cancer in Botswana, pointing to a probable coexistence of cervical cancer, HIV infection, and prior TB infection in the general population. To date, cervical cancer is recognised as one of the leading contributors of cancer-related mortality in Botswana (Dryden-Peterson et al., 2016). Bearden et al. (2020) recently highlighted the increased risk of stroke associated with HIV in Botswana, while other studies warn of an increased frequency and presentation of cardiovascular ailments, due in part to the natural ageing process but also to the complexities of managing chronic HIV disease (Mosepele et al., 2017; Mosepele & Botsile, 2018; Ponatshego et al., 2021).

Conclusion

It has become abundantly clear that Botswana needs to reconfigure its systems to strengthen clinical care and put in place appropriate structures and policies that address the challenges presented by the success of its HIV treatment intervention. There is a need to disentangle the complexities of HIV and ageing and address the multifaceted issue of comorbidity following the implementation of ART. A long-term strategy and perspective aimed at optimising holistic and comprehensive treatment and care for older people living with HIV is essential. Close monitoring of chronic illnesses in these individuals is recommended if we are to improve their quality of life.

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Chapter 3
Reflecting on Health and Illness Through the Lens of the HIV Epidemic in Uganda

Janet Seeley and Joseph Okello Mugisha

Contents

Majse Lind and colleagues (2021) described the resilience of older people in the United States managing life with the COVID-19 pandemic in the following way:

> Older adults have the strength of experience. They have seen the world fall apart and come back together again. They have dealt before with months or years of anxiety about invisible threats, frustration at restrictions on activities, financial insecurity, isolation, and the illness of loved ones. Specific memories of how they handled these times can guide their behavior now. (p. e47)

These words could apply to older people in many other contexts; what someone has lived through provides memories which influence how present and future challenges, including health challenges, are faced (Mohatt et al., 2014). A person in their 70s in rural southern Uganda will remember the political turmoil of the 1970s and 1980s, when violence and destruction threatened lives and livelihoods. That turmoil was followed in the decade thereafter by the HIV epidemic, which cut short

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the lives of many loved ones, some of whom they nursed in the final weeks of their lives. Those memories continue to guide them, to serve as examples of how to manage loss and shortage and how to cope with future ill health and fading strength. That "strength of experience" has served as a template for managing the threats posed by COVID-19: a cruel pandemic that poses a particular danger to older adults in Uganda as they age, just as HIV infection had cast a shadow over the freedoms of their younger selves.

Memories and oft-rehearsed stories of past times are an important part of managing the passing of time in the daily lives of many people, particularly as they age. Barbara Adam (1994) cites Stegmüller (1969) to explain the importance of such repetition: it is not "a mere binding of the present to that which has irrevocably gone, but a deep response to that which has been". Yet such repetition also serves as a way to try and revoke the shadow, the palimpsest, the traces of the past found in the present.

Memory is not only cognitive but also biological. On an individual level, our body has a memory of past illness. Experience of sickness in our childhood affects how we respond to later infections; measles or mumps as a child can confer immunity in adulthood: a memory "forced" by infection or by vaccination. Our body remembers the infection and resists a return of that illness. Equally, if we learn that taking a certain over-the-counter drug, or using a particular herb, can aid our recovery from a cold or from influenza, we will remember to use that remedy when that sickness, or something that seems like it, comes again. Leventhal et al. (2016) draw on this experience for the "Common-Sense Model of Self-Regulation" to describe how individuals use their previous experiences of ill health to inform their management of new health challenges, even if they are not exactly the same. When faced with the diagnosis of diabetes or raised blood pressure, a person may doubt the severity of the condition because there is no telltale high fever or a similar symptom which has signalled a serious illness in the past, such as malaria. Equally, the response to being given information by a nurse about a serious chronic condition (e.g. an early stage of kidney dysfunction which may be almost asymptomatic) may be shaped by people's experience with other conditions such as HIV, which has an asymptomatic phase. Assumptions are made about the likely course of the disease as the person looks out for telltale symptoms and, despite what they may be told at the clinic, questions the diagnosis when the symptoms they anticipate fail to materialise. Even for a new infection or sickness, such as AIDS in the 1980s or COVID-19 in 2020, what people hold beliefs about, and have expectations of, may draw more on their own memory of previous sickness and the beliefs held by people around them than on messaging from health providers. Those health professionals are also learning about the new condition. The treatment strategy for the person with the infection is informed by providers' understanding of the course of other infections, which may mirror the new illness, as they gather new knowledge.

In this chapter we reflect on the timeprint of an epidemic, to adapt a concept developed by Barbara Adam (2008): how far the impact of past epidemics is reflected across time to the management of present (and future) health crises. We look at the ways in which knowledge of the HIV epidemic, at a particular time and at different times and places, shapes the understanding and actions of older people in the present and future when managing sickness and new threats posed by disease.

Method

We draw on the findings of three studies in this chapter, all conducted in a rural subcounty in Kalungu District, which borders Lake Victoria in southern Uganda, where the Medical Research Council/Uganda Virus Research Institute Programme of AIDS established a research base in 1988/1989 (Mulder, 1996).

Setting

Most livelihoods in the area are based on small-scale farming, with families producing food for themselves and small amounts of cash crops such as bananas and coffee. Most homesteads have less than five acres of land. There are only a few sizeable landowners and relatively few householders who are landless. Trading (in food items and clothing), brick making, vehicle and bicycle repair, and running shops and bars as well as hair and beauty salons provide additional livelihood options. In addition, some family members move away for work in the nearby fishing sites on Lake Victoria or in Masaka (a nearby town) or Kampala, the capital city. Most of the population is ethnically Baganda (75%), but there is a large representation of immigrants from Rwanda (15%) and a smaller number (4%) from Tanzania. People from other Ugandan ethnic groups make up the remainder. The main local language is Luganda, which is spoken and understood by all the ethnic groups in the area. The community is predominantly Roman Catholic (58%), but 28% of the population is Muslim and 12% Protestant. Just over 50% of the population is under the age of 15 years. Nahemow (1979) describes the Baganda, one of the dominant ethnic groups resident in central and southern Uganda, as having a "loose patrilineal structure". All children belong to their father's clan (Roscoe, 1965). However, the system of descent does not mean that a father and his children, once they have grown up, stay together. Households are often nuclear with kin living far apart, and the wives of a man who practices polygyny may each have a separate household, with the husband circulating amongst the homes. Under the present laws of Uganda, legal polygamy can only exist if a man marries under customary or Islamic law, but some men in legally monogamous unions go on to "marry" additional wives. The most recent census (Uganda Bureau of Statistics, 2014) records 8% of women being married or cohabiting in a polygamous relationship; the number in informal polygamous unions is likely to be higher than this (Seeley, 2012).

Except for the main highway, which cuts through the district from north to south, there are no tarmac roads in the area, and the mud roads connecting the villages, as well as the main road to Masaka, are often muddy and slippery when it rains or deeply rutted when it is dry, making travel, particularly for older people, difficult.

The population of Kalungu district was just over 350,000 at the time of the last national census in 2014. About 5% of the total population is 60 years old or older (Uganda Bureau of Statistics, 2014).

Research in the Medical Research Council/Uganda Virus Research Institute and London School of Hygiene and Tropical Medicine (MRC/UVRI and LSHTM)[1] cohort, which covers 25 villages in Kalungu District (Asiki et al., 2013), found HIV prevalence in the adult population (age 13+) to be 8.5% in 1990/1991, 7.0% in 1998/1999, 8% in 2004/2005, approximately 9% in 2017, and 10% in 2019. Antiretroviral therapy (ART), which enables people living with HIV (if they adhere to ART) to suppress the virus and live a healthy life into old age, was introduced into the area in 2004.

Study Methods

The first study we draw from is the “Trajectories study” (Seeley et al., 1995; Seeley, 2014). In 1991–1992 the members of 27 households took part in a yearlong ethnographic study of the impact of HIV on people’s lives and livelihoods. The households were chosen purposively from the census list compiled in 1990 to represent a cross section of different household types (by sex and age of household head, as well as socioeconomic status). A team of nine local people (four women and five men), trained in ethnographic research, paid monthly visits to the study households assigned to them for the year to record changes in different aspects of the household, such as composition, employment, health, food consumption, and social networks. Detailed notes were written up immediately after the visit. Monthly meetings were held so that the team could discuss emerging themes and agree on any additional topics, relevant to the season or current events, to focus on in their visits. In 2006–2007 the study was repeated, collecting the same detailed information on day-to-day life, as well as changes in socioeconomic status and household members’ memories of what had happened in the intervening 15 years. This time the research team was made up of two women and three men each of whom visited their own assigned households once a month. Members of 24 of the 27 original households participated in the repeat study. Life histories of all adult members were collected. Eleven of the household heads were the same in 2006 as in 1991, and they and some members from other homes were aged over 60 years in 2006; it is from these people that we draw information for this chapter.

The second study, which took place in 2013, was part of the Research on Older Adults with HIV (ROAH) study. An experienced female interviewer conducted 11

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[1] The MRC/UVRI Uganda Research Unit on AIDS joined with the London School of Hygiene and Tropical Medicine in 2018 to become the MRC/UVRI and LSHTM Uganda Research Unit. “AIDS” was dropped from the name to reflect the broadening of the unit’s health research.

individual in-depth interviews. These interviews were tape recorded, with the participant's agreement. An interview checklist was used, consisting of broad topics such as "care giving" or "visits" to serve as a memory aid for the interviewer. All interviews were, however, conducted in the style of an informal conversation. The interviewer transcribed and translated the taped interviews.

The analysis of the data for both of these projects was done manually by the interviewers and lead social scientists using thematic content analysis. The information in the transcripts was coded on a range of themes agreed on in advance by the team for each study, and thematic summaries were written up on each theme. We ensured that differences and disagreements over coding were resolved through discussion, with constant comparison used throughout the process to avoid shifts in code use over time.

The third study is a COVID-19 survey in 25 cohort villages in 2020 and 2021, where we are collecting quantitative data on the experience of the pandemic, both in terms of infection and knowledge and attitudes towards infection. We draw on some of the broad free text statements older participants made in the course of the ongoing data collection.

All three studies have overall approval from the Ugandan National Council for Science and Technology. Ethical approval was given by the review board of the Uganda Virus Research Institute. All participants provided written informed consent for the use of their anonymised data in publications. All the names used in this chapter are, therefore, pseudonyms.

In her essay on the cultural anthropology of time, Nancy Munn (1992) describes a metaphor from the work of Christine and Stephen Hugh-Jones in Northwest Amazonia (Hugh-Jones, 1977), where the Barasana people describe their generations growing away from their ancestors, like leaves piling up on the forest floor. Performing male initiation rituals is described as "squashing the pile" because the repetition reconnects the new initiates with their ancestors and all those who have performed the ritual in the past. In a way, we can think of the memories of the older people we spoke to as layered; when new health challenges arise, the layers squash to draw from past practice and the things that provided comfort. It is to those memories we now turn.

Memories of Loss

A few years before her death, Sara, who was then in her early 80s, recalled a time when the home she now shared with her co-wife Lydia was full of their offspring and bustling with visitors. They were a well-off family, with plenty of land and resources, enough to ensure all the children were educated. She sighed and reflected on the past 20 years, the two decades since their husband died in 1992. "All our children are finished", she said. Of Sara's 8 children, only 2 were still alive in 2012, while Lydia, who had given birth to 11 children, had only 3 still alive. All had died of AIDS-related illnesses; all were buried in the family plot close to their main house (Seeley et al., 2009).

A new, unfinished house stood close to their main house. Sometimes a niece slept there with Lydia to ensure the place remained in use and was secure. Lydia commented:

> Our son who was our right hand put up this [the new structure] house so that he could care for us when near us, but he died, and it was his dead body that entered here. His grave is also over there where his father's [grave] is.

Eunice, their neighbour, recalled a time when she and her family would become tense when they heard a vehicle at night on the dirt track which ran between her home and the plot where Lydia and Sara stayed, assuming another dead or dying person was being taken to her neighbours' home for burial or for care in their final days. Eunice commented that in the 1990s HIV "almost killed the whole village!" Eunice's own husband and son had died because of HIV, and she was living with HIV herself and taking antiretroviral drugs.

For Sara, Lydia, and Eunice, the threat posed by HIV infection was a shadow over their lives, a threat that had resulted in death. The place they lived, about 100 kilometres north of the Tanzanian border, had once been the epicentre of the HIV epidemic in Africa (Barnett & Blaikie, 1992). That epidemic was the reason the research organisation we work for was based there: in 1988 an agreement between the Ugandan and British Governments led to the establishment of the then Medical Research Council and Uganda Virus Research Institute Research Programme on AIDS. The purpose of the programme was to study the HIV epidemic—to increase the understanding of an infection that had taken hold in that area since the first documented cases in 1982 (Serwadda et al., 1985; Mulder, 1996). Mixed in with the growing body of knowledge about an infection which attacked the immune system so violently it resulted in death were the accounts of people struggling with grief. Increasingly families witnessed the loss of the young people they had invested resources in so they would be educated to secure the family's future and care for the older people in their final years.

Memories and History to Guide the Present

Howard Phillips (2020) reflects on the value of history in understanding the COVID-19 pandemic, which has swept the globe in 2020 and 2021:

> It is necessary to recognise that history, or more precisely, our knowledge (such as it is) of the past is closely tied to the present too. Not only does it explain how the present has been reached—every current problem has its source in the past—but it is also able to offer comparative historical examples, helping us to keep the present in perspective.

He reminds us that South Africa (where he lives) has experienced many pandemics: smallpox (eighteenth and nineteenth centuries), bubonic plague (1901–1907), "Spanish" flu (1918–1919), polio (1944–1963), and HIV (1982–continuing). In a

2004 publication on the history of HIV in South Africa, Phillips takes to task those who had claimed that there was “no parallel” in history for the HIV epidemic, quoting from a paper presented at a conference in Johannesburg on “AIDS in Context” where the speaker, Coovadia (2001), said HIV was an epidemic “the likes of which we have never seen before”. This language resonates with the frequent claims that COVID-19 is “unprecedented”. The global response with widespread lockdowns and other containment measures may be unprecedented (Yan, 2020); but the COVID-19 pandemic, and indeed the HIV epidemic, is not, a point we return to at the end of this chapter.

In Uganda, as in South Africa, the HIV epidemic followed other disease trajectories. In the nineteenth century, outbreaks of plague and smallpox as well as endemic malaria affected the area, the Buganda Kingdom, where Sara, Lydia, and Eunice lived at the time of our research. In 1905, sleeping sickness in Buganda and neighbouring Busoga killed about 250,000 people and resulted in the then British colonial government moving people away from the shores of Lake Victoria to resettle 24 kilometres inland. The evacuation caused widespread disruption, but it did help to reduce the number of deaths (Berrang-Ford et al., 2006; Seeley, 2014). Syphilis dominated the discourse on the health of the population up to the 1930s, with debate as to whether the disease seen was endemic syphilis, venereal syphilis, yaws, or tropical ulcer (Lyons, 1994). Davies (1956) believed that endemic syphilis was an old disease in Buganda, spread nonsexually, which most of the population had had and which conferred some immunity to venereal syphilis. Meanwhile, migrant labour from neighbouring countries (particularly Rwanda and Burundi) was affected by “the imposition of strict quarantine measures in Ruanda-Urundi on account of outbreaks of typhus, smallpox and cerebro-spinal [sic] meningitis” (Powesland, 1954). These distant epidemics are long forgotten by the majority of contemporary Ugandans, just as the so-called “Spanish” flu pandemic in the early twentieth century was barely remembered, until recently, in many parts of the world. Indeed the outbreaks in 1918 have been called “a ‘forgotten pandemic,’ lost in the archives, amidst records of the Great War, the armistice, and the new era of modernity ushered in by these cataclysmic events” (Hovanec, 2011). Some commentators (such as Bristow, 2010, 2012) suggest that the ways in which that epidemic was “forgotten” are bound up with the war (the First World War) which had just ended; people wanted to get on with their lives.

People the age of Lydia, Sara, and Eunice, all in their 80s, certainly knew of outbreaks of disease in the past, and famine and crop failure, but they had also all lived through long periods of political instability. President Yoweri Museveni came to power in 1986 following a prolonged bush war which ousted President Milton Obote, and before that, in 1979, Tanzanian troops crossed the border to support Obote in the liberation war against Idi Amin. When we first met them in 1990, the stories of their experience of the wars were fresh in their memories, and they and others recalled hearing fighting near their homes in 1979 and hiding from soldiers. By 2006, when older people talked about the past, those stories of war, even if not forgotten, were overshadowed, covered in a layer if you will, by tragic accounts of children and grandchildren lost to HIV and, for Lydia and Sara, the management of their own ill health. (Lydia had a breast removed because of cancer and also suffered from diabetes, and Sara had broken her hip in a fall.) The HIV epidemic was seen through the lens of the care provided for their ailing children, who could not at that time be saved from an early death, and their more recent doubts about the new drugs (ART) that might keep their grandchildren living with HIV alive.

As the "common-sense model" developed by Leventhal et al. (2016) suggests, people draw on their past experience to manage health challenges, but the memories of managing other challenges in their lives also guide coping measures. DeLongis and Morstead (2019) point to the importance of the social context in understanding the "common sense" that a person draws on when confronting illness; the knowledge of an older female relative may be heeded more readily than that of a young female nurse in a public health clinic. Likewise, religious teachings and beliefs in divine support may provide comfort when the outcome of a diagnosis hangs in the balance. Sara, for example, recalled how she used to cope with news of her husband's other wives (he had children by at least five women) by saying the Rosary to calm herself and give her strength. She said that she used that same ritual of prayer, and the memory of the support she had felt from that action, to cope with the strain of nursing her own children and some of her husband's other children who came to stay at their house. Her faith gave her strength through the terminal stages of their AIDS-related illness.

The Layering of Experience and New Knowledge

The experience of illness in past times, or actions taken to comfort in times of stress, may conflict with treatment for a new sickness and adversely affect treatment outcomes. We encountered this in our own work on chronic kidney disease (Seeley et al., 2020), where people in the early stages of kidney dysfunction expressed disbelief that their condition was serious or indeed life-threatening because they were prescribed only a short course of treatment (often for a urinary tract infection for those in the early stages of kidney dysfunction), which contrasted with the lifelong treatment required for other serious illnesses, such as HIV infection. The dramatic transformation in the management of HIV, the changing of guidelines as new treatments have evolved, presents a challenge to the experience older people gained from supporting their loved ones in often difficult and painful last illnesses as they died. For some, the confidence of health-care providers and others that new treatments have transformed a fatal illness to a manageable chronic condition is met with incredulity, if not disbelief, and perhaps suspicion. The clash of the different experiences of the HIV epidemic was illustrated in the illness history of Mary, whom we met in 2013.

Mary was 67 years old when we met her, living with HIV. She had been on antiretroviral therapy for about 7 years at that time. As she told her illness story, she recalled the episodes of sickness that had prompted her to seek a test for HIV, following the death of her husband (in about 2003). She said that she had lost a lot of weight and “could no longer see properly”. She recognised the signs and was not surprised when she learnt of her infection.

Her feelings of stigma about her condition meant that she had only told one daughter about her infection and only told her when she was staying with her, because the daughter saw her taking her tablets. She was wary of people mocking her for being an older woman living with HIV. She said people would criticise her for becoming infected with what was considered a young person’s illness. She knew people did not know that her husband died of AIDS-related illnesses because the family had kept that a secret. Many families chose not to disclose the cause of death because of the stigma and fear which still surrounds the condition. Mary told us that when she learnt of her condition, she avoided going to social events where people might gossip about her and would whisper, she feared, that she has slept with many men (like a young woman). Mary said that she took care to follow the instructions given to her by the doctors: “feeding myself, doing less work as well as getting enough rest. They told me to eat greens, jack fruits, and paw-paw; they told me to eat all those things that build up the body”.

She went on to say that her children helped her with food when she could not get enough from her garden. The daughter who knew about her infection paid particular attention to checking that she had good food. Mary’s memory of how ill she had been before she began the antiretroviral drugs haunted her:

> I was very sick and nearing death, having become swollen and they even gave me supplements so that I get more blood. Was I not nearly dying and following my husband? All these legs had swollen and a person who used to have clear skin on my feet, the feet now turned dark!

She had watched her husband suffer and die from the symptoms she had suffered from; he died before the new drugs had come to the clinic. Yet Mary saw her drugs as providing a temporary pause before the serious sickness returned. Even though Mary was adhering to her antiretroviral drugs, she believed that she was going to die soon. She commented that she would now die before her remaining children. However, at the same time she anticipated her own death she was fearful of losing her children first, as so many neighbours had done. She explained:

> If they happen to die before me, who can be there to care for me? It is very bad for the young ones [children] to go and we the oldies to remain! It is worrying to lose someone who would have cared for you and that is the one you bury! That upsets us very much and personally I pray it does not happen that way.

Mary had received her diagnosis just as the antiretroviral drugs came into use in the clinic. While the drugs had restored her health, they had not taken away her memories and fear of what HIV can do to a body, her body. The drugs could not take away her certainty that she was just about to die.

Eunice, who had nursed children in her household until their deaths, recalled the suffering in the early days of the epidemic when no one knew how to treat those who were so ill. She recalled vividly the sickness people suffered from. She said that people in the past used to have wounds all over the body, their hair would fall out, and they would have severe diarrhoea, and to make matters worse, she said it was believed that the disease used to “chop off men’s private parts and for the women it could make holes in their private parts”. Eunice recalled the first time that they heard of the new drugs and marvelled at the people whom she had seen get so thin and who had been ready to die, but who had got better when they had accessed that treatment. Still, she worried about a time when the drugs would stop working, and like Mary, she could not believe that these new drugs could keep working against such a powerful condition. She was convinced that when the drugs failed, HIV would once more “finish the young people off”. Eunice knew that HIV was still something to be concerned about, and these worries about the future of their children “raised parents’ blood pressure”, she said.

Managing COVID-19 by Drawing on the Memories of HIV

Sara, Lydia, Eunice, and Mary all complained that young people no longer took HIV seriously; the children had not seen the pain HIV could bring. Adolescents and people in their early 20s had no memory of the suffering the infection caused because they were small children or not yet born when ART became available. The messages on HIV were the familiar backdrop to their lives on the radio, television, and posters, a litany to which many paid no heed.

The particular calendar time a person encounters HIV and the stage they have reached in their life course affects their understanding of the infection and their perception of the nature of ill health the virus could cause. The social and historical context of a person’s life therefore shapes their concerns about the risks HIV might pose.

With this in mind, it is perhaps not surprising that when a national lockdown was imposed in March 2020 in Uganda to prevent the spread of the new SARS-CoV-2, which causes COVID-19, many people—particularly older people—were very fearful. Older people expressed the view that the infection must be much worse than HIV, if the government told everyone to stay at home. Such a measure had never been put in place for HIV or Ebola. Older people were worried for their children and grandchildren who work and stay in towns, because they were being told at the time of lockdown that COVID-19 was mostly infecting people who stayed in big towns and those who travelled a lot, particularly those who were travelling outside Uganda. Remembering HIV, which had affected so many younger people, the threat of COVID-19 caused many who had travelled to go home to the rural areas, urged to do so by parents and grandparents. Yet, while younger people in towns seemed to be a risk group for carrying the virus, the messages about “risk groups” for severe COVID-19 caused consternation; these groups were older people and people with diabetes and hypertension. Some older people were very worried by these messages because they thought that getting COVID-19 would lead to their death, since most of them were already living with comorbidities, particularly hypertension, or were frail because of age. A report compiled by the Partnership for Evidence-Based

Response to COVID-19 on the state of knowledge of COVID-19 in different countries around the world noted:

> Nearly three-quarters of respondents in Uganda said that they thought COVID-19 would affect very many people in the country…. More than 60% of survey respondents in Uganda said that they believed COVID-19 would seriously affect their health if they were infected…. Belief that the virus would seriously affect their health was highest among older respondents (>age 45). (PERC, 2020)

Meanwhile, government officials were quietly confident that the country could manage the threat. Measures in place to counter other infectious diseases were repurposed to address COVID-19. The speed at which the lockdown came and the borders were closed led many to believe that SARS-Cov-2 would be kept out.

"When much of the world was waking up to the enormous implications of a global pandemic [COVID-19], Uganda was already a step ahead thanks to Ebola". So begins an article on the World Health Organization (WHO) Africa website in September 2020 (WHO Africa, 2020). Melissa Parker et al. (2020) note that in the west and north of Uganda, where recent Ebola outbreaks were vivid memories and concerns about Ebola coming back over the border with the Democratic Republic of Congo were widely discussed, there was "a willingness on the part of Ugandans, whose livelihoods are not threatened, to respond seriously to the threat of COVID-19" (p. 667). This response marked a sharp contrast to much of Europe and North America, where, early on, COVID-19 was dismissed as little more than a cold, and there were widely held beliefs, which persist, that the seriousness of the pandemic was overblown and the news of the pandemic was a hoax (van der Linden et al., 2020). In places where life-threatening illness is rare, and pandemics happen to other people, or in other parts of the world, a common-sense model would suggest that COVID-19 might result in a few days in bed at worst, like a bout of influenza, and then the sickness would pass. Older Ugandans draw on other "common sense" and arrive at a different conclusion.

It is hardly surprising that parallels are drawn between conditions such as HIV and COVID-19 in Uganda. The belief that once a person is infected with SARS-CoV-2, infection will lurk in the body forever and a person will continue to be a threat to others makes sense against the backdrop of HIV. Masks and physical distancing, signs of contagion, amplify the threat, as does misinformation on social media. Families whose members have had COVID-19 are experiencing stigma and prejudice.

The long period of time over which HIV can unfold in an individual's life, in a family, and in different societies is firmly embedded in the memories of older people in Uganda. These memories contain the rumours and uncertainties which have evolved over time and combine with new, factually correct prevention messages to create a shifting backdrop which colours the understanding not only of HIV but also of new threats like infection from SARS-CoV-2 and the resulting illness, COVID-19.

A Palimpsest of Epidemic Responses

A temporal appreciation of these changes allows us to comprehend the timescape of an epidemic for someone like Eunice, or Sara and Lydia, or Mary. They all knew a world before HIV; they all nursed children who suffered and died; they knew of new drugs which allowed people like Mary to regain her health. But this timescape is not a neat progression; memory and knowledge from one time period mix with others, to tinge hope with despair. The experience of these women is very different from that of a 15-year-old born in 2005, born into a world in which the HIV epidemic seems manageable, and the COVID-19 pandemic is something that happens to people in other countries.

Carol Kidron (2009) describes the "lived presence of the past" in her ethnography of Holocaust trauma survivors and their descendants in Israel. She describes how she began to understand that even though the past was not spoken about by survivors, their descendants felt "the silent presence of the Holocaust in the everyday life of the survivor home" (p. 6) through the behaviour of their parents or a chance remark. So it is in many families which have been scarred by deaths in the past because of conflict and HIV. And even if stories are told, not only may children and young people quickly tire of older people reminiscing about the past, but perhaps because of the nature of the epidemic and the shame attached to the infection, it is something many would prefer not to talk about at all. This is one of the "timeprints" of the epidemic. The immorality and fear attached to HIV taints the present and soils new contagious conditions like COVID-19 into the future.

Conclusion

As Roth (2020) observes, the "de-emergence" of a pandemic, unlike its emergence and spread, can be hard to place in time. The end of a pandemic is surrounded by uncertainty as some rush to forget and get on with their lives and others remain fearful and watchful, conscious of a lurking threat. Understanding the lens through which both infectious and noncommunicable diseases are viewed by different people, particularly older people who may draw on many years of experience to manage sickness, is essential for future prevention and support. Understanding not only the temporalities of disease and treatment progression, but also the context in which disease emerges and is managed, is essential for public health messaging and epidemic response. Documenting the "making sense" of disease and misfortune which goes on in people's homes and families, as well as on social media, is an important contribution to the management of present and future outbreaks. Our ongoing findings, and those of others, contribute to a dialogue about the need to work with people in different places, to tailor global responses and coproduce the messaging (Turk et al., 2021).

The influenza outbreak which began in 1918 may have killed many millions of people around the world, but it lasted for 2 years, and then, for many, it was over; people wanted to forget. The same may be true for COVID-19, or perhaps COVID-19 becomes a seasonal illness managed with an annual vaccination. The same is not true for HIV. Even though it can be managed with ART, a cure is not yet assured, and many people continue to suffer with AIDS-related illness and death because they are diagnosed too late or not at all. The concerns expressed by the older people in the area in which we work in Uganda, who remained watchful, serve as a reminder of the lasting emotional pain pandemics can and do cause.

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Chapter 4
Sexual Health and Behavior Among Older Adults with HIV in Sub-Saharan Africa

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Introduction

The population of people with HIV aged 50 and older in sub-Saharan Africa is approaching 4 million (Autenrieth et al., 2018), and research on their sexual risk behavior is increasing, but little is known about their sexual health. Sexual health and intimacy are critical dimensions of well-being in later life (Syme, 2014). In the United States and elsewhere, sexual health has been associated with physical and psychological well-being among older adults (Brennan-Ing et al., 2021; Burnes et al., 2017; Dean et al., 2013; Edwards & Coleman, 2004), and a majority of those surveyed feel that sex is still important (Brennan-Ing et al., 2021).

Older adults in sub-Saharan Africa may not consider themselves at risk for HIV (Freeman & Anglewicz, 2012; Schatz et al., 2019). HIV testing and prevention programs tend to target younger adults, and counseling on sexual health risks is limited (Kiplagat & Huschke, 2018; Kuteesa et al., 2012; Negin et al., 2012). In a study of older adults in South Africa, fewer than half the respondents over 50 had ever had an HIV test, yet participants displayed an awareness of the need to test in order "to have a good life" (Schatz et al., 2019). However, there are important regional differences in accessing HIV testing in sub-Saharan Africa. One study from southern Africa, in Botswana, found that older men with HIV were more aware of their status compared to younger men, though less aware than older women (Matlho et al., 2019). A study of adults aged 50 and older from rural Uganda in East Africa found that HIV testing in the past 12 months was associated with younger age (50–59 years), recent sexual activity, past diagnosis of a sexually transmitted infection, male circumcision, and engagement in transactional sex, but did not differ by gender per se when controlling for these other factors (Wandera et al., 2020).

Research on Sexual Activity in Sub-Saharan Africa

Several studies in sub-Saharan Africa have examined sexual activity and risk behaviors in older adults with HIV or compared older adults based on HIV serostatus (Bajunirwe et al., 2009; Chirinda & Zungu, 2016; Freeman & Anglewicz, 2012; Houle et al., 2018; Matlho et al., 2019; Mojola et al., 2015; Negin et al., 2016; Peltzer et al., 2010; Rosenberg et al., 2017). Older adults in this region, especially men, remain sexually active. Sexual activity decreases with advancing age, but a majority of men over 65 report having had sex in the past year (Freeman & Anglewicz, 2012; Mojola et al., 2015; Peltzer et al., 2010; Rosenberg et al., 2017), and more than one third report being sexually active after age 80 (Peltzer et al., 2010; Rosenberg et al., 2017). Sexual activity among women in sub-Saharan Africa drops substantially after age 50, but on average, around half of women in their 50s and up to 30% in their 60s say they have had sex in the past year (Freeman & Anglewicz, 2012; Mojola et al., 2015; Peltzer et al., 2010; Rosenberg et al., 2017).

Living with a partner and having better health are associated with a greater likelihood of being sexually active among older adults (Lindau et al., 2007), including older people with HIV in sub-Saharan Africa (Bajunirwe et al., 2009; Negin et al., 2016). Matlho et al. (2019) found that HIV status made a difference in the likelihood of being sexually active among women aged 50–64, but not among men. Namely, 33% of women with HIV were sexually active compared to 48% of women who were HIV-negative, and 79% of older men were sexually active regardless of serostatus. Marital status could be a confounding factor, however, as women living with HIV in that study were significantly less likely to be married than women without HIV, while there was no difference in marital status among men. Chirinda and Zungu (2016) had similar findings among older women in South Africa, with an HIV diagnosis significantly associated with less sexual activity, even after adjusting for marital status; in contrast, they found a non-significant tendency toward more sexual activity among older men with HIV.

Condom Use

Research in Africa has found condom use within marriage to be infrequent (de Walque & Kline, 2011; Maharaj & Cleland, 2004). In a review of studies in 13 sub-Saharan countries, no more than 11% of respondents reported using a condom during their last sexual intercourse with their spouse, even where condom use was common for extramarital sex (de Walque & Kline, 2011). Low condom use in polygamous marriages may multiply the risk for HIV in situations where nonresident co-wives or husbands have extramarital affairs, putting other partners at risk for infection (Bertocchi & Dimico, 2019). More recent research finds that most older adults do not use condoms consistently, and percentages dwindle to single digits among those aged 60 or older in rural South Africa (Houle et al., 2018; Mojola et al., 2015; Rosenberg et al., 2017). It may be that older adults, who came of age before the HIV epidemic, are less familiar with condoms (Mojola et al., 2015) or that prevention messaging is aimed at younger adults (Kiplagat & Huschke, 2018). Greater awareness does appear to make a difference. Among adults over 50 in Botswana, where HIV prevalence is high and increasing, condom use has risen from 19% in 2008 to 42% in 2013 (Matlho et al., 2019).

HIV status affects condom use. Older people with HIV are more likely to use condoms than those without HIV; among men aged 50–64 surveyed in Botswana, 76% of those with HIV used condoms regularly with their main partner, compared with 30% of those without HIV; for women aged 50–64, the corresponding percentages are 59% and 34% (Matlho et al., 2019). A similar trend was found among older adults in South Africa, although the proportions were lower (Mojola et al., 2015). In another South African study, adults aged 40 or older with a positive lab diagnosis of HIV and self-report of HIV were far more likely to use condoms than those with a negative self-report (Rosenberg et al., 2017). Moreover, in rural Uganda, 36% of older men with HIV said they usually or always used a condom (Negin et al., 2016). While two thirds of the older adults in the Botswana study were able to negotiate condom use all the time (Matlho et al., 2019), it has been found to be more difficult in other settings (Lekalakala-Mokgele, 2016; Mojola et al., 2015). There may be resistance to condom use in the context of a marital relationship (Maharaj & Cleland, 2004); for example, introducing condoms into a longtime marriage may be perceived as implying or exposing infidelity (Lekalakala-Mokgele, 2016). Condom negotiation between women and their husbands can invite physical violence in some cases through misperceptions that the woman is having an affair or does not wish to bear children (Lince-Deroche et al., 2018).

Multiple Sexual Partners

Men and women face different cultural expectations in terms of multiple sexual partners. In South Africa, for example, traditional ideals of masculinity tend to emphasize strength, virility, and sexual conquest, with women expected to be complacent and accepting (Hunter, 2005; Jewkes & Morrell, 2010). In Uganda, polygamy is common (Uganda Bureau of Statistics, 2018). As they age, both men and women express the belief that men's sex drive continues, while women's desire often ends with menopause (Lekalakala-Mokgele, 2016; Mojola et al., 2015). Sexual activity in older women may be seen as shameful (Okiria, 2014).

Very few older women in the studies in sub-Saharan Africa said they had had more than one partner recently, but anywhere from 5% to 20% of older men reported having multiple partners (Freeman & Anglewicz, 2012; Houle et al., 2018; Matlho et al., 2019; Mojola et al., 2015; Peltzer et al., 2010; Rosenberg et al., 2017; Todd et al., 2009). While there may be a reporting bias causing men to claim more partners and women to claim fewer, a striking gender difference is found consistently throughout the literature in sub-Saharan Africa, and in some surveys, men over 50 reported multiple partners more often than younger men (Negin & Cumming, 2010). Men's extramarital activity was no surprise to women, who often believed their partners were not monogamous (Freeman & Anglewicz, 2012)—especially women living with HIV (Mojola et al., 2015). Few studies parse older adults' condom use by type of partner. Of the five older men with HIV surveyed in Botswana who said they had had more than one partner in the past year, only one admitted inconsistent or no condom use with that partner (Matlho et al., 2019). Among older men with HIV in Uganda, condom use was somewhat more common with a casual partner (50% said they usually or always used one) than with a spouse (33% usually/always) (Negin et al., 2016).

A prominent driver of extramarital sex in sub-Saharan Africa is labor migration. In rural South Africa at the turn of the twenty-first century, more than half the men and one in five women of working age were temporary migrants (Clark et al., 2007). Some research supports the prevalent idea that older men have sex with younger women, acquire HIV, and pass it on to their wives in rural homes, with whom they do not use condoms (Clark et al., 2007; Houle et al., 2018), but other studies find the risk of HIV acquisition decreases for women with older male partners (Harling et al., 2015). Mojola et al. (2015) suggest that celibacy is a protective approach for some older women.

Sexual Health

In rural Uganda, 41% of older men with HIV said sex was extremely or very important to them, compared with only 5% of older women with HIV (Negin et al., 2016). Yet sexual satisfaction and the link between sexual activity and well-being are rarely studied among older adults in the region. This study aims to address the gap in knowledge by presenting data on sexual activity, satisfaction, problems, and risk behavior from two samples of older adults with HIV, in South Africa and rural Uganda.

Purpose and Rationale

Building on our prior research among older people with HIV in Uganda (Negin et al., 2016), we incorporated data from a companion study in South Africa to shed further light on the sexual activity, attitudes, and challenges of older people with HIV in sub-Saharan Africa. Given the well-documented differences in sexual activity and health between older men and women, we also considered gender as a key variable in our analyses. We aimed to answer the following research questions:

1. What are the similarities and differences in the sexual health and risk behaviors between older people with HIV in South Africa and in Uganda and between older men with HIV and women with HIV in these two countries?
2. What factors are associated with sexual activity and condom use among older people with HIV in South Africa and Uganda?

Method

Sources of Data

This study used data from the Research on Older Adults with HIV (ROAH) Africa project, the first comprehensive survey to provide detailed information on psychosocial issues focused on older people with HIV in sub-Saharan Africa (Brennan-Ing et al., 2016; Negin et al., 2016). Eligibility criteria were being aged 50 or older at the time of the interview and having an HIV-positive serostatus. The total sample size consisted of 209 participants. An interviewer-administered quantitative method survey was used to collect information on demographics, mental health, physical health, social networks, HIV treatment experience, treatment adherence, health-related quality of life, and sexual behavior. Each in-person one-to-one interview lasted approximately 1–1.5 h. Interviews were translated from English into the local language of the participants. Written informed consent was obtained.

Uganda participants ($n = 101$) were recruited from enrollees in the World Health Organization's Health and Wellbeing of Older People Study (WOPS) who were living in a rural area of Kalungu district in southwestern Uganda and in the periurban Wakiso district located in the vicinity of Entebbe (Nyirenda et al., 2013). The ethnicity of the majority of Uganda participants was Baganda, one of the prominent ethnic groups in eastern and southern Uganda (Nahemow, 1979). Participants in the Uganda arm of the study were compensated for their time with a bar of laundry soap worth 4000 Uganda shillings (US $1.50). ROAH Uganda was approved by the Science and Ethics Committee of the Uganda Virus Research Institute and the Uganda National Council for Science and Technology.

South Africa participants ($n = 108$) came from an adult antiretroviral therapy clinic in central Johannesburg, South Africa (Nyirenda et al., 2015). In terms of ethnicity, most South African participants reported being either Tswana (44%) or Zulu (22%), with less than 10% reporting other ethnicities (e.g., Xhosa, North and South Sotho, Afrikaans). Participants in South Africa did not receive compensation for taking part in the interview. ROAH South Africa was approved by the institutional review board of the University of New England (Australia) and the Human Subjects Ethics Committee of the University of the Witwatersrand (South Africa).

Measures

Sexual Activity and Sexual Health

Questions on sexual activity, health, and condom use were adapted from a ROAH project study conducted in the United States with sexual and gender minority older adults (Brennan-Ing et al., 2021; Negin et al., 2016). Some of these items had been previously adapted from the National Social Health and Aging Project (Lindau et al., 2007).

Sexual Activity Participants were asked about the frequency of sexual activity in the past year on a 6-point ordinal scale ranging from "none" to "several times per week." We also asked participants about their satisfaction with the frequency of their sexual activity in the past year, which was ranked on a 5-point scale from "much less often than you would like" to "much more often than you would like." Participants reported on how important sex was to them on a 5-point scale ranging from "not at all" to "extremely important." We also asked about the type of relationship participants had with their sexual partners, and these responses were recoded into no sexual partners, partner/spouse only, casual partner only, and partner/spouse and casual partner. Lastly, we asked participants if their partner(s) knew they were HIV-positive (yes/no) and if they knew the serostatus of their partner(s) (yes/no).

Sexual Inactivity and Sexual Health Participants were presented a list of reasons that may have interfered with them being sexually active, including health and psychosocial problems they experienced themselves or problems that their partners may have had (yes/no). Participant problems included being HIV-positive, not being interested in sex, health problems or limitations, emotional problems, belief that children or family members would not approve or friends would not approve, religious beliefs that prohibit sex outside of marriage, sex being painful, being currently grieving, wanting to avoid a sexually transmitted disease (STD), lack of privacy, and not having an opportunity to have sex. Partner problems included the partner not being interested in sex, partner's health problems or limitations, and partner's emotional problems.

Condom Use and Reasons for Not Using Condoms We asked separate questions about the frequency of condom use during sex with one's partner/spouse and with casual partners, for those who were sexually active. Participants responded on a 5-point ordinal scale ranging from "never" to "always." We asked participants, even if they used condoms regularly, what reasons would make them consider having unprotected sex (yes/no). These included that they were having sex with their regular partner/spouse, they really wanted sex, they really needed affection, they were with a sexy or attractive person, their partner said they did not want to use a condom, they thought their partner did not want to use a condom, they thought the risk of STDs was low, they felt depressed, or they were intoxicated (drunk or high).

Covariates

Sociodemographic Characteristics Age in years was measured as a continuous variable. Gender was measured as a dichotomous variable of female or male. Marital status was a categorical variable with six possible responses: married, widowed, divorced/separated, cohabitating, being a co-wife, and single or never married. Living alone was a dichotomous variable (yes/no) and derived from a question about the presence of other people living in the participant's household. Employment status was collapsed into four categories: working full- or part-time, unemployed, retired or living on a pension, and disabled or unable to work. Highest level of education consisted of five categories: none, primary (grades 1 through 7), secondary (grades 8 through 12), vocational or technical school, or tertiary. We asked participants to identify the geographic area where they lived in one of five categories: city, suburb, town, trading center, or village. The research site was coded as South Africa = 1 and Uganda = 2.

Health Participants were asked to rate their health on a 5-point ordinal scale: excellent, good, fair, poor, or very poor. Due to the small number of responses in the last two categories, they were combined into a single category of poor/very poor. Participants indicated how they thought they had become infected with HIV: sex with a partner/spouse, sex with multiple wives, sex with a casual partner, sex with multiple partners, or some other reason. Participants were asked whether they had ever been diagnosed with acquired immune deficiency syndrome (AIDS), which was coded as a dichotomy (yes/no). The number of comorbid conditions in addition to HIV was calculated from responses to whether the participant had any of 26 medical conditions, inclusive of an "other condition" with an open-ended description.

Depression and Loneliness Depressive symptomatology was measured with the abbreviated 10-item version of the Center for Epidemiologic Studies Depression Scale (CES-D 10) (Andersen et al., 1994; Radloff, 1977). Participants were asked about depressive symptoms experienced over the past 7 days and responded on a 4-point ordinal scale: none of the time (less than 1 day or not at all), a little of the time (1–2 days), some of the time (3–4 days), or most of the time (5–7 days). Two items were reverse coded ("I felt hopeful about the future" and "I was happy"). Responses were summed, and higher scores indicated greater depressive symptomatology (range = 0 to 30). Cronbach's alpha for the ten items was .72, indicating acceptable internal consistency reliability. The CES-D 10 scale has been successfully used with people with HIV in Uganda ($\alpha = 0.92$) (Natamba et al., 2014) and South Africa ($\alpha = 0.69–0.89$) (Baron et al., 2017). Loneliness was measured with the 3-item version of the UCLA Loneliness Scale (Russell, 1996). Participants respond to items on a 3-point ordinal scale ranging from "hardly ever" to "often." Responses are summed with higher scores indicating greater loneliness. Cronbach's alpha for this scale in the present sample was .73.

Stigma HIV stigma was measured with the 13-item Sowell Stigma Scale (Sowell et al., 1997). Participants were asked how often they had thoughts and feelings related to HIV stigma over the past 6 months on a 4-point scale ranging from "not at all" to "often." Sample items include "Felt blamed by others for my illness" and "Avoided getting treatment because someone might find out." Responses to these items were summed, with higher scores indicating greater HIV stigma. Cronbach's alpha for the Sowell Stigma Scale with the current sample was .75.

Psychological Well-Being Assessment of positive affect was obtained from the positive affect subscale of the Positive and Negative Affect Schedule (PANAS)

(Watson et al., 1988). Participants were asked to rank their experience of five positive feelings over the past few days (excited, enthusiastic, alert, determined, and inspired) on 5-point ordinal scale ranging from "not at all" to "extremely." These responses were summed with higher scores indicating greater positive affect. Cronbach's alpha for the Sowell Stigma Scale in the current sample was .94. Life satisfaction was measured with a single item that asked, "All things considered, how satisfied are you with your life these days?" (Brennan & Karpiak, 2009). Participants rated their life satisfaction on a scale from 0 to 10 with 0 indicating completely dissatisfied and 10 indicating completely satisfied.

Design and Analysis

This study used a cross-sectional design. We examined differences in sociodemographic characteristics, health, and mental well-being by project site (Uganda and South Africa) and differences in sexual activity, sexual health, and safer sex practices among older people with HIV based on project site and gender (female and male), using one-way ANOVA for continuous data and chi-square analysis for categorical data.

To better understand factors associated with being sexually active in the past year and consistent condom use with a regular partner, we conducted hierarchical logistic regression analyses. We collapsed the data on frequency of sexual activity in the past year into two categories (no sexual activity and any sexual activity). Similarly, we collapsed the responses on condom use with a regular partner into two categories (never/rarely/sometimes vs. usually/always). We were not able to examine condom use with a casual partner in multivariate analysis due to the small number who responded to this question ($n = 20$). Prior to regression analyses, we examined the association between potential independent variables and dependent variables with correlational analysis. Due to the relatively small sample sizes and the need for parsimonious regression models, only independent variables that were significantly associated with dependent variables at the bivariate level were retained for multivariate analysis. Prior to conducting the logistic regressions, we examined independent variables for potential multicollinearity (i.e., $r \geq .70$) and detected none. We used listwise deletion for missing data. We used hierarchical entry of independent variables for association with sexual activity (demographics, health, reasons for sexual inactivity, and site) and condom use (age/health, depression/stigma/well-being, sex variables, and site) and report the final model controlling for all covariates. Regression models were evaluated by significance of the odds ratios (OR) and the Nagelkerke R^2.

Results

Sample Characteristics

The average age of the sample was 59.6 years. The older people with HIV from Uganda were significantly older on average compared to their peers from South Africa (61.0 years and 58.3 years, respectively; see Table 4.1). The South Africa sample had a significantly greater proportion of women (72%) than the Uganda sample (58%). Similar proportions of both groups were married, but older people with HIV in Uganda were significantly more likely to be widowed (46%) and less likely to be single or never married (0%) compared to their South African peers (25% and 22%, respectively). Older people with HIV in South Africa were more than twice as likely as older people with HIV in Uganda to report living alone (25% and 9%, respectively).

The vast majority of the older people with HIV in Uganda were working either full- or part-time (93%). In South Africa, while 50% of the older people with HIV were working, 19% reported being unemployed, and 31% were retired or receiving a pension. There were no significant differences between the two samples in highest level of education; nearly two thirds reported attending only primary school and about one in five had attended secondary school. Given the differences in data collection procedures between the two samples, it was not surprising that nearly all participants in Uganda lived in a village or trading center (90% and 8%, respectively). In South Africa, most participants lived in urban areas such as in a city (8%) or the suburbs (76%).

A majority of the older people with HIV in Uganda rated their health as excellent or good (14% and 46%, respectively), significantly more than their peers in South Africa (1% and 31%, respectively). Older people with HIV in Uganda were significantly more likely to believe they had contracted HIV through sex with a spouse or partner (59%) or sex with multiple partners (8%) compared to their South African peers (47% and 2%, respectively). In contrast, older people with HIV in South Africa were more likely to report being infected through sex with a casual partner compared to those in Uganda (46% and 31%, respectively). Despite their more positive evaluation of their health status, older people with HIV in Uganda were significantly more likely to report a prior AIDS diagnosis compared to those in South Africa (59% and 14%, respectively) and, on average, reported a greater number of comorbid conditions in addition to HIV (5.3 and 1.2, respectively).

Older people with HIV in Uganda also had higher average levels of depressive symptoms (12.3) compared to those in South Africa (7.5). However, there were no significant differences by site in loneliness scores, with a combined group average of 4.6 (SD = 1.6). Older people with HIV in South Africa had significantly higher average stigma scores (47.9) compared to their counterparts in Uganda (20.7). Regarding psychological well-being, older people with HIV in Uganda had both significantly higher positive affect and life satisfaction scores (18.4 and 6.9, respectively) compared to those in South Africa (15.2 and 5.5, respectively).

Table 4.1 Demographic and health profile of older adults with HIV in South Africa and Uganda

	Total		South Africa		Uganda	
	N	%	*N*	%	*N*	%
Gender*						
Male	72	34.4	30	27.8	42	41.6
Female	137	65.6	78	72.2	59	58.4
Marital status***						
Married	51	24.5	28	26.2	23	22.8
Widowed	73	35.1	27	25.2	46	45.5
Divorced/separated	42	20.2	20	18.7	22	21.8
Cohabitating	18	8.7	8	7.5	10	9.9
Co-wife	1	0.5	1	0.9	0	0.0
Single/never married	23	11.1	23	21.5	0	0.0
Lives alone**	36	17.3	27	25.0	9	9.0
Employment status***						
Working full- or part-time	146	70.5	54	50.0	92	92.9
Unemployed	22	10.6	20	18.5	2	2.0
Retired/pension	36	17.4	33	30.6	3	3.0
Disabled/unable to work	3	1.4	1	0.9	2	2.0
Education						
None	32	15.4	17	15.9	15	14.9
Primary (grades 1–7)	129	62.0	63	58.9	66	65.3
Secondary (grades 8–12)	38	18.3	24	22.4	14	13.9
Vocational/technical school	2	1.0	0	0.0	2	2.0
Tertiary	7	3.4	3	2.8	4	4.0
Geographic location***						
City	9	4.3	9	8.3	0	0.0
Suburb	82	39.2	82	75.9	0	0.0
Town	9	4.3	7	6.5	2	2.0
Trading center	8	3.8	0	0.0	8	7.9
Village	101	48.3	10	9.3	91	90.1
Self-rated health***						
Excellent	15	7.2	1	0.9	14	13.9
Good	79	38.2	33	31.1	46	45.5
Fair	88	42.5	62	58.5	26	25.7
Poor/very poor	25	12.1	10	9.4	15	14.9
How infected with HIV**						
Sex with partner/spouse	101	52.9	45	46.9%	56	58.9
Sex with multiple wives	2	1.0	0	0.0%	2	2.1
Sex with casual partner	73	38.2	44	45.8%	29	30.5
Sex with multiple partners	10	5.2	2	2.1%	8	8.4
Other	5	2.6	5	5.2%	0	0.0
AIDS diagnosis***	73	35.8	15	14.2	58	59.2
	M	***SD***	***M***	***SD***	***M***	***SD***

(continued)

Table 4.1 (continued)

	Total		South Africa		Uganda	
	N	%	*N*	%	*N*	%
Age**	59.60	7.10	58.26	6.08	61.03	7.82
Number comorbid conditions***	3.21	3.03	1.22	1.05	5.34	3.00
CES-D depressive symptoms***	9.81	6.16	7.52	4.22	12.26	6.94
Loneliness	4.58	1.63	4.73	1.56	4.41	1.69
Sowell Stigma Scale***	34.73	14.59	47.86	4.97	20.69	5.55
PANAS positive affect***	16.71	5.74	15.17	3.81	18.37	6.91
Life satisfaction***	6.16	2.11	5.53	1.66	6.85	2.33

Note. Total $N = 209$, South Africa $N = 108$, Uganda $N = 101$. Chi-square tests of significance for categorical variables and one-way ANOVA for continuous variables. Percentages may not sum to 100% because of rounding

* $p < .05$, ** $p < .01$, *** $p < .001$

Sexual Activity

Sexual Activity by Site Overall, 41% of older people with HIV reported being sexually active in the past year (see Table 4.2). Older people with HIV in South Africa were more likely to report moderate amounts of sexual activity in the past year (several times per month, 21%, and weekly, 12%) compared to their peers in Uganda (8% and 7%, respectively). However, older people with HIV in Uganda were more likely to be at the extremes, either to say that they had not been sexually active in the past year (69%) or had sex several times per week (8%), compared to 50% and 2%, respectively, of their peers in South Africa. When asked about their satisfaction with the frequency of sexual activity in the past year, older people with HIV in Uganda were significantly more likely to report having sex as often as they liked (67%) compared to those in South Africa (51%). Older South Africans were more likely to say that they had sex more often than they liked (20% either somewhat or much more often) compared to 4% of older Ugandans. This finding may partially reflect the greater proportion of women in the South African compared to the Ugandan sample (72% and 58%, respectively) and the concomitant gender differences in response to this item (see Table 4.3). In terms of the importance of sex in their lives, older people with HIV in Uganda were more likely than those in South Africa to say that it was not important at all (63% and 45%, respectively), but they were also more likely to say sex was extremely important (12%) than were their South African peers (0%). In line with data on sexual activity, 67% of older people with HIV in Uganda reported having no sexual partners, compared with 57% of those in South Africa. In terms of the nature of sexual partnerships, older people with HIV in South Africa were more likely to report having sex only with their partner/spouse (31%) or with both a partner/spouse and a casual partner (13%) compared to older Ugandans (19% and 5%, respectively). However, 9% of older people with HIV in Uganda reported only a casual sexual partner compared to none (0%) in the South African sample. In terms of HIV disclosure to sexual partners, older people with HIV in Uganda were more likely to report that their partner knew they were HIV-positive and that they

Table 4.2 Sexual activity among older adults with HIV in South Africa and Uganda by research site

	Total		South Africa		Uganda	
	N	%	*N*	%	*N*	%
Sexual frequency past year**						
None	121	58.7	53	49.5	68	68.7
Once or twice	17	8.3	11	10.3	6	6.1
Monthly	8	3.9	6	5.6	2	2.0
Several times per month	30	14.6	22	20.6	8	8.1
Weekly	20	9.7	13	12.1	7	7.1
Several times per week	10	4.9	2	1.9	8	8.1
Satisfied with sex frequency*						
Much less often than liked	23	13.1	12	12.1	11	14.5
Less often than liked	28	16.0	17	17.2	11	14.5
Often as would like	101	57.7	50	50.5	51	67.1
Somewhat more often than liked	10	5.7	8	8.1	2	2.6
Much more often than liked	13	7.4	12	12.1	1	1.3
Importance of sex***						
Not at all	109	53.7	46	44.7	63	63.0
Somewhat	38	18.7	29	28.2	9	9.0
Moderately	28	13.8	20	19.4	8	8.0
Very	16	7.9	8	7.8	8	8.0
Extremely	12	5.9	0	0.0	12	12.0
Sexual partnerships***						
No sexual partners	129	61.7	61	56.5	68	67.3
Partner/spouse only	52	24.9	33	30.6	19	18.8
Casual only	9	4.3	0	0.0	9	8.9
Partner/spouse and casual	19	9.1	14	13.0	5	5.0
Partner knows is HIV-positive*	66	85.7	39	79.6	27	96.4
Knows partner's serostatus*	60	77.9	34	69.4	26	92.9

Note. Total $N = 209$, South Africa $N = 108$, Uganda $N = 101$. Chi-square tests of significance. Percentages may not sum to 100% because of rounding
* $p < .05$, ** $p < .01$, *** $p < .001$

knew their partner's serostatus (96% and 93%, respectively), compared to those in South Africa (80% and 69%, respectively).

Sexual Activity by Gender Among the older people with HIV in our samples, men were more likely to be sexually active in the past year (63%) compared to women (30%) (see Table 4.3). Older men were also more likely to be sexually active on a weekly basis or several times per week (20% and 11%, respectively) compared to older women (4% and 2%, respectively). Despite their greater frequency of having sex, older men with HIV were less likely than women to be satisfied with the frequency of sex (47% and 63%, respectively) and more likely to report having sex less often or much less often than they would like (26% and 18%, respectively) compared to their female counterparts (11% and 11%, respectively). Older women with HIV

Table 4.3 Sexual activity among older adults with HIV in South Africa and Uganda by gender

	Total		Men		Women	
	N	%	*N*	%	*N*	%
Sexual frequency past year* **						
None	121	58.7	26	37.1	95	69.9
Once or twice	17	8.3	8	11.4	9	6.6
Monthly	8	3.9	3	4.3	5	3.7
Several times per month	30	14.6	11	15.7	19	14.0
Weekly	20	9.7	14	20.0	6	4.4
Several times per week	10	4.9	8	11.4	2	1.5
Satisfied with sex frequency*						
Much less often than liked	23	13.1	10	17.5	13	11.0
Less often than liked	28	16.0	15	26.3	13	11.0
Often as would like	101	57.7	27	47.4	74	62.7
Somewhat more often than liked	10	5.7	2	3.5	8	6.8
Much more often than liked	13	7.4	3	5.3	10	8.5
Importance of sex* **						
Not at all	109	53.7	20	30.3	89	65.0
Somewhat	38	18.7	7	10.6	31	22.6
Moderately	28	13.8	15	22.7	13	9.5
Very	16	7.9	14	21.2	2	1.5
Extremely	12	5.9	10	15.2	2	1.5
Sexual partnerships* **						
No sexual partners	129	61.7	29	40.3	100	73.0
Partner/spouse only	52	24.9	25	34.7	27	19.7
Casual only	9	4.3	5	6.9	4	2.9
Partner/spouse and casual	19	9.1	13	18.1	6	4.4
Partner knows is HIV-positive	66	85.7	35	85.4	31	86.1
Knows partner's serostatus	60	77.9	31	75.6	29	80.6

Note. Total *N* = 209, Men *N* = 72, Women *N* = 137. Chi-square tests of significance. Percentages may not sum to 100% because of rounding
* $p < .05$, ** $p < .01$, *** $p < .001$

were more than twice as likely as older men to indicate that sex was not important to them (65% and 30%, respectively). Over one third of older men with HIV felt sex was either very (21%) or extremely important (15%), a much greater share than older women with HIV (2% and 2%, respectively). Almost three quarters of women reported having no sexual partners compared with 40% of their male counterparts. Older men with HIV were more likely to report partner/spouse, casual, or both spouse and casual sexual partners (35%, 7%, and 18%, respectively) than older women (20%, 3%, and 4%, respectively). There were no significant gender differences in the proportions reporting that their sexual partners knew their HIV status (86%) or that they knew their sexual partner's serostatus (78%).

Reasons for Sexual Inactivity by Site and Gender There were no significant differences between older people with HIV in South Africa and those in Uganda in reported reasons for sexual inactivity in the past year (see Table 4.4). Forty-three percent reported that their HIV status interfered with being sexually active. The most highly endorsed reason for not being sexually active, however, was that the older person with HIV was not interested in sex (59%), while 9% said that their partners were not interested in sex. By gender, there were several significant differences in reasons for sexual inactivity. Older women with HIV were significantly more likely to say they were not interested in sex (69%) compared to older men (38%). Older men with HIV were significantly more likely to say their partner was not interested in sex (20%) compared to older women (3%). Older men were also more likely to report not being sexually active because of an emotional problem their partner had (6%), compared to less than 1% of older women with HIV. Last, older women with HIV were more likely to say they had not been sexually active because a child or other family member would disapprove of them having sex (7%), while none of the older men with HIV endorsed that reason.

Condom Use and Reasons for Not Using Condoms Older people with HIV in South Africa were more likely to consistently use condoms compared to their peers in Uganda (see Table 4.5). Regarding using condoms with a partner/spouse, 58% of older people with HIV in Uganda reported "never" and 6% reported "rarely" using condoms. In South Africa, all participants having sex with a partner or spouse reported using condoms at least some of the time. The vast majority of older South African people with HIV reported "always" or "usually" using a condom with a partner/spouse (79% and 13%, respectively), compared to 27% and 6%, respectively, of older people with HIV in Uganda. When it came to casual partners, condom use was somewhat more frequent; 17% of older people with HIV in Uganda always used condoms with casual partners and 33% usually did, still less often than their South African peers (71% and 21%, respectively). When asked why they might not use a condom, older people with HIV in South Africa were more likely to say they needed affection or they thought their partner did not want to use a condom (10% and 8%, respectively) compared to older Ugandans (2% and 2%, respectively). Older people with HIV in Uganda were more likely to say they might not use a condom if they were intoxicated (drunk or high) compared to their South African peers (8% and 2%, respectively). There were no significant gender differences in the likelihood of condom use. Regarding reasons for not using a condom, the only significant gender difference was that older men were more likely to forgo condoms because they "really wanted sex" (15%) compared to older women (2%).

Multivariate Analyses on Sexual Activity and Condom Use

Sexual Activity in the Past Year Age was negatively associated with being sexually active in the past 12 months (OR = 0.90, 95% CI [0.83, 0.97]; see Table 4.6). Every year of greater age was associated with 10% lower odds of being sexually active. Older people with HIV who were married had 15 times greater odds of being sexually active (95% CI [4.4, 52.4]). Older people with HIV who felt sex was important (vs. not at all important) had 24 times greater odds of being sexually active (95% CI [7.1, 82.8]). Naming one's HIV status as a reason for sexual inactivity was associated with 80% lower odds of being sexually active (OR = 0.22 [0.08, 0.62]). Female gender, the number of comorbid conditions, depression, loneliness, other reasons

Table 4.4 Reasons for sexual inactivity and sexual problems among older adults with HIV in South Africa and Uganda by site and gender

	Total		South Africa		Uganda	
	N	%	*N*	%	*N*	%
Because HIV-positive	90	43.3	45	41.7	45	45.0
Not interested in sex	122	58.7	57	52.8	65	65.0
Partner not interested in sex	18	8.7	8	7.4	10	10.0
Health problems/limitations	26	12.5	17	15.7	9	9.0
Partner health/limitations	11	5.3	7	6.5	4	4.0
Emotional problems	14	6.7	5	4.6	9	9.0
Partner emotional problems	5	2.4	3	2.8	2	2.0
Child/family wouldn't approve	10	4.8	4	3.7	6	6.0
Friends wouldn't approve	2	1.0	0	0.0	2	2.0
Religious: sex out of marriage	0	0.0	0	0.0	0	0.0
Sex is painful	2	1.0	2	1.9	0	0.0
Grieving	13	6.3	10	9.3	3	3.0
Want to avoid STD	3	1.4	1	0.9	2	2.0
Lack of privacy	5	2.4	2	1.9	3	3.0
Have not had an opportunity	18	8.7	13	12.0	5	5.0
	Total		**Men**		**Women**	
	N	%	*N*	%	*N*	%
Because HIV-positive	90	43.3	31	43.7	59	43.1
Not interested in sex***	122	58.7	27	38.0	95	69.3
Partner not interested in sex***	18	8.7	14	19.7	4	2.9
Health problems/limitations	26	12.5	12	16.9	14	10.2
Partner health/limitations	11	5.3	4	5.6	7	5.1
Emotional problems	14	6.7	3	4.2	11	8.0
Partner emotional problems*	5	2.4	4	5.6	1	0.7
Child/family wouldn't approve*	10	4.8	0	0.0	10	7.3
Friends wouldn't approve	2	1.0	0	0.0	2	1.5
Religious: sex out of marriage	0	0.0	0	0.0	0	0.0
Sex is painful	2	1.0	0	0.0	2	1.5
Grieving	13	6.3	2	2.8	11	8.0
Want to avoid STD	3	1.4	1	1.4	2	1.5
Lack of privacy	5	2.4	3	4.2	2	1.5
Have not had an opportunity	18	8.7	8	11.3	10	7.3

Note. Total $N = 209$, South Africa $N = 108$, Uganda $N = 101$. Men $N = 72$, Women $N = 137$. Chi-square tests of significance. Percentages may not sum to 100% because of rounding
* $p < .05$, ** $p < .01$, *** $p < .001$

for sexual inactivity, and research site were not associated with the odds of being sexually active in the final model. The significant factors explained 73% of the variance in sexual activity in the past year.

Table 4.5 Condom use and reasons for non-use among older adults with HIV in South Africa and Uganda by site and gender

	Total		**South Africa**		**Uganda**	
	N	%	*N*	%	*N*	%
Use condom spouse/partner***						
Never	19	23.8	0	0.0	19	57.6
Rarely	2	2.5	0	0.0	2	6.1
Sometimes	5	6.3	4	8.5	1	3.0
Usually	8	10.0	6	12.8	2	6.1
Always	46	57.5	37	78.7	9	27.3
Use condom casual partner*						
Never	2	10.0	0	0.0	2	33.3
Rarely	1	5.0	0	0.0	1	16.7
Sometimes	1	5.0	1	7.1	0	0.0
Usually	5	25.0	3	21.4	2	33.3
Always	11	55.0	10	71.4	1	16.7
Reasons not to use condom						
With spouse/regular partner	17	8.1	6	5.6	11	10.9
Really want sex	13	6.2	7	6.5	6	5.9
Really need affection**	13	6.2	11	10.2	2	2.0
With very sexy/attractive person	5	2.4	1	0.9	4	4.0
Partner says doesn't want to	9	4.3	4	3.7	5	5.0
Think partner doesn't want to*	11	5.3	9	8.3	2	2.0
Think STD risk low	1	0.5	1	0.9	0	0.0
I feel depressed	1	0.5	0	0.0	1	1.0
I am drunk or high*	10	4.8	2	1.9	8	7.9
	Total		**Men**		**Women**	
	N	%	*N*	%	*N*	%
Use condom spouse/partner						
Never	19	23.8	13	30.2	6	16.2
Rarely	2	2.5	1	2.3	1	2.7
Sometimes	5	6.3	3	7.0	2	5.4
Usually	8	10.0	4	9.3	4	10.8
Always	46	57.5	22	51.2	24	64.9
Use condom casual partner						
Never	2	10.0	2	14.3	0	0.0
Rarely	1	5.0	1	7.1	0	0.0
Sometimes	1	5.0	1	7.1	0	0.0
Usually	5	25.0	4	28.6	1	16.7
Always	11	55.0	6	42.9	5	83.3
	Total		**Men**		**Women**	
	N	%	*N*	%	*N*	%
Reasons not to use condom						
With spouse/regular partner	17	8.1	4	5.6	13	9.5

(continued)

Table 4.5 (continued)

Really want sex***	13	6.2	11	15.3	2	1.5
Really need affection	13	6.2	7	9.7	6	4.4
With very sexy/attractive person	5	2.4	2	2.8	3	2.2
Partner says doesn't want to	9	4.3	3	4.2	6	4.4
Think partner doesn't want to	11	5.3	5	6.9	6	4.4
Think STD risk low	1	0.5	1	1.4	0	0.0
I feel depressed	1	0.5	0	0.0	1	0.7
I am drunk or high	10	4.8	6	8.3	4	2.9

Note. Total $N = 209$, South Africa $N = 108$, Uganda $N = 101$. Men $N = 72$, Women $N = 137$. Chi-square tests of significance. Percentages may not sum to 100% because of rounding
* $p < .05$, ** $p < .01$, *** $p < .001$

Consistent Condom Use with a Partner/Spouse A number of factors were associated with consistent condom use in bivariate analysis (younger age, fewer comorbidities, lower depressive symptoms, greater HIV stigma, lower positive affect and life satisfaction, having sex with a casual partner, and partners not saying no to condom use). However, in the final model, the only significant factor was one's partner saying they did not want to use a condom, which predicted 98% lower odds of consistent condom use (OR = 0.02, 95% CI [0.01, 0.42]; see Table 4.7). The regression model explained 62% of the variance in consistent condom use.

Discussion

We found that older adults living with HIV in Uganda and South Africa generally report sexual activity consistent with previous research in sub-Saharan Africa, but study participants in the two countries differed from each other in certain areas. Older people with HIV in South Africa were more likely than those in Uganda to report having sex in the past year. Nearly three quarters of older people with HIV in Uganda reported having no sexual partners, compared with 56% in South Africa. Yet older people with HIV in Uganda were significantly more likely than those in South Africa to report having sex as often as they liked and less likely to report having sex more often than they would like. Almost two thirds of older people with HIV in Uganda said sex was not important at all, compared with 45% in South Africa, but 8% of those in Uganda said sex was extremely important, compared with none in South Africa.

Gender differences reflect the consensus in the literature (Freeman & Anglewicz, 2012; Mojola et al., 2015; Peltzer et al., 2010; Rosenberg et al., 2017): men attached greater importance to sex. Men were about twice as likely as women to report sexual activity, but less likely to be satisfied with the frequency of sex, preferring to have sex more often. One in eight men, in the combined sample, reported having more than one sexual partner, whereas no women reported more than one.

Table 4.6 Logistic regression on being sexually active in the past 12 months for older adults with HIV in South Africa and Uganda

	r	*B*	S.E.	*p* value	Odds	95% CI
Age	−.24**	−.111	.041	.006	.90	[.83, .97]
Female	−.32**	−.641	.655	.327	.53	[.15, 1.90]
Married	.47**	.635	.655	.000	15.09	[4.35, 52.35]
Number comorbidities	−.20**	.127	.774	.379	.89	[.70, 1.15]
CES-D	−.17*	.049	.050	.324	1.05	[.95, 1.16]
Loneliness	−.24**	−.248	.162	.127	.78	[.57, 1.07]
Sex important	.56**	3.186	.627	.000	24.20	[7.08, 82.77]
Not interested	−.36**	−.892	.563	.114	.410	[.14, 1.24]
Partner not interested	.21**	1.666	.934	.075	5.29	[.85, 33.05]
Family disapproval	−.14*	−2.649	1.422	.062	.07	[.01, 1.15]
No opportunity	.20**	−.190	.861	.825	.83	[.15, 4.47]
HIV status	−.21**	−1.503	.522	.004	.22	[.08, .62]
Site	−.19**	−1.030	.702	.142	.36	[.09, 1.41]

Note. Pairwise correlations ($N = 209$). Listwise $N = 202$. Model X^2 (13) = 156.35. Nagelkerke $R^2 = .727$

* $p < .05$, ** $p < .01$, *** $p < .001$

Reasons for sexual inactivity did not differ significantly by site. Many older people with HIV said they were not interested in sex—seven out of ten women and four out of ten men—and sizable proportions of both men and women cited their HIV status. This finding may be due in part to wanting to avoid transmitting HIV to a sexual partner. In multivariate analysis, sexual activity had a strong positive association with being married and feeling that sex was important and a negative association with age and naming HIV status as a reason to avoid sex. This is consistent with the findings of Chirinda and Zungu (2016) in South Africa. Unlike some previous research, however, the present study did not find a significant association between health and sexual activity (Chirinda & Zungu, 2016; Lindau et al., 2007; Negin et al., 2016).

The difference in HIV stigma scores between the two sites is notable. Average stigma score in Uganda was less than half that in South Africa, echoing findings by Mugisha et al. (2018) that HIV stigma has faded in Uganda. The difference in stigma is plausibly a factor in the greater disclosure of HIV status between partners in Uganda, where nearly all respondents said they and their partners knew each other's status, compared with somewhat lower proportions in South Africa.

Greater disclosure of HIV status did not translate into more condom use in Uganda, however. While older people with HIV in South Africa overwhelmingly said they always or usually used condoms with their spouse or regular partner, only one third of those in Uganda did. It is possible that many of the couples in Uganda were both living with HIV, because most respondents there said they had contracted HIV from their spouse. In South Africa, older people with HIV were equally likely to identify their spouse or a casual partner as the source. Condom use with casual partners in Uganda was more common than with regular partners, but still far lower

Table 4.7 Logistic regression on usually/always using condom with regular partner for older adults with HIV in South Africa and Uganda

	r	B	S.E.	p value	Odds	95% CI
Age	−.29**	−.098	.059	.093	.91	[.81, 1.02]
Number comorbidities	−.49**	−.347	.238	.145	.71	[.44, 1.13]
CES-D	−.23**	.066	.096	.491	1.07	[.89, 1.29]
Sowell Stigma Scale	.56**	−.010	.080	.899	.99	[.85, 1.16]
PANAS positive affect	−.22*	.141	.106	.182	1.15	[.94, 1.42]
Life satisfaction	−.30**	−.371	.255	.146	.69	[.42, 1.14]
Sex with casual partner	.22*	1.472	1.099	.180	4.36	[.51, 37.55]
Partner says no condom	−.30**	−3.76	1.479	.011	.023	[.01, .42]
Site	−.62**	−2.558	2.726	.348	.08	[.01, 16.22]

Note. Pairwise correlations ($N = 209$). Listwise $N = 79$. Model X^2 (9) = 45.20. Nagelkerke $R^2 = .620$
* $p < .05$, ** $p < .01$, *** $p < .001$

than among the older people with HIV in South Africa. Even in Uganda, these levels of condom usage are higher than has been found among older adults in sub-Saharan Africa generally (de Walque & Kline, 2011), although older people with HIV tend to have more consistent condom use than those who are HIV-negative (Matlho et al., 2019; Mojola et al., 2015; Rosenberg et al., 2017).

Reasons for forgoing condoms varied widely. In Uganda, the top reasons were sex with one's regular partner/spouse, being drunk or high, and really wanting sex. In South Africa, the top reasons were really needing affection, thinking one's partner did not want to use a condom, really wanting sex, and having sex with one's partner/spouse. Comparing genders, men were most likely to say they really wanted sex or really needed affection, and women were most likely to say they were with their partner/spouse or that their partner didn't want to use a condom. In the multivariate analysis, consistent condom use with a spouse or regular partner was negatively associated with the partner saying no.

Limitations

The use of cross-sectional data prevents us from making causal inferences about the relationships between sexual activity, condom use, and various factors. The samples that provided data for the current analysis represent only two countries in sub-Saharan Africa, and these findings may not be generalizable to all older people with HIV living in this region. Our findings are based on self-report of sexual activity, sexual problems, and condom use and may be subject to recall or reporting bias. In addition, differences noted between Ugandan and South African older people with HIV are partially attributable to differences in geographic location (rural, periurban, urban) and/or the level of economic development and healthcare systems. Finally, the numbers of sexually active older adults in these samples are small, especially when assessing gender differences.

Conclusion and Implications

As reflected in our data, a substantial minority of older adults living with HIV are sexually active. The inclination to refrain from sexual activity because one has HIV deserves further exploration and may be due to a number of potentially overlapping factors, including fear or unwillingness to disclose one's HIV serostatus due to stigma, concerns about infecting others with HIV, and traumatization after acquiring HIV through sexual contact (Kaida et al., 2015). Considering that being sexually active is associated with greater psychological well-being (Brennan-Ing et al., 2021; Burnes et al., 2017; Dean et al., 2013; Edwards & Coleman, 2004), reducing barriers to sex due to one's HIV serostatus warrants attention.

These findings underscore the need for continued secondary HIV prevention efforts among people with HIV, including older adults. These data predate the widespread adoption of treatment as prevention against the spread of HIV, with studies finding that people with HIV with undetectable viral loads are highly unlikely to pass on the virus through sexual contact (Eisinger et al., 2019). Pre-exposure prophylaxis (PrEP) as an HIV prevention strategy is becoming more available in sub-Saharan Africa and could help further reduce the spread of HIV. PrEP is especially useful in situations when the partner with HIV does not have a well-controlled viral load, when condom use is difficult due to issues like erectile dysfunction, or when condom negotiation is problematic (Irungu & Baeten, 2020; O'Malley et al., 2019; Li et al., 2020). However, older adults are not currently a priority population for PrEP uptake efforts in sub-Saharan Africa. Many older adults in the region may have not heard of PrEP, but when made aware of it, some have shown willingness to use it (Olilo et al., 2019; Ware & Ajonina, 2021).

What is clear is that sexual health among older adults in this region should be addressed in clinical settings in order to reduce HIV incidence and support quality of life for older people in sub-Saharan Africa, including those with HIV.

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Chapter 5
“Ask Those Who Are Ahead About a Buffalo”: Well-being of African Grandparents with HIV

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Contents

Sub-Saharan Africa continues to be the region of the world most profoundly affected by HIV/AIDS. Of the estimated 20.7 million people with HIV in the region (UNAIDS, 2020), close to 3 million are aged 50 or older (Autenrieth et al., 2018). As a result of multigenerational or skip-generation households, it is common for older adults to be living with younger children in countries of sub-Saharan Africa (United Nations, 2019). Older adults are frequently involved in grandchild care in Africa, and although much is known qualitatively about grandparents who are caring for grandchildren orphaned by or living with HIV (Chazan, 2014; Kasedde et al., 2014; Rutakumwa et al., 2015; Schatz & Seeley, 2015), quantitative information on the impact of caring on grandparents who are themselves HIV positive is scarce.

Gerontological frameworks, such as successful aging, activity theory, and gerotranscendence, suggest that grandparenthood has a positive impact on well-being (Havighurst, 1961; Rowe & Kahn, 1997; Tornstam, 1996). Caring for grandchildren is physically, emotionally, socially, and cognitively engaging, and such engagement is linked to better outcomes for older people. Abundant research supports the positive impact of grandchild care. In the Berlin Aging Study, a 20-year longitudinal study of adults aged 70 and older, grandparent caregivers had a 37% chance of living longer when compared to noncaregiving grandparents and nongrandparents (Baltes & Mayer, 2001). Grandparenthood provides purpose in older age while at the same time combating isolation and loneliness; recent findings suggest loneliness is as damaging to longevity as obesity (Bruce et al., 2019). Additionally, grandparent caregiving has been associated with a reduction in depressive symptoms (Sheppard & Monden, 2019) or no association with depression (Ardington et al., 2010).

In contrast, caregiver stress frameworks, such as the stress process model, stress and coping model, and resiliency model of family stress, adjustment, and adaptation, would posit that grandparenthood stress has a negative impact on psychological well-being (Lazarus & Folkman, 1984; McCubbin et al., 1996; Pearlin, 1999). Many studies have not found robust evidence that grandparent status is positively associated with well-being. In fact, Small and colleagues’ meta-analysis (2019) reported that negative associations with psychological well-being were found for older adult caregivers in sub-Saharan Africa in the majority of the 81 articles. In Europe, Di Gessa et al. (2020) found that positive psychological well-being outcomes were seen only in first-time grandmothers, not grandfathers, and only for those whose daughters were the parents. In the United States, greater depressive symptomology was reported by grandparent caregivers compared with grandparent noncaregivers in a nationally representative sample of over 10,000 grandparents (Blustein et al., 2004) and in a longitudinal study of grandmothers (Musil et al., 2011).

In the Kenyan Grandparents Study, a longitudinal study of grandparents over the age of 60, Ice et al. (2012) reported that grandparent caring was associated with greater stress when compared to that of grandparents without caring responsibilities. In South Africa, Nyirenda et al. (2015) found that although older adult caregivers living with HIV were in better physical health when compared to noncaregivers, declines were seen over time, and 69% of caregivers reported poor psychological well-being. In Uganda, grandparent caregivers reported considerable stress, psychological distress, and experiences of HIV stigma in qualitative interviews (Matovu & Wallhagen, 2020; Rutakumwa et al., 2015; Ssengonzi, 2007).

Conceptual Model

Based upon the inconsistency of the aforementioned literature and the dearth of studies specific to grandparent caregivers living with HIV, we proposed a conceptual framework (see Fig. 5.1) for this study based on the stress process model (Pearlin, 1999) and past empirical work on the association of stress and coping on well-being in older adults living with HIV (Porter et al., 2017; Porter et al., 2019). The stress process model posits that caregiving is a stressor that negatively impacts psychological well-being, positioning stressors within a structural context of social inequality that results in health inequality (Pearlin et al., 2005). Moreover,

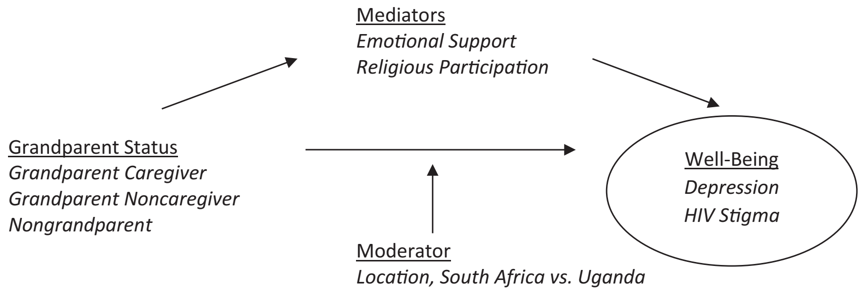

Fig. 5.1 Conceptual model of grandparent stress and psychological well-being

differences in social and economic capital and access to resources result in geographic inequity (Pearlin et al., 2005).

Psychological well-being constructs in our model are measures of depression, as previously discussed, and perceived HIV stigma, found to have a negative impact on psychological well-being in older adults living with HIV (Porter et al., 2017; Porter et al., 2019). Grandparent caregivers in Africa may experience multiple stigmas from ageism, their own HIV status, and the HIV status of the children they are caring for (Lindsey et al., 2003; Matovu & Wallhagen, 2020; Small et al., 2019). Critical covariates include sociodemographic characteristics (e.g., age, gender, marital status, financial strain) and health status (e.g., number of comorbid conditions).

Pearlin and Bierman (2013) hypothesized that coping resources, namely, cognitive and emotional strategies, help to reduce the adverse impact of stress on well-being, thus mediating this relationship. Coping constructs in our model include perceptions of availability and adequacy of emotional support and religious participation. Social-emotional support has been associated with greater psychological well-being in grandparent caregivers in the United States (Smith et al., 2015), has been shown to mediate the impact of depression for African American grandmother caregivers (Whitley et al., 2016), and has been reported as a positive coping strategy for Ugandan grandparent caregivers (Matovu & Wallhagen, 2020). In Kenya, Ice et al. (2012) found that multigenerational households engender emotional support that buffers the negative impact of grandparent caregiver stress. Yet in a literature search of 81 articles, emotional support was found notably lacking for caregivers in many sub-Saharan countries (Small et al., 2019).

Similarly, coping via religious attendance and spiritual practice may provide social support via community participation as well as existential support to emotionally and cognitively process living with serious illness (Brennan, 2004). Spirituality was found to mediate the stress process in a large study of older adults living with HIV ($N = 640$) in the United States (Porter et al., 2017; Porter et al., 2019) and Canada (Rueda et al., 2014). Religious participation and beliefs have been reported as a positive coping strategy for grandparent caregivers in South Africa (Dobin-MacNab et al., 2016; Small et al., 2019) and Uganda (Matovu & Wallhangen, 2020).

Study Purpose and Hypotheses

This study of older adults living with HIV in sub-Saharan Africa aims to enhance our current understanding of the role of grandparent caregiver stressors and coping in psychological well-being. A deeper understanding of how grandparent status impacts depression and perceived HIV stigma may aid in the development of new clinical diagnostic and screening tools and allow us to assess underlying factors that may explain well-being in this population. Moreover, this study will help to fill the gap in the knowledge base on the unique stressors and resilience of grandparent caregivers living with HIV themselves. This study (a) investigates the association between grandparent caregiver status and psychological well-being (e.g., depression and HIV stigma); (b) evaluates various coping resources as mediators between the association of grandparent status and psychological well-being; and (c) evaluates geographic site location as a moderator between the association of grandparent status and psychological well-being.

It is hypothesized that due to caregiver stress, grandparent caregiving will be negatively associated with psychological well-being among those living with HIV in sub-Saharan Africa. Further, coping resources are hypothesized to mediate, or buffer, this negative association. Last, it is hypothesized that there are significant geographic location differences in psychological well-being outcomes. Ugandan participants are expected to have poorer psychological well-being outcomes when compared to those living in South Africa, where there is much greater access to and availability of social grant programs (i.e., disability grants and old-age pensions; Ralston et al., 2019; Satumba et al., 2017).

Multiple covariates associated with psychological well-being in this study include age, gender, marital status, health status, and financial strain. While older age is negatively correlated with depression in grandparent caregivers (Musil et al., 2011), grandmotherhood may correlate with better psychological well-being when compared to grandfatherhood (Di Gessa et al., 2020). Lower socioeconomic status and more compromised health status are correlated with greater rates of depression in people with HIV (Brennan et al., 2009; Havlik et al., 2011). Marriage or partnership may be protective of psychological well-being via emotional support but may also correlate with conflict (Hayslip et al., 2019).

Method

Data Source

This study used data from the Research on Older Adults with HIV (ROAH) Africa project, the first comprehensive survey to provide detailed information on psychosocial issues affecting the HIV/AIDS population aged 50 and older (Brennan-Ing et al., 2016; Negin et al., 2016). Adults living with HIV aged 50 and older ($N = 208$) were recruited in two areas of Uganda (one rural and one peri-urban) and from an adult antiretroviral therapy clinic in central Johannesburg, South Africa. A quantitative interviewer-administered survey was used to collect information on demographics, mental health, physical health, social networks, HIV treatment experience, treatment adherence, health-related quality of life, and sexual behavior. Each in-person one-on-one interview was approximately 1–1.5 h long. Written informed consent was obtained.

The study in Uganda was approved by the Science and Ethics Committee of the Uganda Virus Research Institute and the Uganda National Council for Science and

Technology. The study in South Africa was approved by the institutional review board of the University of New England and the Human Subjects Ethics Committee of the University of the Witwatersrand.

Study Sample

The study sample had a mean age of 59 and included 100 older adults living with HIV in Uganda (48%) and 108 (52%) living in South Africa; the majority (66%) were female. Of the total, 42% identified as grandparent caregivers, 48% identified as grandparent noncaregivers, and 10% did not report grandchildren. Marital status was closely split, with 34% reporting being partnered, which included those married and in plural marriages or co-habitating; 35% reporting being widowed; and 31% reporting being single, which included those divorced and separated. Thirty-one percent reported financial need due to their HIV, and 78% regularly attended religious services. Participants reported an average of three comorbidities in addition to HIV.

Measures

Psychological Well-being This study used two continuous dependent variables to measure psychological well-being.

Depressive symptomatology was measured with the abbreviated ten-item version of the Center for Epidemiologic Studies Depression Scale (CES-D-10; Andersen et al., 1994). Participants were asked ten questions pertaining to their experiences over the last 7 days. The 4-point response categories were: none of the time (less than 1 day or not at all), a little of the time (1–2 days), some of the time (3–4 days), or most of the time (5–7 days). Responses were coded such that higher scores indicated greater depressive symptomatology and were then summed to obtain a total depression score with a range of 0–30. Cronbach's alpha for the ten items was .72, indicating good internal consistency reliability. The CES-D-10 scale has been favorably tested in people living with HIV in Uganda ($\alpha = 0.92$; Natamba et al., 2014) as well as in South Africa ($\alpha = 0.69–0.89$; Baron et al., 2017).

HIV stigma was measured with the 13-item Sowell Stigma Scale (Sowell et al., 1997). Responses were summed to obtain a total score with a range of 13–52; higher scores indicate greater perception of HIV stigma. Cronbach's alpha for the 13 items was .75, indicating good internal consistency reliability. The Sowell Stigma Scale was developed in women living with HIV in the southern United States and has been validated for use with older adults living with HIV (Emlet, 2005), but not in Africa to our knowledge.

Grandparent Status The primary independent variable in this study is grandparent status. Participants were asked whether they had any grandchildren or great-grandchildren (yes = 1; no = 0). If yes, they were asked whether they are currently caring for a grandchild, great-grandchild, or child from another family (yes = 1; no = 0). Responses were dichotomously coded into three groups: grandparents currently caring for a child ("carers"), grandparents not currently caring for a child ("noncarers"), and nongrandparents.

Mediating Variables Coping resources were measured using two variables. Emotional support was asked with two questions with Likert-type responses. The first asked about availability: "How about if you needed emotional support such as someone to talk to or help you make a big decision, do you have someone that you could count on to help you?" The 4-point scale options were recoded such that a higher score represented better support: all/most of the time (coded as 4), some of the time (3), only occasionally (2), or not at all (1). The second asked about adequacy: "In the past year how much more emotional support did you need?" The 4-point scale options were as follows: a lot more (coded as 1), some more (2), a little more (3), or I got all that I needed (4). A sum score of these two questions measured total emotional support.

Regular religious participation was asked by "Do you regularly attend or participate in religious services?" and coded as yes = 1 and no = 0.

Individual Characteristics Age in years was measured as a continuous variable. Gender was measured as a dichotomous variable (female = 1; male = 0).

Marital status was a categorical variable that was recoded into three dummy variables for analysis. Partnered (yes = 1; no = 0) represented people who were married, were cohabitating, were a co-wife, or had multiple wives. Widowed (yes = 1; no = 0) represented those widowed. Single (yes = 1; no = 0) represented those who were single, divorced, or separated.

Health status was measured as a continuous variable by a sum of the number of self-reported comorbid medical conditions in addition to HIV. Twenty-five comorbidities were provided in a check-off list with an additional open-ended blank for "other."

Financial need was asked by: "Have you ever needed financial help because of HIV/AIDS?" and measured as a dichotomous variable. Responses were coded as follows: "yes I currently need help" coded as yes = 1; "no, I have never needed help" coded as no = 0; or "not now, but I have in the past" coded as no = 0.

Moderator Variable Site was coded as South Africa = 1 and Uganda = 2.

Analytic Strategy

This cross-sectional study used several steps for data analysis. Descriptive statistics were first analyzed for the full sample, then stratified into three groups by grandparent status (grandparent carer, grandparent noncarer, and nongrandparent), and then stratified by site (South Africa and Uganda). Second, differences in study variables based on grandparent status variables and site were tested for statistical significance using *t*-tests for continuous variables and either chi-square analysis for categorical variables or Fisher's exact test in variables with cell frequencies below 5. Third, hierarchical models were tested using ordinary least squares (OLS) linear regression for each of the dependent psychological well-being variables. Regressions used a listwise deletion by dropping individuals with any missing data for a final total sample of $N = 184$.

With regard to HIV stigma, Model 1 was unadjusted to examine the relationship between the Sowell Stigma Scale and grandparent carers and noncarers, compared with nongrandparents as the reference group. Model 2 adjusted for the coping resources, emotional support, and religious participation. Model 3 adjusted for the number of comorbidities and financial strain. Model 4 adjusted for demographic variables (e.g., age, gender, and marital status). Model 5 adjusted for the site location. In Model 6 the potential moderating effects of location were evaluated using the centered, multiplicative terms of (a) Site × Comorbidities and (b) Site × Financial Need (Aiken et al., 1991).

With regard to depressive symptoms, Model 1 was unadjusted to examine the relationship between the CES-D-10 score and grandparent carers and noncarers, compared with nongrandparents as the reference group. Model 2 adjusted for the coping resources, emotional support, and religious participation. Model 3 adjusted for sociodemographic and health covariates (e.g., age, gender, marital status, number of comorbidities, and financial need). Model 4 adjusted for the site location.

In models evaluating stigma and those evaluating depression, potential mediation variables were tested using the calculation for the Sobel test, an interactive calculation tool for mediation tests (Preacher & Leonardelli, 2001; Sobel, 1982). SPSS software version 27 was used to analyze the data. Significance levels were set at $p < .05$.

Results

Descriptive Statistics

Of the 208 older adult participants living with HIV, 42% were grandparent carers, 48% grandparent noncarers, and 10% were not grandparents (see Table 5.1). Those caring for grandchildren were more likely to be female (77%), widowed (46%), and live in Uganda (59%). Participants scored an average of 9.8 on the CES-D-10 scale with scores ranging from 0 to 21. Participants scored an average of 34.8 on the Sowell Stigma Scale with scores ranging from 29 to 52. Participants scored an average of 5.8 for adequate and available emotional support with scores ranging from 2 to 8.

Grandparent carers were vulnerable when compared to noncarers and to nongrandparents. Carers reported a significantly higher average number of comorbidities than noncarers and nongrandparents (4.1 vs. 2.7 vs. 1.9, respectively), scored higher on the CES-D-10 depression scale (11.2 vs. 9.1 vs. 7.3, respectively), and reported greater financial need due to their HIV (42% vs. 23% vs. 19%, respectively).

Table 5.1 Grandparent status differences in ROAH Africa (2013, Age 50+, $N = 208$)

Variable	Full sample $N = 208$		Grandparent caregivers $n = 88$ (42%)		Grandparent noncaregivers $n = 99$ (48%)		Nongrandparents $n = 21$ (10%)		Comparison statistic
	N	*%*	**n**	*%*	**n**	*%*	**n**	*%*	
Gender									$\chi^2 = 8.83$, $p = .01$
Male	71	34%	20	23%	42	42%	9	43%	
Female	137	66%	68	77%	57	58%	12	57%	
Marital status									
Partnered/ married	70	34%	24	27%	35	36%	10	48%	$F = 11.18$, $p = .02$
Widowed	73	35%	40	46%	31	32%	2	9%	
Single/ divorced	65	31%	24	27%	32	32%	9	43%	
Site location									
South Africa	108	52%	36	41%	55	56%	17	81%	$F = 12.03$, $p = .002$
Uganda	100	48%	52	59%	44	44%	4	19%	
Need financial help because of HIV									
Yes	65	31%	37	42%	23	23%	4	19%	$F = 8.92$, $p = .01$
Do you regularly attend religious services?									
Yes	155	78%	75	87%	66	69%	14	78%	$F = 8.99$, $p = .009$
	M	***SD***	***M***	***SD***	***M***	***SD***	**M**	**SD**	
Age (50–77)	59.53	7.04	59.61	6.77	59.97	7.39	57.10	6.27	$F = 1.46$, $p = .23$
# Comorbid (0–5)	3.21	3.03	4.09	3.18	2.70	2.88	1.95	2.01	$F = 7.36$, $p = .001$
CES-D Scale (0–21)	9.79	6.17	11.22	6.02	9.06	6.43	7.29	3.95	$F = 4.95$, $p = .008$
Sowell Stigma Scale (29–52)	34.82	14.56	32.24	14.07	35.48	14.80	42.52	12.93	$F = 4.58$, $p = .01$
Emotional support (2–8)	5.81	1.32	6.06	1.35	5.66	1.30	5.43	1.17	$F = 3.03$, $p = .05$

However, compared to noncarers and nongrandparents, grandparent carers had access to or utilized better coping resources, scoring lower on the Sowell Stigma Scale (32.2 vs. 35.5 vs. 42.5, respectively) and reporting higher levels of emotional support (6.1 vs. 5.7 vs. 5.4, respectively). Carers were also more likely to participate in religious services when compared to noncarers and nongrandparents (87% vs. 69% vs. 78%, respectively).

Table 5.2 presents demographic and covariate variable differences by site. Of the 208 participants, 52% of participants were in South Africa and 48% in Uganda. The South African participants, when compared to those in Uganda, were more likely to be grandparent noncarers (51% vs. 44%), female (72% vs. 58%), and single (including those divorced or separated; 40% vs. 22%). The Ugandan older adults living with HIV were vulnerable when compared to those in South Africa, as they were significantly more likely to be grandparent carers (52% vs. 33%), widowed (45% vs. 25%), and in need of financial help because of HIV (51% vs. 12%). They reported a higher number of comorbidities (5.3 vs. 1.2) and scored higher on the CES-D-10 depression scale (12.2 vs. 7.5). However, participants in Uganda also reported greater attendance at religious services (85% vs. 70%), scored higher on having adequate and available emotional support (6.2 vs. 5.5), and scored lower on the Sowell Stigma scale (20.7 vs. 47.9).

Unadjusted Model Analysis

Two unadjusted linear regression models, shown in Tables 5.3 and 5.4, were estimated using two of the three grandparent status variables, grandparent carer and noncarer. These analyses yielded a statistically significant relationships between HIV stigma and grandparent carer ($\beta = -.03$, $p = .009$) and between depression and grandparent carer ($\beta = .029$, $p = .01$). Grandparent carers score 9 points lower on the stigma scale, but 4 points higher on the depression scale compared to nongrandparents (see Table 5.1).

HIV Stigma: Hierarchical Regression and Moderation Analyses

To evaluate perceived HIV stigma, six hierarchical regression analyses were estimated and presented in Table 5.3 beginning with the unadjusted Model 1 above. Model 2 adjusted for coping resources and yielded statistically significant negative relationships between stigma and grandparent carers ($\beta = -.27$, $p = .03$), emotional support ($\beta = -.17$, $p = .02$), and religious participation ($\beta = -.16$, $p = .03$). Model 3 adjusted for health and wealth, yielding statistically significant negative relationships between stigma and emotional support ($\beta = -.19$, $p = .001$), comorbidities ($\beta = -.58$, $p < .001$), and financial need ($\beta = -.11$, $p = .05$), while all other variables fell out of significance. Model 4 adjusted for demographic variables (e.g., age,

Table 5.2 Site differences in ROAH Africa (2013, Age 50+, $N = 208$)

Variable	Total $N = 208$		South Africa $n = 108$ (52%)		Uganda $n = 100$ (48%)		Comparison statistic
	N	***%***	***n***	***%***	***n***	***%***	
Grandparent status							
Grandparent caregiver	88	42%	36	33%	52	52%	$F = 12.03, p = .002$
Grandparent noncaregiver	99	48%	55	51%	44	44%	
Nongrandparent	21	10%	17	16%	4	4%	
Gender							
Male	71	34%	30	28%	42	42%	$\chi^2 = 4.41, p = .04$
Female	137	66%	78	72%	59	58%	
Marital Status							
Partnered/married	70	34%	37	35%	33	33%	$F = 34.84, p < .001$
Widowed	73	35%	27	25%	46	45%	
Single/divorced/separated	65	31%	43	40%	22	22%	
Need financial help due to HIV							
Yes	64	31%	13	12%	51	51%	$\chi^2 = 36.33, p < .001$
Do you regularly attend religious services?							
Yes	155	78%	70	70%	85	85%	$\chi^2 = 6.45, p = .01$
	M	***SD***	***M***	***SD***	***M***	***SD***	
Age (50–77)	59.5	7.04	58.26	6.08	61.03	7.82	$t(207) = -2.87, p = .005$
# Comorbidities (0–5)	3.21	3.03	1.22	1.05	5.34	3.00	$t(207) = -13, p < .001$
CES-D-10 Scale (0–21)	9.79	6.17	7.52	4.22	12.24	6.94	$t(207) = -6, p < .001$
Sowell Stigma Scale (29–52)	34.82	14.56	47.86	4.97	20.69	5.55	$t(207) = 37, p < .001$
Emotional support (2–8)	5.81	1.32	5.49	1.04	6.16	1.50	$t(207) = 37, p < .001$

gender, partner status), yielding statistically significant negative relationships between stigma and emotional support ($\beta = -.16, p = .003$), religious participation ($\beta = -.12, p = .04$), and comorbidities ($\beta = -.54, p < .001$) and positive association with female gender ($\beta = .12, p = .05$). Model 5 adjusted for the site location, yielding a negative association between stigma and location ($\beta = -.97, p < .001$) as the sole statistically significant variable remaining in the model. Specifically, participants in Uganda reported lower stigma. R^2 in the full model increased from .09 to .88.

Table 5.3 Results of hierarchical regression analyses for variables predicting HIV stigma ($N = 208$)

	Model 1				Model 2				Model 3				Model 4			
	B	SE B		β	B	SE B		β	B	SE B		β	B	SE B		β
Grandparent status[a]																
Grandparent caregiver	−9.08	3.43	**	−0.31	−7.84	3.68	*	−0.27	−1.54	2.93		−0.05	−1.25	2.94		−0.04
Grandparent noncaregiver	−5.83	3.39		−0.20	−6.85	3.63		−0.24	−4.08	2.84		−0.14	−3.18	2.81		−0.11
Coping variables																
Emotional support					−1.86	0.77	*	−0.17	−2.03	0.60	**	−0.19	−1.78	0.60	**	−0.16
Religious participation					−5.41	2.46	*	−0.16	−3.28	1.93		−0.09	−4.00	1.91	*	−0.12
Mediator variables																
Number of comorbidities									−2.80	0.29	***	−0.58	−2.63	0.29	***	−0.54
Need financial help									−3.55	1.82	*	−0.11	−3.07	1.83		−0.10
Demographic variables																
Age													−0.15	0.12		−0.07
Female													3.78	1.93	*	0.12
Partnered[b]													−0.35	2.11		−0.01
Widowed[b]													3.66	1.95		−0.12
Site location																
R^2		0.03				0.09				0.45				0.48		
Adjusted R^2		0.03				0.07				0.43				0.46		
F for Δ in R^2		3.76	*			4.53	**			25.4	***			17.1	***	

	Model 5				Model 6			
	B	SE B		β	B	SE B		β
Grandparent status[a]								
Grandparent caregiver	0.47	1.45		0.02	0.74	1.41		0.02
Grandparent noncaregiver	−0.12	1.39		−0.01	−0.35	1.35		−0.01

	Model 5				Model 6			
	B	SE B		β	B	SE B		β
Coping variables								
Emotional support	0.36	0.31		0.03	0.35	0.30		0.03
Religious participation	−1.30	0.95		−0.04	−1.19	0.92		−0.03
Mediator variables								
Number of comorbidities	0.17	0.18		0.04	−1.52	0.87		−0.10
Need financial help	1.66	0.92		0.05	0.36	0.45		0.02
Demographic variables								
Age	−0.04	0.06		−0.02	−0.02	0.06		−0.01
Female	1.05	0.96		0.03	0.73	0.94		0.02
Partnered[b]	0.91	1.04		0.03	0.46	1.02		0.01
Widowed[b]	−0.46	0.97		−0.01	−0.89	0.95		−0.03
Site location	−28.11	1.18	***	−0.97	−12.72	0.72	***	−0.88
Moderating variables[c]								
Financial need x Site					0.84	0.44		0.05
Comorbidities x Site					2.43	0.84	**	0.12
R^2		0.88				0.88		
Adjusted R^2		0.87				0.87		
F for Δ in R^2		112	***			105	***	

[a] Grandparent status was represented as three dummy variables with nongrandparent serving as the reference group

[b] Marital status was represented as three dummy variables with single serving as the reference group

[c] Moderation variables were centered at their means in Regression 6

*$p < .05$ **$p < .01$ ***$p < .001$

Table 5.4 Results of hierarchical regression analyses for variables predicting depression ($N = 208$)

	Model 1				Model 2				Model 3				Model 4			
	B	SE B		β	B	SE B		β	B	SE B		β	B	SE B		β
Grandparent status[a]																
Grandparent caregiver	3.67	1.44	**	0.29	3.89	1.57	**	0.31	1.27	1.37		0.10	1.23	1.37		0.10
Grandparent noncaregiver	1.52	1.43		0.12	1.77	1.55		0.14	0.84	1.31		0.07	0.77	1.31		0.06
Coping variables																
Religious participation					0.35	1.05		0.02	−0.63	0.89		−0.04	−0.69	0.90		−0.05
Emotional support					−0.85	0.33	**	−0.18	−0.76	0.28	**	−0.16	−0.81	0.29	**	−0.18
Demographic variables																
Age									−0.06	0.05		−0.07	−0.07	0.05		−0.07
Female									0.94	0.90		0.07	1.00	0.91		0.08
Partnered[b]									−0.30	0.98		−0.02	−0.33	0.99		−0.02
Widowed[b]									0.06	0.91		0.01	−0.02	0.92		−0.002
Number of comorbidities									0.99	0.13	***	0.48	0.92	0.17	***	0.45
Need financial help									2.65	0.85	**	0.20	2.54	0.87	**	0.19
Site location													0.69	1.11		0.06
R^2		0.04				0.07				0.38				0.38		
Adjusted R^2		0.03				0.05				0.34				0.34		
F for Δ in R^2		4.67	**			3.41	**			10.97	***			9.97	***	

[a] Grandparent status was represented as three dummy variables with nongrandparent serving as the reference group

[b] Marital status was represented as three dummy variables with single serving as the reference group

*$p < .05$ **$p < .01$ ***$p < .001$

In Model 6 the potential moderating effects of location were evaluated using the centered, multiplicative terms of (a) Site × Comorbidities and (b) Site × Financial Need. When the Site x Financial Need interaction term was tested (results not shown), it had a positive association with stigma (β = .06, $t = 2.03$, $p = .04$), whereas comorbidities became nonsignificant (β = .03). When that interaction term was removed and the Site x Comorbidities interaction term was tested, the latter also had a positive moderating effect on stigma (β = .13, $t = 2.98$, $p = .003$), whereas financial need became nonsignificant (β = .05). When both interaction terms were included, depicted in Table 5.3, Model 6 (see Fig. 5.2 for stigma interaction plot), Site x Comorbidities had a positive moderating effect on stigma (β = .12, $t = 2.89$, $p = .004$), whereas Site x Financial Need had a nonsignificant moderating effect on stigma (β = .05, $t = 1.91$, $p = .06$). Site location by itself remained significant (β = −.88, $t = -17.71$, $p < .001$). In other words, there was a stronger association between comorbidities and stigma among Ugandan older people with HIV compared to those in South Africa, while their South African peers experienced greater stigma on average overall.

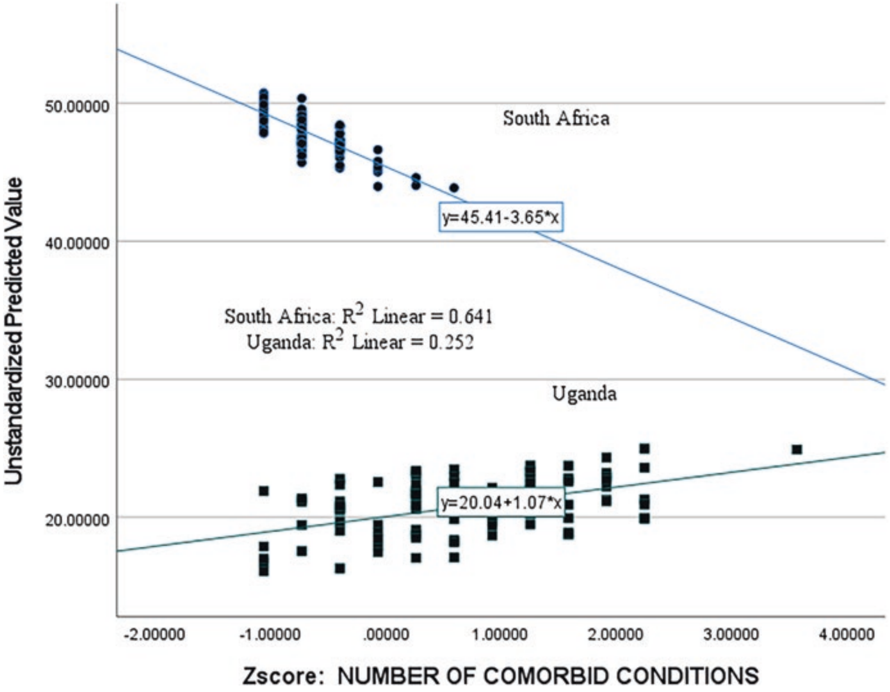

Fig. 5.2 Site moderation of stigma interaction plot

Depression: Hierarchical Regression

To evaluate depression, four hierarchical regression analyses were estimated and presented in Table 5.4 (see Unadjusted section above for Model 1). Model 2 adjusted for coping resources and yielded a statistically significant positive relationship between depression and grandparent carers (β = .31, *p* = .01) and a negative relationship with emotional support (β = −.18, *p* = .01). Model 3 adjusted for demographic covariates, yielding a statistically significant negative relationship between depression and emotional support (β = −.16, *p* = .007) and positive associations between depression and comorbidities (β = .48, *p* < .001) and financial need (β = .20, *p* = .002), while the carer variable fell out of significance. Model 4 adjusted for site location, yielding the same statistically significant relationships as Model 3 (emotional support β = −.18, *p* = .006, comorbidities β = .45, *p* < .001, and financial need β = .19, *p* = .001). R^2 in the full model increased from .07 to .38.

Mediation Analyses

There was evidence that the number of comorbidities and financial need mediated depression relative to grandparent caregiving, with a higher number of comorbidities and greater financial need associated with greater levels of depressive symptomology. Table 5.5 shows the Sobel mediation test results (Preacher & Leonardelli, 2001; Sobel, 1982). As required for mediation, the impact of grandparent status on depression and on stigma was significantly reduced when the effects of financial need and comorbidities were considered. A Sobel test was conducted and found partial mediation by financial need (*z* = 2.04, *p* = .04) and full mediation by comorbidities in the model evaluating depression (*z* = 2.85, *p* = .004).

Discussion

The aim of this study was to contribute to the research literature by investigating the relationship between stressors and psychological well-being in older grandparents living with HIV in Africa. Moreover, this chapter sought deeper understanding of the role of grandparent caregivers, as the existing literature has concentrated on grandparents caring for children with HIV and not grandparents living with HIV themselves. The present study contributes to the literature by demonstrating that for older adults living with HIV in sub-Saharan Africa, the positive association of grandparent caregiving with depression is mediated by health comorbidities and financial need. That is, the increased vulnerability to depression found in grandparent caregivers is explained by poorer health (i.e., greater number of comorbidities) and partially explained by greater financial strain. These relationships between

Table 5.5 Sobel mediation test results

	Mediators	
	Financial	Comorbidities
Dependent variable:	CES-D-10	
IV -> Mediator[a]	0.24	2.09
IV -> Mediator (SE_a)	0.11	0.70
Mediator -> DV[b]	4.59	1.13
Mediator -> DV (SE_b)	0.88	0.12
IV -> DV[c]	2.57	1.31
Z Sobel test statistic	2.04	2.85
Standard error	0.54	0.83
Two-tailed *p*-value	0.04	0.004
Mediation	Partial	Full

Note. SE_a Standard error of the relationships between the IV and the mediator variable; SE_b Standard error of the relationship between the mediator variable and the DV; DV[b] Dependent variable

[a] Unstandardized path coefficient from IV to the mediator variable

[b] Unstandardized path coefficient from mediator variable to the DV

[c] Unstandardized path coefficient from IV to DV (total effect)

comorbidities and financial need and grandparent caregiving may in fact be bidirectional. Caregiving stressors may result in, or exacerbate, comorbidities and greater financial need, for example, if they need to share their old-age pension with more people in the household. Having more comorbidities may predispose an older adult to engage in caregiving as an alternative to, or in addition to, physically demanding labor like farming (Small et al., 2019).

The differences in the association of stigma with grandparent caregiving involvement among older people with HIV were explained by geographic location and comorbidities in the current sample. Participants in South Africa experienced much higher levels of stigma whether or not they were grandparent caregivers. Comorbid conditions had a stronger association with stigma among Ugandan participants compared to their South African peers. Financial need also had a stronger association with stigma among Ugandan participants compared to those in South Africa in one multivariate model (Site x Financial Need interaction), but became marginally nonsignificant with the addition of the Site x Comorbidities interaction term in the final model. The availability of a universal old-age pension in South Africa since the 1980s (and for some groups, before that date) may help to explain why financial need may have been a stronger factor in Uganda with regard to stigma (Armstrong & Burger, 2009; Ralston et al., 2019; Satumba et al., 2017). The social grant system in Uganda, supported by international donor assistance, commenced in 2011 in a limited number of districts and is still being implemented (Kidd, 2016). In addition to differences in coverage, the younger age eligibility in South Africa (60 years and older) means there is wider access than in Uganda, where age eligibility may be

65 years or older or over 80 years depending upon the district (Gelders & Athias, 2019).

The study also explored whether coping resources, namely, emotional support and religious attendance, provided a stress process buffer; results of this study did not support the proposed hypothesis. Greater emotional support was significantly associated with lower depressive symptomology; however, a mediation effect was not found. Religious attendance showed no significant association with depression; this may be related to the lack of variability in the sample, given that the importance of religion was universal. Both emotional support and religious attendance were significantly associated with lower perceptions of perceived stigma; however, the significance did not hold up once site was included in the model. Social support has been found to negatively correlate with HIV stigma in Uganda (Takada et al., 2014), so it may be that emotional support and religious participation are acting as proxies for social support in this study.

These findings suggest that while grandparent caring does come with additional stressors, as was reported in Ice et al. (2012) and Nyirenda et al. (2015), those stressors can be fully buffered by additional resources to reduce comorbid conditions and financial need. Contrary to findings by Lindsey et al. (2003) in which caregivers reported heightened stigma, these findings suggest that caregiving was protective against perceived stigma, perhaps via aforementioned bidirectional or reciprocal caregiving whereby emotional support is made available through the presence of grandchildren and/or by their adult children.

How well a society cares for its elders has been used as a measure for morality; what should it measure when those elders are the caregivers themselves? Although informal caregiving may be given freely by grandparents, it is certainly not a zero-sum transaction. Grandparent caregivers pay for these stressors with capital and often at the expense of their own health and well-being. Yet the position of grandparents in society and the potential role of bidirectional caregiving are largely defined by culture (Aldwin, 2007; Nyirenda et al., 2015; Small et al., 2019). Contrary to resource-rich countries, the lack of infrastructure, employment, and food security in countries in sub-Saharan Africa compounds layers of stressors upon older adults, especially those who are living with HIV. Yet here, where grandparent carers are more likely living in multigenerational households (Nyirenda et al., 2015), bidirectional or reciprocal caregiving may be why we see grandparent caregiver resilience, including more robust emotional support and lower perceptions of stigma (Dolbin-MacNab et al., 2016; Rutakumwa et al., 2015; Small et al., 2019).

In addition, subjective measures of psychological well-being may be skewed by cultural differences in cognitive appraisal of grandchild caregiving (Aldwin, 2007). The AIDS epidemic repositioned grandparents in sub-Saharan Africa as primary child caregivers due to the “missing generation” of parents who died from AIDS, which resulted in 12 million orphans (Small et al., 2019). Even in households without a missing generation, a large percentage of African grandparents provide care to grandchildren (He et al., 2020). In South Africa, this was often the result of circular migration and separation of families that was encouraged by apartheid legislation;

parents were forced to urban areas for employment, while children remained in rural homes (Schatz & Seeley, 2015).

These findings should be considered in light of several limitations. First, this study is cross-sectional; therefore, causal inferences from regression analyses cannot be made. Caregiving over time may lead to different outcomes, as was found in the longitudinal study of grandparents in Kenya where carers reported better health than noncarers cross-sectionally, but over time carers reported poorer outcomes (Ice et al., 2012). In addition, Baker and Silverstein (2008) found that depression was highest upon the onset of the caregiving role but decreased over time. Psychological well-being among grandparent carers may be impacted by a complexity of relationship factors (Tompkins & Vander Linden, 2020).

In summary, we found significant differences in older adults with HIV by grandparent caregiving status, location of Uganda versus South Africa, adequacy and availability of emotional support, and health and financial status. Aging adults, especially those who are also caregivers and living with HIV, have a high risk of mental distress and poor physical health. Providing increased access to health care that includes better screening, monitoring, and treatment of comorbidities in older adults with HIV is recommended, especially in more rural and resource-poor areas. Despite the vulnerabilities found, grandparent caregivers exhibit resilience. Future longitudinal research is needed to elucidate and enhance these found strengths. Investing in policy and practices designed to financially stabilize grandparent caregiver families, while reducing multimorbidity, has long been needed. As expressed in the African proverb “ask those who are ahead about a buffalo” (*inyathi ibuzwa kwabaphambili*), grandparent caregivers are a vital resource who provide functional support as well as impart guidance to future generations (Makiwane et al., 2017).

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Chapter 6
Mental Health in Older People Living with HIV in Sub-Saharan Africa: State of the Art and Future Research Recommendations

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Contents

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Introduction

Sub-Saharan Africa represents the region with the largest number of older people living with HIV (4.5 million; Autenrieth et al., 2018; UNAIDS, 2019). Since the introduction of antiretroviral treatment (ART) in this region, substantial declines in the mortality of people with HIV have been observed, leading to a considerable increase in their life expectancy. HIV infection is now considered a chronic disease. But even if people with HIV now have a good life expectancy, older people receiving ART are at an increased risk of age-associated noncommunicable comorbidities, such as cardiovascular diseases, renal diseases, diabetes, cancer, and osteoporosis, as well as mental health disorders (Bendavid et al., 2012; Schouten et al., 2014).

In this context, based on the Rowe and Kahn definition, the possibility of "successful aging" (i.e., the absence of pathologies or risk factors in older adults) could be compromised (Rowe & Kahn, 1997). But this definition has long been debated and discussed as being too strict and failing to take the aging process into account (Martinson & Berridge, 2015). Interestingly, a multidimensional definition of successful aging considers that the presence of chronic diseases does not systematically lead to unsuccessful aging (Young et al., 2009). Psychological and social domains could compensate for physiological limitations (i.e., multiple chronic conditions) and allow individuals, even in the context of disease and disability, to experience a good quality of life (Young et al., 2009). This seems to be relevant in the context of HIV infection, as older people living with HIV experience a lot of complications in the physiological domain because of a compromised immune system, with the involution of the thymus,[1] ART side effects,[2] and polypharmacy[3] (Vance et al., 2011). In the United States, people living with HIV aged 56 to 65 without depression reported aging more successfully compared to both depressed people with HIV and depressed or not depressed counterparts without HIV with the same age range (Rooney et al., 2019).

Unfortunately, insufficient attention has been paid to mental health issues in older people living with HIV in low- and middle-income countries, particularly in sub-Saharan Africa. In that population, depression and cognitive impairment are among the three most common mental disorders, with depression being the most prevalent (Chibanda et al., 2014). These disorders have consequences on linkage to care and HIV response that should not be neglected. First, in middle-aged people with HIV, depression and cognitive impairment predict nonadherence to ART (Chibanda et al., 2014; Nakimuli-Mpungu et al., 2012). Second, these disorders are associated with poor health status overall, poor HIV outcomes (low CD4, detectable

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[1] The thymus assists in CD4+ cell maturation, whereas the HIV eliminates CD4+ cell.

[2] Some iatrogenic effects may be observed, depending on the ART molecules: anemia, leucopenia, peripheral neuropathy, toxicity of the central nervous system, sleep problems, insulin resistance, gastrointestinal disorders, lipoatrophy, and cardiovascular disease.

[3] Polypharmacy is a concern in older people with HIV. With advancing age, renal and hepatic systems work less well than before. So the processing and clearance of ART and medications treating other comorbidities become more difficult, with a possible impact on biological health and the onset of new comorbidities.

viral load, faster progression to AIDS), and mortality (Abas et al., 2014; Ayano et al., 2018; Chibanda et al., 2014; Mayston et al., 2012). As in the general population, depression is highly associated with suicide, the most significant associated risk, but one that is understudied in older people living with HIV (Kinyanda et al., 2012). Finally, depression and cognitive impairment impact daily activities and the quality of life in people with HIV, leading to unemployment, social isolation, stigmatization, and disability (Abas et al., 2014; Asangbeh et al., 2016; Chibanda et al., 2014; Endeshaw et al., 2014; Mugisha et al., 2016).

Addressing the mental health needs of older people living with HIV through screening and management is critical to accelerate progress toward the UNAIDS 95-95-95 targets in this region and to promote successful aging.[4] Hence, the purpose of this chapter is to provide a general overview of the morbidity experienced by older people living with HIV in sub-Saharan Africa, focusing first on depression and then on cognitive impairment. We also discuss implications for further research and recommendations.

Depression

Prevalence and Age Effects on Depression

The prevalence of depression in people living with HIV has already been reported in various publications but in samples including adults with a wide range of ages (18 years old and older). Data presenting the prevalence specifically in people living with HIV aged 50 or older are scarce. In South Africa, the prevalence of major depressive disorders was 14% among older people on ART for at least 1 year and was 15.5% for those not yet on ART or on ART for 3 months or less (Nyirenda et al., 2013). In Tanzania, a 16.6% prevalence of major depressive disorders was reported in older people living with HIV, of whom 95.5% were on ART (Kellett-Wright et al., 2020). In West Africa (Senegal and Côte d'Ivoire), a 17.9% prevalence of severe depressive symptoms was observed in older people with HIV on ART for at least 6 months (Bernard et al., 2020b). From a study in Uganda, the prevalence of depression among people with HIV aged 50–59, 60–69, and 70+ was 12.6%, 8.5%, and 7.4%, respectively, with no significant difference in comparison to older people without HIV (Mugisha et al., 2016).

Interestingly, in rural Uganda, a lower prevalence of probable depression was observed in older people with HIV on ART (aged 40 and above, mean age of 52 years old) compared to their counterparts without HIV (21.4% vs. 33.8%, respectively; Manne-Goehler et al., 2019). A trend of fewer depressive symptoms was also

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[4] In March 2021, the Joint United Nations Programme on HIV/AIDS (UNAIDS) Council adopted a new global strategy for ending AIDS by 2030. It is now recommended that 95% of people living with HIV know their HIV status, 95% of people living with HIV who know their HIV status are on ART, and 95% of the people living with HIV on ART have a reduced viral load.

observed in rural South African people living with HIV in comparison to people without HIV, where 82% of the participants were aged over 50 (Geldsetzer et al., 2019). These two last results are part of an emerging literature from sub-Saharan Africa reporting that people with HIV on ART do not have poorer mental health than those without HIV (see also Donald, 2017).

The prevalence of major depressive disorder or severe depressive symptoms observed in sub-Saharan Africa seems to be lower in Western countries. In the United States, severe depressive symptoms were observed in 28.2% of people living with HIV aged 56–65, of whom 94% were on ART (Rooney et al., 2019). In Portugal, among people living with HIV aged 50 years or older on ART for at least 6 months, 23.9% presented chronic anxiety or depression (Serrão et al., 2019). As explained by Manne-Goehler et al. (2019), this observation could suggest context-specific differences in the drivers of depression. Specifically, in low- and middle-income countries, in comparison to the general population, people living with HIV could benefit from the social and health system support offered in ART programs. Regular medical visits have the potential to identify chronic pathologies, such as hypertension, diabetes, hyperlipidemia, etc., earlier than in the general population. In health services that include a social service, patients can also benefit from support.

The aging experience for older people living with HIV in sub-Saharan Africa has not been well documented. Research from Western countries indicates that older people with HIV face a different life reality than those who are younger. Due to age, they could experience specific concerns about disclosure (Rosenfeld et al., 2016; Schatz et al., 2019) and higher stigma (Grov et al., 2010), but a recent publication observed a lower level of stigma in older people with HIV compared with younger ones (Emlet et al., 2015). They may also experience an uncertainty about the future, particularly about how HIV, aging, and long-term ART effects could interact and impact health (Rosenfeld et al., 2016). They also may be anxious about the unfamiliar nature of the aging process and fear discrimination and the risk of social isolation (Rueda et al., 2014). In addition, longtime survivors might have to face different problems compared to those diagnosed more recently: for example, confusion about surviving so long and mourning friends or family members lost to AIDS (Owen & Catalan, 2012). As observed in other chronic diseases (Clarke & Currie, 2009), the chronicity of the HIV disease and the increase in comorbidities with age could play a role in HIV-related depression. Noncommunicable diseases are also associated with depression (Pandey et al., 2019). Further studies are needed to better understand the reality of the aging experience in people with HIV living in sub-Saharan Africa to offer them more comprehensive mental health support.

Depressive Symptoms Presentation

Depression is not systematically evaluated in people living with HIV and is often underdiagnosed and undertreated (Abas et al., 2014). Depression could be difficult to diagnose due to its common symptoms with HIV (fatigue, sleeping problems, loss of appetite; Watkins & Treisman, 2012). People living with HIV, particularly older ones, also report somatic symptoms more easily than emotional or affective ones (Ngo et al., 2013). In addition, stigma around mental illness may be a barrier to diagnosis and care (Henderson et al., 2013). In rural Uganda, depressed people with HIV on ART (aged over 40) were more likely than individuals without HIV to report no symptoms over the past week in terms of feeling unhappy and worrying, blaming themselves, feeling hopeless, or falling asleep (Manne-Goehler et al., 2019). In West Africa, based on the CES-D scale, older people living with HIV reported mostly somatic symptoms, then depressive symptoms and negative affect, and fewer interpersonal deficits (Bernard et al. 2020b). Interestingly, in this study, the expression of depressive symptoms was also different between men and women, which is important information for clinicians. Compared to men, women reported more frequently the following symptoms: "being restless," "crying spells," "sadness," "not enjoying life," and that their life is a failure (Bernard et al., 2020b). Further studies are needed to better define the clinical profile of depressed older people with HIV living in sub-Saharan Africa, according to gender.

Factors Associated with Depression or Severe Depressive Symptoms

To limit the occurrence of depression in older people living with HIV, it is necessary to identify the profile of these depressed individuals. Indeed, identifying the associated factors will allow healthcare professionals to be able to more carefully monitor people with HIV who present such associated factors. To date, few data from sub-Saharan Africa are available in the literature. Even though no relationship was observed between HIV outcomes and severity of depressive symptoms, some sociodemographic factors, comorbidities, and psychosocial factors seem to be associated with the severity of depressive symptoms.

Age Effects

Some studies from different countries in sub-Saharan Africa evaluated age effects on the severity of depressive symptoms either when comparing two age groups (e.g., <40 and ≥40 years old) or by testing the association with regression analyses (age used as a linear variable or in different categories). The majority reported either no age effects (Bongongo et al., 2013; Chikezie et al., 2013; Gaynes et al., 2012; Nakimuli-Mpungu et al., 2011) or a significant association between depressive symptoms and younger age (Akena et al., 2012; Ngum et al., 2017; Seth et al., 2014), but these studies included a limited number of people living with HIV aged 50 or older (<14%, except in Nakimuli-Mpungu et al., 2011, where 47% were 40 or older) and people with HIV who were on ART or not. In Ghana, it was observed that older people with HIV experienced a higher level of stress but did not present a higher level of depression or anxiety (Oppong Asante, 2012). In rural Uganda, in ART-naïve people with HIV, those aged over 50 had a twofold risk of having severe depressive symptoms compared to those aged 18–30 (Kaharuza et al., 2006).

Other Sociodemographic Factors

In rural Namibia, among 147 people living with HIV on ART, being female and having a higher educational level appeared to be protective against depression (Kalomo et al., 2020). Yet in rural Uganda, it was reported that women both with and without HIV had a two-fold greater risk of reporting depressive symptoms in comparison to men (Manne-Goehler et al., 2019).

In West Africa, older people living with HIV with severe depressive symptoms were more likely to be unemployed (Bernard et al., 2020b). The condition of unemployment provides indirect information about income, and poverty is commonly associated with depression or severe depressive symptoms in middle-aged people living with HIV (mean age <45 years) living in sub-Saharan Africa (Berhe & Bayray, 2013; Kitshoff et al., 2012; Ngum et al., 2017). Unemployment acts as a stressor and could lead to difficulties with health expenses, particularly those related to comorbidities that tend to grow more numerous with aging. The impact of retirement on mental health should also be investigated in this population.

In rural Uganda, among women both with and without HIV, an inverse relationship was also observed between depression and wealth (Manne-Goehler et al., 2019).

Comorbidities

In West Africa, older people with HIV with severe depressive symptoms were more likely to be current or former tobacco smokers but were less likely to be overweight or obese (Bernard et al., 2020b). As observed in a large study in West African countries, middle-aged and older people with HIV (aged ≥40) were more likely to be regular smokers (Jaquet et al., 2009). In Western countries, in middle-aged people with HIV, associations between current cigarette smoking or nicotine dependence and severe depressive symptoms or major depression have been reported (Benard et al., 2007; Carmo Filho et al., 2013; Cropsey et al., 2016; Webb et al., 2007). As people with HIV who smoke might be vulnerable, it appears essential to screen depression in such patients.

As discussed in Bernard et al., (2020b), in people living with HIV, the association between BMI and severe depressive symptoms is not systematically explored, and there is no consensus (Kinyanda et al., 2011; Myezwa & Hancock, 2016; Nyongesa et al., 2019; Zoungrana et al., 2017). In West African social representations, HIV infection and mental illness are often associated with thinness. As a low BMI could be an indirect marker of either a loss of appetite or advanced disease, being overweight or obese may forestall judgments and questions and thus be protective against stigmatization and thus indirectly protective against stress and depressive symptoms. Further investigations are needed to explore this possibility.

Stigma and Psychosocial Factors

Stigma and stress are also concerns. Kalomo et al. (2020) reported that older people living with HIV who had a mental health issue developed double stigmatization (Nyirenda et al., 2013). In rural Namibia, HIV stigma was significantly associated with severe depressive symptoms, but high levels of resiliency seemed to be protective (Kalomo et al., 2020). Reduced stress related to HIV, particularly stigma, and the development of coping factors would be important ways to decrease depressive symptoms and help older people with HIV experience well-being and have a better quality of life. As described in the next section, psychotherapeutic interventions could help such individuals.

Hence, the determinants of depression in older people living with HIV are scarcely evaluated. Comparison within the literature is very limited since the majority of the studies did not focus specifically on this population. To better understand the determinants of depression in older people with HIV in sub-Saharan Africa, further studies are needed.

Psychotherapeutic Interventions

Although depression has deleterious effects on people living with HIV, it is a modifiable condition, and the management of depression in older people with HIV living in sub-Saharan Africa needs to be encouraged. The task-shifting approach, described below, is highly recommended by the World Health Organization to overcome the lack of mental health specialists in low- and middle-income countries (World Health Organization, 2008). This approach has emerged as a promising strategy to increase access to care and to treat depression in people living with HIV in this region (Kulisewa et al., 2019).

Evidence suggests that depression screening and interventions could be effectively conducted by non-mental health professionals (lay health workers) in sub-Saharan Africa, after appropriate training and supervision (Parcesepe et al., 2018; Pence et al., 2014; Wagner et al., 2016). In West Africa, a survey among HIV primary care staff revealed that the main barrier influencing task-shifting was a lack of training, but the staff was highly interested in leading a support group after training (Bernard et al., 2020c). Promising results have already been reported from a culturally sensitive psychotherapeutic intervention in Uganda that used task-shifting for middle-aged people living with HIV (Nakimuli-Mpungu et al., 2015) and from a group-based counseling intervention in South Africa (Petersen et al., 2014). For example, in Uganda, through eight sessions, people with HIV will learn how to develop positive coping skills, problem-solving skills, skills for coping with stigma and discrimination, and income-generating skills (Nakimuli-Mpungu et al., 2015). However, to our knowledge, no intervention study focusing on older people with HIV has been conducted. As HIV experience could be different according to age and as the oldest people with HIV are less likely than younger ones to be engaged in behavioral health treatment for depression (Moore et al., 2017), psychotherapeutic interventions need to be adapted to their specific needs.

Recommendations

Numerous gaps exist in our understanding of the identification and management of depressed older people living with HIV in sub-Saharan Africa. To guarantee the achievement of the 95-95-95 objectives and encourage successful aging in this population, screening and management of depression need to be integrated into the standard of care (Kulisewa et al., 2019). In this context, the authors recommend the following research priorities:

- *To examine the prevalence and the determinants of depression in older people living with HIV in sub-Saharan Africa.* In addition, the incidence and the impact of depression on HIV outcomes also need to be investigated. Longitudinal studies could be interesting to evaluate the onset and the trajectory of depressive symptoms. Due to the numerous scales used to evaluate depressive symptoms in the peer-reviewed publications, substantial variability in the measurements is observed in the literature. Efforts are needed to harmonize tools used (scales, number of items, cut-off points) and to evaluate their validity in the countries in this region.
- *To better understand the reality of the lives of older people with HIV in sub-Saharan Africa*. Causes of stress related to HIV (e.g., HIV-related stigma, disclosure concerns, issues with ART, physical changes), socioeconomic difficulties, and quality of life should be investigated specifically in this population. All these factors could negatively impact mental health. It is important for clinicians to be aware that the expression of depressive symptoms may differ from what is observed in the general population and may differ by gender, as these factors could complicate the diagnosis of depression.
- *To evaluate the feasibility, acceptability, and effectiveness of task-shifted psychotherapeutic interventions adapted to the specific needs of older people living with HIV*. These psychotherapeutic sessions would need to take into account specific problem areas, corresponding to the reality of their lives.

HIV-Associated Neurocognitive Disorders

According to Antinori's criteria, HIV-associated neurocognitive disorder (HAND) is sub-classified according to its severity as asymptomatic neurocognitive impairment (ANI), mild neurocognitive disorder (MND), or HIV-associated dementia

(HAD; Antinori et al., 2007). Despite widespread use of ART, the prevalence of HAND remains high (Cholewińska & Szymańska, 2009; Heaton et al., 2010; Vance et al., 2012), suggesting that neurological damage continues to occur. A recent meta-analysis reported estimated prevalence in middle-aged people living with HIV for each HAND type: ANI 26.2%, 95% confidence interval (CI) [20.7, 32.7], MND 8.5% [5.6, 12.7], and HAD 2.1% [1.2, 3.7] (Wei et al., 2020). While HAND has long been described, the cognitive profile of adults with HIV has evolved: motor dysfunction became less prevalent, whereas deficits in learning, memory, and executive functioning are reported to a greater extent (Heaton et al., 2011).

However, in the course of aging, an age-related cognitive decline is observed. Therefore, HAND could be aggravated, putting older people at higher risk for neurocognitive impairment than younger ones, as observed in Western countries (Cohen et al., 2015; Heaton et al., 2010; Wendelken & Valcour, 2012). The literature finds no consensus on independent additive or synergic effects of age and HIV status on cognition (Ances et al., 2012; Becker et al., 2011; Cysique et al., 2011; Seider et al., 2014).

Prevalence

There are few data in the literature about the prevalence of HAND in older people on ART in sub-Saharan Africa. In Tanzania, in older people with HIV (94% on ART), high prevalence of MND and HAD was reported, at 21.7% and 3.6%, respectively (Eaton et al., 2020). Another study in Tanzania, focusing on people with HIV aged over 50, also reported a high prevalence of HAND: 25.3% ANI, 18.2% MND, and 3.6% HAD (Flatt et al., 2021; Kellett-Wright et al., 2020). Based on their data at 1-year follow-up, incidence and reversibility appeared high (Flatt et al., 2021). Further studies need to confirm this. Even if prevalence was comparable to that observed in Western countries, the authors warned of the poor diagnostic accuracy of the two tools used in their study (i.e., the International HIV Dementia Scale [IHDS] and the Identification and Interventions for Dementia in Elderly Africans [IDEA] scale) for broadly defined HAND (Kellett-Wright et al., 2020).

Cognitive Profile

Among people with HIV on ART, HAND is mostly characterized by both cortical and subcortical features, with executive functioning and working memory being the most altered cognitive functions (Sacktor, 2018).

The literature has not specifically described the cognitive profile of older people living with HIV in sub-Saharan Africa. Both comorbidities and heterogeneity of clinical presentation present a challenge in screening for HAND. Identifying “pure” HAND could be difficult. Even if no consensus has been made in the literature, there are concerns that HIV could precipitate neurodegenerative processes, leading to Alzheimer's or Parkinson's disease (Cohen et al., 2015; DeVaughn et al., 2015; Milanini & Valcour, 2017). Vascular cognitive impairment could also overlap with the HAND profile (Cysique & Brew, 2019). In this context, some researchers question the accuracy of the diagnostic criteria (Saloner & Cysique, 2017). Studies on this topic need to be conducted in sub-Saharan Africa to identify the most appropriate tools and diagnostic criteria.

In the context of aging, screening of neurocognitive impairment appears to be necessary to document sudden cognitive deterioration in older people living with HIV.

Neuroimaging studies can also contribute to clarifying the mechanism involved in HAND in older people. A recent study conducted in Senegal reported good feasibility and acceptability of an MRI study with high-resolution scans in virologically suppressed older people with HIV compared to older people without HIV. This study revealed a high prevalence of cerebral alterations (i.e., global atrophy and severe white-matter hyperintensities) without showing a clear impact from HIV infection (Bernard et al., 2020a). As hypertension was highly prevalent in older people with HIV and associated with those alterations, further studies are also encouraged to describe the impact of cardiovascular disease on the brain in this specific population (Bernard et al., 2020a).

Factors Associated with Cognitive Impairment

To date in sub-Saharan Africa, determinants of HAND in older people living with HIV have scarcely been investigated.

Age Effects

In other studies carried out in sub-Saharan Africa, an association between older age and dementia or cognitive impairment has been reported among people with HIV, more than 90% of whom were on ART (Atashili et al., 2013; Sanmartí et al., 2020). A recent publication in Kenya reported a 1.06-fold risk of HAND per year of age among people with HIV ages 18–65 (Mohamed et al., 2020). Where studies showed no significant association (Debalkie Animut et al., 2019; Eaton et al., 2020; Kabuba et al., 2018; Yusuf et al., 2017), this might be due to age-adjusted norms and/or a limited proportion of people with HIV aged over 60 included in the sample.

In Western countries, studies on interactions between aging and HIV on cognitive function made no consensus (Cysique et al., 2011; Hardy & Vance, 2009). This could be a complex issue in which specific individuals' differences must be taken into account (e.g., genetic characteristics, addictions). Cysique et al. (2011) mentioned that some methodological issues could also influence the results: survivor bias for people with HIV with long-term infection, the age of the cohorts (not too old), and the fact that age is not often used as a continuous variable, limiting the possibility to assess its linear and nonlinear effects on neurocognitive performance (Cysique et al., 2011). Data in sub-Saharan Africa on this topic are needed.

Other Factors

In Tanzania, illiteracy, living alone, and being older at the time of HIV diagnosis were associated with symptomatic HAND (i.e., MND and HAD), whereas no association was observed with CD4 level, smoking, body mass index, or blood pressure (Eaton et al., 2020).

One study in South Africa reported no impact of ART or viral suppression on cognitive functioning (Asiimwe et al., 2020).

Major Difficulties in Cognitive Evaluation

Concerning the evaluation of HAND in sub-Saharan Africa, some challenges need to be taken into account.

Assessment of HAND is often impractical in routine clinical practice. Indeed, a formal diagnosis requires finding a deficit in two different neurocognitive domains; the cognitive function should be assessed by a comprehensive neuropsychological test battery administered by an experienced clinician or neuropsychologist (Kellett-Wright et al., 2020). In sub-Saharan Africa, the diagnosis of HAND is not based on standardized protocols; some authors used large neuropsychological battery tests, whereas others used the IHDS. Moreover, cognitive performance tests have been developed in Western countries where a large majority of the population has a high literacy level (Asiimwe et al., 2020) and therefore are not specifically adapted to local populations. Prevalence of HAND has been evaluated based on IHDS, but Kellett-Wright et al. (2020) found that this scale has a low accuracy when used to identify people with HAND. Even if we encouraged the use of a large comprehensive battery, it is crucial for both clinical practice and research that test accuracy be established with normative data (Wei et al., 2020), based on age and educational level, and adapted for cultural differences. In addition, health professionals need to be trained in the administration of neuropsychological tests.

Apart from the tests, some methodological issues need to be addressed to promote the reproducibility of results. Study participants should be well characterized in terms of CD4 level, viral load, and ART status. HIV subtypes could also affect the prevalence of HAND, particularly in sub-Saharan Africa (Sacktor et al., 2007). Although there is no consensus on the relationship between HIV subtypes and cognitive impairment (Belete et al., 2017; de Almeida et al., 2013; Santerre et al., 2019), some clades seem to be more pathogenic than others. In Uganda, a higher prevalence of dementia and lower psychomotor performance are shown in untreated HIV patients with subtype D compared to those with subtype A (Sacktor et al., 2009).

Finally, the diagnosis of opportunistic infections or neurologic or cardiovascular comorbidities needs to be assessed, since some of them impact cognitive functioning.

Cognitive Interventions

According to our knowledge, no studies have evaluated the impact of a cognitive intervention on HAND in sub-Saharan Africa. In Western countries, few studies have investigated cognitive training strategies in people living with HIV. But among the strategies evaluated, computerized cognitive training has been proposed to improve cognition in this population. Although the results are encouraging (improved daily life, mood, and quality of life), more studies are needed to establish treatment guidelines (Vance et al., 2019). A recent paper reported interesting results based on an individualized targeted computerized cognitive training in people living with HIV (Vance et al., 2021). In that study, even though HAND status was not changed directly by the intervention, speed of processing improved, in turn improving other cognitive domains.

Recommendations

Numerous gaps exist in our understanding of HAND in older people living with HIV in sub-Saharan Africa. The authors recommend the following research priorities:

- *To describe the prevalence of HAND and the cognitive clinical phenotype of older people with HIV in the region.* Identifying the most affected cognitive domains will allow (1) the development of a standardized HAND screening test battery and (2) a better understanding of the physiopathological process underlying HAND, particularly if neurodegenerative processes are involved.
- *To develop normative data, adapted according to age, gender, and educational level, as these are the main factors usually associated with cognitive impairment.* Accurate tools are urgently needed to evaluate and monitor the cognitive evolution of people with HIV, in both clinical practice and research. Regular screening of neurocognitive impairment in older people with HIV is necessary to document sudden cognitive deterioration.
- *To build longitudinal cohort studies with several follow-up points to better understand the course of HAND over time in older people with HIV in sub-Saharan Africa.* MRI studies could also be an important innovation to provide an in-depth description and understanding of the physiopathology of HAND in this region.

Conclusion

To guarantee the achievement of the UNAIDS 95-95-95 objectives and encourage successful aging in people living with HIV in sub-Saharan Africa, efforts are needed to integrate screening and management of mental health disorders, specifically depression and cognitive impairment, in the standard of care. Further studies are needed to build an in-depth description and understanding of the prevalence and determinants of depression and cognitive impairment, as these conditions may cause severe problems for patients' organization of care and follow-up. Finally, psychotherapeutic and cognitive interventions adapted to the specific needs of older people with HIV are important to ensure good quality of life and well-being.

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Chapter 7
"The Support Keeps Me Strong": Social Support Among South Africans Ageing with HIV

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Introduction

South Africa has the highest prevalence of HIV worldwide along with the highest proportion of people aged over 50 (older people) in Africa. Together with the world's largest HIV treatment programme (UNAIDS, 2019), these factors have resulted in an increasing proportion of adults ageing with HIV (Mojola et al., 2015). In South Africa, model simulations have estimated that HIV prevalence among those over 50 years of age will double over the next 30 years, with significant consequences for health care and social systems (Hontelez et al., 2011). In 2017, national estimates of HIV prevalence in the South African population over 50 years of age were 18.7% for women and 15.3% for men (Human Sciences Research Council, 2018). This is a marked increase from previous national prevalence data that showed that only 7.6% of adults over 50 years were infected (Zuma et al., 2016). In comparison, the estimate of HIV prevalence for the population over 50 in the United States is about 0.5% (Centers for Disease Control and Prevention, 2020). Health implications associated with ageing with HIV include multiple comorbidities, slower rates of ART response, swifter disease progression, and reduced life expectancy compared to individuals who are HIV negative (Munthree & Maharaj, 2010; Rohr et al., 2017).

Literature on ageing with HIV from high-income countries, where the HIV epidemic predominantly affects populations of men who have sex with men (MSM), highlights the triple stigma that people ageing with HIV experience: ageism, homophobia, and HIV-related stigma (Emlet, 2006b; Hart et al., 2013; Kia et al., 2020). The threat of these stigmas, combined with high mortality among men who have sex with men in the early part of the HIV epidemic, led to contracting social networks and a lack of social support for many of those ageing with HIV (Shippy & Karpiak, 2005a). This stigma has been associated with depression and isolation, sometimes with subsequent poor medication adherence (Stieber Roger et al., 2013) and poor reported quality of life (Nideröst & Imhof, 2016). In countries such as the United States, there are concerns that those ageing with HIV are largely dependent on formal care and support networks, at a time when these resources are becoming increasingly overburdened (Shippy & Karpiak, 2005b). There has been limited examination of social support available to people ageing with HIV in less well-resourced, particularly African, countries. Indeed, in the early years of the HIV epidemic, it was thought that older adults were more likely to be "affected by" rather than "infected" when considering HIV implications and burdens (Schatz & Ogunmefun, 2007). Early research in South Africa therefore focused particularly on the caregiving roles that older people play in a society where loss of life due to HIV was concentrated among young adults with dependent children (Chazan, 2014; Munthree & Maharaj, 2010; Schatz & Ogunmefun, 2007). More recently, there has been an interest in examining the experiences of older people as they themselves manage HIV infection, and a small body of research has examined these issues from across sub-Saharan Africa (de Klerk & Moyer, 2017; Harling et al., 2020; Mugisha et al., 2018; Nyirenda et al., 2012).

HIV has changed and will continue to change social fabrics and interactions; therefore, an understanding of the support available to older people ageing with HIV is needed, particularly in societies where there are limited or inadequate social security systems and where traditional familial support structures have previously been eroded (National Research Council, 2006). This lack of knowledge means that challenges, barriers, and social consequences are not understood and therefore cannot be addressed. This qualitative study examines social support experiences among South African older adults, aged 50 years and over, who are ageing with HIV.

Method

Qualitative semistructured interviews were undertaken in inner-city Johannesburg, South Africa: a region with high unemployment, poverty, and in-migration from rural areas and neighbouring African countries (Landau, 2005; Todes et al., 2010). The interviews were one component of a larger study that included both the interviews and a survey.

Participant Recruitment

Participants were recruited at an HIV treatment clinic located within a tertiary-level public hospital. An information session was provided to patients waiting in the queue to visit the HIV treatment centre. Interested participants who were eligible by virtue of being 50 years of age or older had a further opportunity to discuss the project with the fieldworker before agreeing to take part. There were no existing relationships between participants and researchers, and participants remained anonymous. Given the time required for interviews, those who agreed to participate were provided with a future date for their interview to be conducted at research offices close to the recruitment site. Participants were excluded from the study if they were visiting the hospital for a non-scheduled emergency visit or if they fell outside the age bracket.

Interview Process

Prior to the interviews, information and consent forms were completed in isiZulu, seSotho, or English according to the participants’ preference. Travel compensation of ZAR50 (approximately USD5) was provided to the interview participants to cover travel costs to the scheduled interview. There were also refreshments available.

Due to the nature of the study and the potential for participants to disclose physical and psychological harms, participants who disclosed intimate partner violence, distress related to social isolation, depression, or suicidal ideation were referred to an appropriate service through a detailed distress protocol. Interviews lasted approximately one hour, using a topic guide that was developed from key concepts emerging from the literature and that focused on four major issues: well-being, care giving/receiving, HIV care, and sexual well-being. In the section on care, we specifically focused on emotional, economic, and instrumental support. Participants were asked to comment on who provided it to them, whom they provided it to, and whether they felt they were receiving adequate support. This component of the interviews is discussed in this chapter.

A social anthropologist conducted the interviews with a fieldworker who assisted with recruitment and translation. The anthropologist is a British female with a PhD qualification who was able to communicate in basic isiZulu and who had previously worked on HIV in South Africa. The fieldworker was a tertiary-educated South African woman in her late 30s, fluent in both isiZulu and seSotho. Interviews were digitally recorded and then transcribed and translated by the interviewer and fieldworker.

Data Analysis

Analysis of the data was conducted by two researchers (MM and CM) through several key steps for qualitative data analysis, such as familiarisation, synthesis, and interpretation (Gale et al., 2013; Miles & Huberman, 1994; Ulin et al., 2005). Both content and thematic analyses were conducted.

Initially, familiarisation of data and transcripts occurred through reading the transcripts several times to ensure adequate understanding of the data (Miles & Huberman, 1994; Ulin et al., 2005). “Nodes” were developed in QSR NVivo for Mac 11.4.1, initially using the interview guide under themes of well-being, care giving and receiving, HIV care, and sexual well-being. Later in the analysis, nodes were developed inductively for recurring or otherwise identified themes. After coding, the data were reduced through the production of tables for node, case, and quotation comparison (Lee, 2014; Miles & Huberman, 1994; Ulin et al., 2005). Tables were constructed based on coding frequencies, usefulness of data, relevance of nodes, and quotations from each transcript.

Finally, the data were analysed and interpreted to determine key themes, differences, and similarities of experiences associated with ageing with HIV (Gopaldas, 2016). The analysis phase was conducted through frequent discussion between two of the authors (MM and CM). Throughout the coding, analysis, and writing, we reflected on the COREQ criteria to ensure rigor of the qualitative study (Tong et al., 2007).

Ethics Approvals

Ethics approval for the study was obtained from the University of the Witwatersrand (M130759) and the University of New England (HE13-131 01) Human Research Ethics Committees. Pseudonyms have been provided for each of the participants to preserve their anonymity.

Results

Fifteen interviews were conducted between September and October 2014 with eight female and seven male participants (Table 7.1). The majority of participants were aged between 60 and 64 years, all were parents, and many were grandparents. Given the age of the participants and the fact that many reported that their HIV disease manifested in a range of comorbidities, the majority were retired or currently not working. Among those still working, the most common occupations were low-skilled employment such as domestic work or driving. The participants in this study had experienced HIV beyond their own illness. Two-thirds indicated that members of their extended family, including spouses, children, and siblings, were either living with HIV or had died of AIDS. However, few reported specifically caring for AIDS orphans as a result.

There were several key demographic differences by gender. Male participants were more likely to be currently married than females, with a greater proportion of females reporting being divorced. Females were also more likely to report never having married and/or currently being single, while a number of men reported being both married and having an additional partner at the same time. Widows were more common than widowers in the sample, and widows and widowers were evenly spread across all ages. Government social grants were an important source of income for participants. The majority (9 of 15 participants) reported receiving a South African Old Age Pension, and one additional female participant noted that she was in the process of renewing her Disability Pension. Some participants did not provide specific information on the duration of their ART treatment, but among those who did, duration ranged from newly diagnosed (6 months) to long-term treatment (11 years).

Support from Children and Spouses

Overall, participants remarked on strong social support—all were vehement about not feeling isolated. These connections were largely within the nuclear family and particularly from their adult children, to whom all participants had disclosed their HIV status. In contrast, disclosure outside of the family was less common, and

Table 7.1 Participant attributes

Participant[a]	Sex	Age	Occupation	Relationship status	Pension	Children	Duration of treatment
Prince	M	60–64	Not working	Widower	Yes	Yes	6 months
Kabelo	M	55–59	Tavern owner	Married	Yes	Yes	8 years
Precious	F	65–69	Not working	Single	Yes	Yes	3 years
Thandeka	F	50–54	Not working	Divorced	Not discussed	Yes	4 years
Lerato	F	65–69	Not working	Widow	Yes	Yes	11 years
Buhle	F	60–64	Not working	Widow	Yes	Yes	Not specified
Siyabonga	M	65–69	Not working	Widower	Yes	Yes	Not specified
Dumi	M	60–64	Plumber	Married	Yes	Yes	8 years
Blessing	F	60–64	Not working	Widow	Yes	Yes	2 years
Luthando	F	60–64	Domestic worker	Married	No	Yes	Not specified
Zodwa	F	50–54	Domestic worker	Never married	No	Yes	5 years
Lungile	M	55–59	Truck driver	Married	Not discussed	Yes	6 years
Mandla	M	50–54	Driver	Married	Not discussed	Yes	Not specified
Sibusiso	M	60–64	Part-time work unspecified	Married	Yes	Yes	Not specified
Sibongile	F	50–54	Domestic worker	Divorced	Yes	Yes	8 years

[a]All names are pseudonyms allocated to participants during analysis

relying on nonfamily individuals for support was almost nonexistent. Lerato, a widowed pensioner with five adult children, explained this:

> I was told [by the clinic] to tell somebody, somebody who I trusted and somebody who would give me support. I told them that I've got five kids, so it's best that I tell my kids. I told my kids that I was HIV positive.

Thandeka told of her decision to tell her children about her HIV status after her diagnosis just over a decade ago. "My mother asked me what I was going to do, whether I was going to tell my kids or not. I said to my mum 'Yes, I'm going to tell them'. They even encourage me". For other participants, the decision about disclosure in the family was mediated by the diagnosis of a spouse. Sibusiso, a married man with five children, noted that he and his wife were diagnosed at much the same time. They made the decision to share their diagnoses with their family, but they preferred to keep this information private rather than discussing it more broadly in their community:

> People today! They tend to talk about other people, so I prefer not to tell people because they will go round spreading it. So if it's only known by myself, my wife and my kids … only us in the family, then I think that's better.

Despite the concerns articulated above, participants reported few worries about possible negative responses to HIV disclosure within their immediate families. Indeed, participants were more likely to be concerned about the impact that their diagnosis might have on their family. Sibongile said that she took her time telling her family about her diagnosis, to ensure that she could support them through the process of coming to terms with it:

> I didn't tell my kids immediately after finding out because back then I was really sick. So I decided to tell them later when I was feeling strong. Sometimes when you tell kids too soon, some of them commit suicide. They can drink poison and all of those things. So even though my kids are grown up now I didn't want them to feel that their mother was going to die anytime soon, so that's why I decided to keep it to myself a bit longer.

There were no differences in support from children based on the sex of their parent with HIV or marital status. Male participants were as likely to discuss having disclosed to their children as female participants, and they seemed to experience the same degree of close support enjoyed by women. Kabelo had two adult children and noted that they had been a significant support to him: "I really thank God for my two kids because we are really in this thing together".

Participants identified support from their children particularly relating to what we classified as "financial" and "practical or instrumental" support. This was manifest specifically through support and assistance with the medical requirements of living with HIV. Support from family members related to simple tasks such as reminding their parents to take treatment and providing financial assistance to attend treatment centres. Sibongile said, "My eldest daughter phones me to find out when I am going for check-ups and if I need money to go to the hospital", and Kabelo declared, "My daughter is always on my case about drinking my pills! She always brings the pills in front of me and then tells me to drink, and I do! Then I take the pills".

Instrumental non-HIV-specific support included domestic duties such as cooking and cleaning. Some participants mentioned support with bathing and shopping, such as Precious, who explained, "This one [daughter], she bathes me, she rubs me … all of this. They've got patience. They do everything for me". There were few in our study who did not mention support from children, and they tended to be those who were single and did not have living children to assist them. Overall, parents ageing with HIV expressed their gratitude for support provided by their children.

In contrast to the shared experience of support from their children, men and women had vastly different experiences of support from intimate partners. Many female participants discussed experiences of divorce or separation due to their husbands' infidelity as an explanation for a lack of partner support or noted that their partners had died. Buhle's husband had died of AIDS, and she seemed relieved to be out of an unhappy marriage, but she had not had an intimate partner's support since. She noted that "Since my husband passed away, I've not had a boyfriend or been with anyone else. So I'm not getting support from anyone".

Luthando, a married woman whose husband is also HIV positive, discussed HIV in her relationship and revealed, "We don't usually talk about it because we've just accepted it and moved on", but she did not explicitly speak about support that she might receive from her husband. Support from partners was evidently different for men, with a majority noting that they received support largely from a spouse or partner. Many alluded to their partner providing practical, domestic, and emotional support, as illustrated by Sibongile's discussion below of her continued caring role for her partner, despite her own HIV status:

> I'm still staying with the very same boyfriend who gave me this illness.… You know, so I said that I should help him out. …My boyfriend was very grateful to me for helping him.

Partner support was an important aspect of ageing for men in this study, as they rely heavily on their partner for instrumental and some degree of emotional support. Prince discussed his need for support when he said, "When you are my age you have to stay with a person, so that when you get sick or anything happens at least there is someone there to care for you". Support ranged from cooking, cleaning, and ironing to talking as well as the possibility of continued support through sickness.

Support from Other Family Members

Beyond children and spouses, we explored support within other familial relationships and from people outside the family, be they friends, individuals with shared interests, or fellow members of community or social groups. Among female participants, extended family was an important secondary source of support in ageing with HIV, specifically adult siblings and mothers to a lesser degree. Male participants were less likely to have support from their extended family. Sibusiso, a married part-time worker, explained that "I only told my close family that I was positive … In my house it's my secret". Only one male participant, Prince, mentioned extended family support—specifically that his sister sometimes cooked for him—but he noted that she had other responsibilities to older people through her work and therefore was not consistently available.

Women may have been more likely to speak of support from their extended family because fewer were married at the time of our interviews and therefore could not rely on the support of a spouse. Precious immediately identified her brothers as central to her ongoing happiness and support:

> I helped them with the money for school, and now that my daughters work, they also spoil me. I have four brothers. Two older. They spoil me. They buy me groceries, they ask me what I want. I've got a good family.

As discussed previously, another female participant, Thandeka, mentioned the important role that her mother played at the time of her diagnosis a decade ago and subsequently. When asked how she felt after receiving her positive HIV test results, she definitively stated, “I’ve never … I didn’t feel bad because I was with my mum, and my mum gave me good support”.

As with children, the majority of participants revealed that they received more support from extended family after disclosing their HIV status than they had before and particularly when they needed it most—“They say that if I am sick, they are also sick” (Sibongile). The significance of their support was evident through all interviews, with only one female mentioning a hesitance to ask family for support.

Support Outside of the Family

Disclosure of HIV status to individuals outside of the family—and therefore potential receipt of support—was markedly less prevalent. A number of participants spoke about not wanting to “bother” people outside of their family with their health issues. For example, Sibongile, a divorced domestic worker, mentioned that “My family will help me when they can but I don’t like being a bother to other people”. When discussing support outside of their family, a number of individuals mentioned that they were concerned about stigma and discrimination and therefore chose not to discuss their HIV status. Few explicitly mentioned experiences of ageism. Blessing, a widowed participant, was an exception, noting that HIV stigma and discrimination were exacerbated by her age and that this tempered her desire to disclose and seek support more broadly. She said:

> Even here at the hospital people pass judgement everywhere. They will look at you and say “How [exclamation of surprise], she is old but she has HIV”. And us as older people, we look at each other when we sit in the queue [for treatment] and think “Oh, that one is the same age as me”. And the young people will be looking at you too and thinking “Why would such an old lady have HIV?”

Within the clinic environment, participants talked of speaking with other patients while they waited for appointments, but most stated that they did not see one another outside of the clinic. Prince explained that fellow patients were not a source of support for him largely because they had no contact with one another once they left the clinic after their appointments. Situational proximity and a common experience of HIV were not sufficient to create supportive patient networks.

There were, however, a small number of examples of strong support from outside the family. In one interview, Precious discussed the relationship that she had with the family for whom she worked as a domestic worker for 14 years. The family had moved overseas but continued to call her weekly and had helped her build a house and given her additional financial support when needed. Blessing described a community group in her hometown that had provided her with support:

> There is a society that we've formed back at home with the women who've been married and now abstain [from sex]. In Rustenburg. So, in the society we have each other. In the years since my husband died, they've come and comforted me.

Four participants talked about their church as a significant source of support to them, although only two provided details. Luthando noted that the Zion Christian Church provided her with support, particularly through a group of older women in the church whom she met with regularly. Mandla also spoke of how important support in the church was for him, particularly before he started treatment and was experiencing stigma as a consequence of being visibly ill. He, however, focused on his relationship with God and was vehement about only seeking support from particular pastors:

> You know when I started to lose weight, people talked too much but I just … I used to talk to my God. Or I can go to church and talk to one of my pastors. And I choose which one, I don't just go to any pastor.

Although participants mentioned other community organisations that they frequented, most had never taken their HIV-related burdens to these groups due to their concern with maintaining privacy and avoiding potential judgement for their HIV status.

Caring for Others When You Need Support

Throughout the interviews, it was not uncommon for participants to snort with derision when asked about receiving support as they age with HIV. Many commented on the fact that they were still providing support to others despite their age, lack of financial resources, and ill health. Many participants had children who were not yet financially independent, and this was the main area in which they continued to support them. In particular, participants were likely to comment along the lines of "It's getting more and more now. The older you get, the more responsibilities you get" (Lungile) or "I'm the one who looks after a lot of people. My kids, and my grandchildren, and my great-grandchildren…" (Buhle). For many, the financial support they provided to their families was a consequence of receiving the South African Old Age Pension, although a number noted that their families still struggled financially.

Men in this study tended to have only immediate family and children as dependents; they rarely provided for grandchildren or other family members. Men most commonly provided financial support and viewed this as their sole responsibility within the family unit, with Sibusiso noting "I'm only providing for my family. I don't have any other responsibilities outside my family". Of the seven male participants, only one commented on his role providing emotional support for his children. Mandla was a widower and sole provider to his family and specifically noted the challenges that this caused when he said that "It's not easy to do, especially when you are a man. 'Cause most of the time you don't even know what the girls need".

Kubelo was an exception in this regard. He spoke of his caregiver role to his granddaughters and the fact that he "loves them with all [his] heart".

Women reported a larger variety of dependents, including children, grandchildren, parents, siblings, and in-laws. Lerato emphatically stated, "It's me who takes care of them! My dad, I'm taking care of him. My dad, my cousin, even my sisters. I look after them all. I'm the one who always takes care of them". Although they provided limited information on what type of support they provided, those who did comment mentioned instrumental, emotional, and particularly financial support:

> Yes. Because my lastborn, my son, he doesn't work. My grandson doesn't work. My granddaughter doesn't work. And my lastborn is a girl and she's working but it's not a real job. She works in a garage. (Buhle)

The burden of caring for others was most common among participants who were widowed. Their ongoing family responsibilities outnumbered those of married participants, who appeared to focus more specifically on their children rather than other family members. Participants discussed their ongoing care and support of others as a burden, with some noting that they felt unappreciated or overworked. Lerato (a widow) noted that "I take care of a lot at home.… So I take care of my brothers' kids at home, and then my 'skweezas' [in-laws] kids as well". Blessing (also a widow) echoed these sentiments:

> I'm also staying with my brother-in-law. He was born in 1953.… He gives me headaches because he's someone who drinks a lot. But then because I don't have a choice, I stay with him so at least there's someone at home when I'm here. But he really doesn't appreciate the fact that I take care of him.

Although a number of participants mentioned family members with HIV or talked about family deaths rumoured to be due to AIDS, the impact of HIV deaths or orphaned children was rarely discussed as causing additional or increasing dependency. More often, participants spoke of unemployment or negligent parenting that resulted in them looking after their grandchildren.

In their discussions of supporting and caring for others, it was clear that men and women experienced this aspect of their lives differently. Among men, there was an acknowledgement that as they aged, their support of others remained the same or largely declined. Dumi, who reported a large family with 2 wives and 11 children, noted that "I'm too old. I'm not going to support them", and Sibusiso, married and with 5 children, commented on how he no longer cared for others as much as he used to: "No. I don't think I'm caring for a lot of people because now my kids are grown and one of them is working". As stated above, men's understanding of supporting others appeared to be largely confined to financial support, and many noted that transitioning to retirement and the relatively low government pension limited the support they could provide. In contrast, women continued to support others both financially and in caretaking. Zodwa, who was slightly younger than many of the other participants, spoke of being exhausted in her full-time domestic employment, but also of continuing to care for others. She commented on the fact that rather than being taken care of, she was the person on whom others were depending. She specifically mentioned that this included her child, who was not working, and her sister's child. Others in the sample echoed this and mentioned that they continued their caregiving despite being physically unwell. For example, Lerato, who was troubled with trembling hands, noted that she had been a single parent to five children for the past 10 years. She continued to provide care for her adult children and teenage grandchildren, who both shared a home with her.

Discussion and Conclusions

The development and increased availability of antiretroviral therapy (Jacob et al., 2013) have changed survival for older people with HIV in poorer countries, with consequent health and social impacts (Reniers et al., 2014). In contrast to the fragile social networks discussed among largely MSM populations ageing with HIV in high-resource countries (Brennan-Ing et al., 2017; Comfort et al., 2010; Emlet, 2006a; Grov et al., 2010; Johnson Shen et al., 2019), the participants in this study reported strongly supportive social connections.

Among our participants, most reported particularly strong networks with their immediate families, especially with their children (Schatz & Ogunmefun, 2007). Giving care and support to people with HIV is often described as a foreign and helpless experience; children who support their parents through a life of HIV do so both to control the disease and to address their inability to control the social context of the diagnosis (Ranjbar, 2016). By providing practical support, such as transportation or medication reminders, and emotional support, children have a sense of control and are assisting their parents in longevity (Ranjbar, 2016). One of the most effective sources of support is conversation or social interaction (Ranjbar, 2016), although this was the least mentioned form of support by our participants.

Female participants also reported being well connected to extended family, although there was surprisingly little discussion of friends as a source of support among both men and women. In this sample, there was a significant difference between men and women's experiences of partner support. The majority of women reported no support from male partners, often because they did not have a partner, while men reported wives and girlfriends who cared for and assisted them. Specific HIV-related support from religious groups such as churches was not particularly common, although some participants commented on their connection to such organisations. Support from other sources, such as community groups or even HIV patient support groups, was rarely mentioned by participants. Overall, financial and instrumental support were discussed most frequently, while emotional support was mentioned less frequently and therefore appeared to be less readily available.

A potential explanation for the different experience of our cohort compared to older people living with HIV in high-income countries may be the fact that, unlike men who have sex with men in high-income countries who are dealing with three intersecting stigmas—ageism, homophobia, and HIV stigma (Emlet, 2006b)—participants in this study were not confronting all three. Traditionally African cultures revere older persons for their wisdom and experience, although more contemporary work would argue that this is changing with Western influence (Abanyam, 2013; Kuteesa et al., 2012; Schatz & Gilbert, 2012). All participants in this study presented as heterosexual and maintained heteronormative lives with marriages or partners and children and were therefore not impacted by the stigma and discrimination faced by individuals who are MSM ageing with HIV. Our findings may have been different had the sample included participants in same-sex relationships.

Although the focus of our research was on who provides care and support for those ageing with HIV, our participants all spoke of their roles as caregivers. This finding is consistent with a large body of research documenting a societal norm in which older people in South Africa continue significant caregiving roles regardless of health status. In particular, the caretaking and support of grandchildren for both economic reasons and because of the HIV epidemic disproportionately impact older women (Button & Ncapai, 2019; Chazan, 2014; Cook & White, 2006; Munthree & Maharaj, 2010; Schatz & Gilbert, 2012; Schatz et al., 2015; Schatz & Ogunmefun, 2007). Overall, caretaking roles are more likely to be taken by women; in one instance, 42% of women responded they were the main caregiver to someone with HIV (Munthree & Maharaj, 2010). In comparison, only 17% of men reported the same. The likelihood of women in caregiving roles may be a result of greater family connections between women and their children, grandchildren, and extended family when compared to men (Cook & White, 2006). Often, men do not have the same involvement in the family due to work commitments—exacerbated by a history of circular migration, in which urban and rural households are connected through kinship and payment of remittance rather than shared full-time dwelling (Spiegel et al., 1996)—family violence, or relationships ending (Cook & White, 2006; Eaton et al., 2003). The likelihood of divorce, separation, or never marrying also increases the prospect of men not being around the family when they are older (Eaton et al., 2003). This is reflected in the large portion of women in our study who reported being either single, divorced, or separated.

Throughout discussions with our participants, those receiving the Old Age Pension spoke of increases to their caretaking responsibilities. Although the pension is modest (maximum ZAR 1910 [USD 136] monthly in 2021), it is a significant safety net for older South Africans and may be the only source of income for the extended family (Ralston et al., 2016). This has both advantages and disadvantages. If used to support adult children, the pension might mean that older people living with HIV have other adults in the household who can provide them with instrumental and emotional support. However, in cases where children are younger and unemployed, or where grandparents use their pension to care for grandchildren, access to the pension is likely to increase financial and caretaking responsibilities, paradoxically adding financial stress for older people living with HIV.

There is a gendered dimension to the impact of pensions on the caretaking burdens of older people living with HIV. Although not borne out in our data, evidence from elsewhere has found that women are more likely than men to receive pensions (Ralston et al., 2016; Schatz et al., 2015). As in the existing literature, our data indicate that it is women who are more likely to financially support extended families, as well as take on additional caring responsibilities for young and ill family members (Hatch & Posel, 2018). Given the almost ubiquitous receipt of the Old Age Pension in our sample, further differences by grant access and gender could not be explored here.

Even as support for people ageing with HIV is largely provided within the family, this situation can result in conflict (Button & Ncapai, 2019; Kearabetswe & Grace, 2019) or become unsustainable as well-being declines due to treatment requirements for multiple comorbidities, greater frailty, and requirements for medical and social assistance. If the ability of families to provide support to those ageing with HIV is diminished, it may be tempting to move provision of support to existing HIV treatment infrastructure within the health system (Bendavid et al., 2012). However, our results suggest that stigma and fear of discrimination among those ageing with HIV may limit the uptake of such services, if indeed they can be obtained through a strained and underresourced health service (Mayosi & Benatar, 2014). In addition, there is a continued burden on older people themselves as they navigate reduced income due to retirement and poor health associated with HIV and other comorbidities, but continue to provide financially and instrumentally for extended families. Broader sociopolitical and economic change is required in countries such as South Africa to buffer older people living with HIV from these responsibilities.

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Chapter 8
A Detailed Analysis of the Social Support Networks of Older Adults with HIV in Uganda and South Africa

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Introduction

Social support is a broad concept measured in a variety of ways, such as by the composition of social networks; the amount of instrumental, emotional, or informational help provided; and perceptions of support availability and adequacy (Bajunirwe et al., 2009; Kinyanda et al., 2011; Moore et al., 2018; Uchino, 2009). Social networks are typically classified, with various refinements, as diverse or integrated, family-based, friend-based, or restricted/isolated (Brennan-Ing et al., 2017; Doubova et al., 2010; Fiori et al., 2006).

Cantor's Hierarchical Compensatory Model of Social Support proposes that older adults prefer support from people closest to them, such as partners, spouses, and children (Brennan-Ing et al., 2017; Cantor, 1979). When the support received from these close others is not available or is inadequate to meet their needs, older adults will turn to more distant family members, friends, or neighbors. If social support needs are still not met, older adults will then turn to formal services such as government or community-based agencies or, in some cases, rely on themselves alone. Many low- and middle-income countries, however, do not have a robust formal service sector (Hove et al., 2013). In sub-Saharan Africa, family members have been characterized as a "social security system" that provides critical support in times of need (Mathambo & Gibbs, 2009).

About 3.7 million adults aged 50 and older are living with HIV in sub-Saharan Africa (Autenrieth et al., 2018). Thanks to the growing availability of antiretroviral therapies, that number is expected to continue to increase in this region and in other low- and middle-income countries (Autenrieth et al., 2018). Older adults with HIV experience high rates of comorbid diseases (Havlik et al., 2011; Sprague & Brown, 2017), suggesting they will require increasing assistance and support from their informal social networks of family, friends, and neighbors. Traditional cultural norms in sub-Saharan Africa identify family members, particularly women, as the primary sources of support for their older relatives, but increasingly these norms have changed, especially in urban settings, resulting in fewer informal support resources (Harling et al., 2020; Small et al., 2019). Data are scarce on the social network dynamics of older people with HIV in sub-Saharan Africa, and it is not clear if their informal networks will be adequate to meet the growing need as they face the challenges of aging, and aging with HIV, given the lack of formal service availability.

An abundance of research in high-income countries has examined the ways social support, or the lack of it, affects physical and mental health, but there is less information from countries with less individualistic, more interdependent cultures (Khamarko & Myers, 2013). The World Health Organization conducted a systematic review of research on social support and health outcomes among people with HIV in low- and middle-income countries. The researchers concluded that social support is positively associated with physical health and health behavior outcomes, as well as mental health outcomes such as greater self-esteem, self-efficacy, and active coping, and reduced psychological distress and depression, though some studies found no effects (Khamarko & Myers, 2013). In a more recent study of people with HIV in South Africa, social support and access to material and nonmaterial resources were strongly associated with well-being (Odek, 2014). While older participants in this study reported a greater number of close friends than younger participants did, they had fewer people they could turn to if they needed help in specific situations. And in a study in rural Namibia, social support from friends, though not from family or neighbors, was negatively associated with depressive symptoms (Kalomo et al., 2021).

Social Support Among Older Adults in Sub-Saharan Africa

The limited research available finds social networks among older adults in sub-Saharan Africa to be predominantly family-based. In a study of older people with HIV in Togo, the average network—defined as people one could call on if ill, talk over important matters with, and enjoy spending time with, excluding spouse or partner—had three members, mostly immediate kin (parents, children, siblings), though non-kin made up 40% of those whom respondents “really enjoy socializing with” (Moore & Prybutok, 2014, p. 334). In the rural area of Agincourt, South Africa, adults 40 and older were asked to name six adults they had been in touch with during the past 6 months. On average, relatives constituted two thirds of the network members providing support of all types (emotional, instrumental, financial, and informational; Moore et al., 2018). On the question of relationship quality, however, those who reported negative interactions most often had them with relatives (55%) or partners (29%). This reflects the phenomenon that greater interaction with one's social network members also provides greater opportunities for negative interactions or so-called negative social support, such as marital discord or perceived criticism (Ahn et al., 2017). Thus, the existence of a network does not automatically mean the network confers only benefits.

Social networks tend to shrink as people grow older and retire, and friends and family members become ill or die. In high-income countries, this process has been described as *socio-emotional selectivity*, whereby people tend to focus on relationships that are the most emotionally important to them, letting other, more peripheral relationships fall by the wayside as they age (Carstensen, 1992). However, studies of social networks of older adults in rural sub-Saharan Africa have not found support for this process (Harling et al., 2020). The reduction in availability of family members to provide support is also a function of children being unavailable, primarily because of migration to obtain employment or from mortality, including death from HIV/AIDS (Harling et al., 2020; Mathambo & Gibbs, 2009; Schatz & Seeley, 2015; Small et al., 2019).

Provision of Assistance and Reciprocity

Many older adults in sub-Saharan Africa are care providers as well as care recipients, with older women providing assistance to partners, dependent adult children, and grandchildren because of the absence of caregivers in middle generations (Harling et al., 2020; Schatz & Seeley, 2015). An important component of social bonds in many societies is not only the receipt but the provision of aid, as seen in studies of older adults with HIV in Uganda and Burkina Faso (Mugisha et al., 2018; Ouedrago et al., 2019). HIV and aging may affect a person's ability to work, and older adults' resources often influence their status and authority as elders. Being able to provide care or perform work of some nature may be essential, lest one's status revert to "child-like" and "useless" (Freeman, 2016, p. 124).

Contextual Factors Affecting Social Support

Family and social networks may change in the wake of an HIV diagnosis. The social context of HIV and the level of stigma in the surrounding culture may greatly affect social support, and gender is also a factor. People with HIV may be blamed for acquiring the disease, and widows of men who died with HIV may lose support from the husband's family, endangering not only their social acceptance but their material support, according to a study in Burkina Faso (Ouedraogo et al., 2019). Family members in other cultures, such as the Igbo in Nigeria, may feel an obligation to support those with HIV (Muoghalu & Jegede, 2010).

Across sub-Saharan Africa, older adults and people with HIV vary in their need for and access to social support. Rural residents in areas with high levels of poverty may depend on each other for food and other material resources (Moore et al., 2018; Tsai et al., 2012). In other areas, modernization and development have spurred migration and social change, which may upset the fulfillment of traditional family roles (Cohen & Menken, 2006). In South Africa, apartheid policies into the 1990s affected family networks by encouraging urban migration for young adults but not their parents or children (Ramlagan et al., 2013).

Importance of Perceptions of Social Support

In terms of coping with the challenges of aging, and aging with HIV, perceptions of the availability and adequacy of social support are often more important than the amount of tangible support that is actually received. In their seminal review, Cohen and Wills (1985) found that while there are direct benefits based on the receipt of assistance from one's social network, positive perceptions of social support sufficiency provide an important buffering effect against stressful life circumstances, an effect that is significantly related to well-being. This buffering hypothesis is supported in research on people with HIV, including older adults. In a US sample of people with HIV including younger and older adults, perceived social support exerted a stronger positive effect on mental health than actual support received (McDowell & Serovich, 2007), while perceived support from friends has been associated with lower perceived HIV stigma among African American people with HIV (Galvan et al., 2008). Among older gay and bisexual men with and without HIV, perceived psychological and emotional connection to the gay community was significantly associated with lower levels of negative self-appraisals and greater engagement in fitness activities (Brennan-Ing et al., 2021). Another study on older men with HIV found that perceptions of adequate emotional support significantly mediated the association between health and depressive symptoms (Ogletree et al., 2019). Thus, when evaluating the impact of social support networks on older people with HIV in sub-Saharan Africa, it is important to understand the factors related to perceptions of sufficient social support in terms of the availability and adequacy of assistance.

Purpose and Rationale

The present study compares the social network characteristics and dynamics of older people with HIV in two sub-Saharan populations: (a) largely suburban and urban South Africa and (b) rural Uganda. The countries are distinct in their economic profiles: South Africa has a larger urban population (65%) compared to Uganda (22%; African Development Bank, African Union Commission, and United Nations Economic Commission for Africa, 2018), with an average household income three times that of Uganda (Phelps & Crabtree, 2013). South Africa has a greater level of formal employment and a pension system (Cohen & Menken, 2006). Uganda had a larger household size in 2017, at 4.7, compared with 3.2 in South Africa and has a largely agricultural, informal economy (United Nations, 2017). Therefore, it is likely that social networks will differ between these two populations. Our analysis aimed to answer the following research questions.

1. What are the similarities and differences in the composition and social network dynamics (frequency of contact, provision of assistance) between older people with HIV in South Africa and Uganda?
2. What factors are associated with perceptions of instrumental and emotional support sufficiency among older people with HIV in South Africa and Uganda?

Method

Sources of Data

This study used data from the Research on Older Adults with HIV (ROAH) Africa project, the first comprehensive survey to provide detailed information on psychosocial issues focused on older people with HIV in sub-Saharan Africa, with a sample size of 209 participants (Brennan-Ing et al., 2016; Negin et al., 2016). Eligibility criteria were being age 50 or older at the time of the interview and having an HIV-positive serostatus.

Uganda participants (*n* = 101) were recruited from enrollees in the World Health Organization's Health and Wellbeing of Older People Study (WOPS) who were living in a rural area of Kalungu district in southwestern Uganda and in the periurban Wakiso district located in the vicinity of Entebbe (Nyirenda et al., 2013). The ethnicity of the majority of Uganda participants was Baganda, one of the prominent ethnic groups in eastern and southern Uganda (Nahemow, 1979). The Baganda have a patrilineal system of kinship and traditionally live in nuclear family households, often separated by large distances, originally because the availability of large areas of fertile land for farming promoted far-flung settlements. Marital instability along with migration for work has contributed to considerable variability in family arrangements, including foster children and widows living with grown sons (Nahemow, 1979; Seeley, 2015). These nuclear families are nested within the larger patrilineal kinship structure of the clan, with children joining the clan of their father and their mother being from a different clan. The bond with a person's clan persists despite geographical and social barriers (Seeley, 2015). The impact of the HIV epidemic in this region may have contributed to the geographic dispersal of nuclear families, but the pattern of dispersed settlement was well-established before the epidemic (Seeley, 2015).

South African participants (*n* = 108) came from an adult antiretroviral therapy clinic in central Johannesburg, South Africa (Nyirenda et al., 2015). In terms of ethnicity, most South African participants reported being either Tswana (44%) or Zulu (22%), with less than 10% reporting other ethnicities (e.g., Xhosa, North and South Sotho, Afrikaans). Tswana society is traditionally clan-based and organized on paternalistic principles with the highest status accorded to ruling families (chiefs) and with social status and resources allocated based on the proximity of one's lineage to these dominant families (Kazankov, 2003). This organization led to the form of heterogenous large-family communities linked by bonds of location (neighbors) and lineage. Marriage forms the structural nexus of kinship ties among the Tswana and incorporates both parallel-cousins (child of parent's same-sex sibling) and cross-cousins (child of parent's opposite-sex sibling) resulting in complex intrafamily relationships (Reece, 2019). The Zulu also have a clan-based kinship system, which is not defined by actual ties of "blood and marriage" but belief in descent from a common ancestor (Loudon, 1957). Zulu clan systems are patriarchal in nature, and marriage between members of the same clan, or with the clan of one's mother, is proscribed, resulting in an exogamous family structure. Typically, Zulu households are organized around a man's household (husband, wife, and unmarried children), with married sons and their wives living in separate domiciles within the same compound (Loudon, 1957).

An interviewer-administered quantitative methods survey was used to collect information on demographics, mental health, physical health, social networks, HIV treatment experience, treatment adherence, health-related quality of life, and sexual behavior. Each in-person one-to-one interview lasted approximately 1–1.5 h. Interviews were translated from English into the local language of the participants. Written informed consent was obtained. Participants in the Uganda arm of the study were compensated for their time with a bar of laundry soap worth 4000 Uganda shillings (US $1.50); participants in South Africa did not receive compensation for taking part in the interview. ROAH Uganda was approved by the Science and Ethics Committee of the Uganda Virus Research Institute and the Uganda National Council for Science and Technology. ROAH South Africa was approved by the institutional review board of the University of New England (Australia) and the Human Subjects Ethics Committee of the University of the Witwatersrand (South Africa).

Measures

Social Support

Social support, demographic, and health questions were adapted from the US ROAH study (Cantor et al., 2009; Karpiak & Brennan, 2009) for sub-Saharan Africa populations.

Social Network Components The presence of a spouse or partner in a participant's social network was determined by responses to the questions on current marital status. Participants were asked whether they had any of the following people in their social networks: children, grandchildren and great-grandchildren, siblings, other relatives in frequent contact, close friends, and neighbors known well. If the participant answered affirmatively, they were then asked how many of these people were in their social networks. In the case of children and grandchildren/great-grandchildren, we asked about the total number who were born as well as the number still living. Functional social network members were designated if the older people with HIV saw at least one of the social network members face to face monthly or spoke to them on the phone at least weekly (Cantor & Brennan, 2000). The number of functional supports was the sum of the number of functional network elements reported by older people with HIV. The size of the social network was a sum of the number of members in the social network. In the case of children and grandchildren/great-grandchildren, the numbers who were currently living were used to compute social network size.

Frequency of Contact with Network Members For participants who reported children, grandchildren/great-grandchildren, siblings, and friends, we asked how often they saw at least one of these people face to face or spoke with them on the telephone using a 5-point ordinal scale ranging from "daily" to "once per year or less often." For participants who reported knowing a neighbor well, we asked how frequently they and their neighbors helped each other with three possible responses: "do not help," "help in emergencies," or "help all the time."

Closeness to Network Members and Friends with HIV/AIDS We asked participants how close they felt to members in their social network on a 4-point scale ranging from "very close" to "not close at all." For participants who reported friends in their networks, we asked how many of their friends also had HIV/AIDS on a 5-point scale ranging from "all" to "none."

Caregiving We asked whether participants were currently caring for a grandchild, a great-grandchild, or another child. For those who were caring for a child, we asked whether they were mainly responsible for the child, shared responsibility, or were not responsible for the child. For those who indicated either being mainly responsible or sharing responsibility, we asked why they were responsible as an open-ended question. We then coded the open-ended responses into eight categories (see Table 8.6). We also asked older people with HIV whether they were currently caring for an adult relative or friend. For those providing care to an adult, we asked about their relationship to the care recipient as an open-ended question. We then coded these responses into six categories of relationships (see Table 8.6). Last, we asked whether caregiving interfered with their ability to care for themselves (yes/no).

Assistance from Family and Friends We asked participants about the types of instrumental help and emotional support they received from family and friends/neighbors, respectively, and how often they received such help on a 6-point scale ranging from "not at all or occasionally" to "every day." We asked about five types of instrumental help with tasks of daily living (shopping or running errands, housework or preparing meals, taking you or driving you somewhere, helping with mail or correspondence, managing money or paying bills) and three types of emotional support (giving advice on big decisions, talking to you if you are feeling low, and talking to you about personal matters). We calculated the number of ways family members and friends/neighbors helped, respectively, by summing the number of types of assistance provided at least once per month.

Negative Social Support We asked participants about the types and frequency of negative interactions with family and friends/neighbors, respectively, on a 6-point scale ranging from "not at all or occasionally" to "every day." The three types of negative interactions were network members being reluctant to talk, upsetting the person or hurting their feelings, and refusing to help them when asked. We calculated the indices of negative support from family and friends/neighbors, respectively, by summing the number of types of negative interactions that occurred at least once per month.

Perceptions of Support Availability and Adequacy Participants were asked about their perceptions of the availability and adequacy of instrumental assistance and emotional support, respectively. For the two questions on instrumental help and emotional support availability, participants responded on a 4-point scale: "all or most of the time," "some of the time," "only occasionally," or "not at all." For the two questions on instrumental help and emotional support adequacy, participants responded on a 4-point scale: "got all the help/support needed," "needed a little more," "needed some more," or "needed a lot more." We created indices of instrumental and emotional support sufficiency, by summing the responses to the two questions on instrumental help and the two questions on emotional support, respectively. For both indices, higher scores indicated more favorable perceptions of social support.

Covariates

Sociodemographic Characteristics Age in years was measured as a continuous variable. Gender was measured as a dichotomous variable of female or male. Marital status was a categorical variable: married, widowed, divorced/separated, cohabitating, being a co-wife, having multiple wives, and single or never married. Living alone was a dichotomous variable (yes/no) and derived from a question about the presence of other people living in the participant's household. Employment status was collapsed into four categories: working full- or part-time, unemployed, retired or living on a pension, and disabled or unable to work. Highest level of education consisted of five categories: none, primary (grades 1 through 7), secondary (grades 8 through 12), vocational or technical school, or tertiary. Participants were asked whether they were able to read and write (literate), which was coded as a dichotomy (yes/no). Participants were asked whether they owned their own phone, had access to someone else's phone, or did not own or have access to a phone. We asked participants to identify the geographic area where they lived in one of five categories: city, suburb, town, trading center, or village. The research site was coded as South Africa = 1 and Uganda = 2.

Health and Mental Health Participants were asked to rate their health on a 5-point ordinal scale: excellent, good, fair, poor, or very poor. Due to the small number of responses in the last two categories, they were combined into a single category of poor/very poor. Participants were asked whether they had ever been diagnosed with acquired immune deficiency syndrome (AIDS), which was coded as a dichotomy (yes/no). The number of comorbid conditions in addition to HIV was calculated from responses to whether the participant had any of 26 medical conditions inclusive of an "other condition" with an open-ended description.

Depressive symptomatology was measured with the abbreviated 10-item version of the Center for Epidemiologic Studies Depression Scale (CES-D 10; Andersen et al., 1994; Radloff, 1977). Participants were asked about depressive symptoms experienced over the past days and responded on a 4-point ordinal scale: none of the time (less than 1 day or not at all), a little of the time (1–2 days), some of the time (3–4 days), or most of the time (5–7 days). Two items were reverse coded ("I felt hopeful about the future" and "I was happy"). Responses were summed and higher scores indicated greater depressive symptomatology (range = 0–30). Cronbach's alpha for the ten items was .72, indicating acceptable internal consistency reliability. The CES-D 10 scale has demonstrated high internal consistency with people with HIV in Uganda ($\alpha = 0.92$; Natamba et al., 2014) and South Africa ($\alpha = 0.69–0.89$; Baron et al., 2017).

Design and Analysis

This study used a cross-sectional design to examine differences in social network characteristics between older people with HIV in Uganda and South Africa. Significant differences in data between research sites were evaluated using chi-square tests for categorical and ordinal data and one-way ANOVA for continuous data. Due to the exploratory nature of this research, we did not adjust statistical significance levels for multiple comparisons and used $p < .05$ as our criterion for significant differences.

To examine independent variables associated with dependent variables of perceptions of instrumental and emotional support sufficiency, we conducted ordinary least squares multiple regression analyses. Prior to multiple regression, we conducted correlational analyses of potential independent variables (demographics, health, social network characteristics, and research site) and retained only those variables that were significant to develop parsimonious regression models. Listwise deletion of missing data was used for analysis. Potential multicollinearity of independent variables was examined during the correlational analysis and through multicollinearity diagnostics in the multiple regression procedure. No significant multicollinearity was detected in the independent variables retained in the regression models. Regression models were evaluated by the significance of the model F-test, the amount of variance explained (R^2), and the significance of the individual regression coefficients.

Results

Sample Characteristics

The average age of the sample was 59.6 years (see Table 8.1). The older people with HIV from Uganda were significantly older on average compared to their peers from South Africa (61.0 years and 58.3 years, respectively). The South Africa sample had a significantly greater proportion of women (72%) than the Uganda sample (58%). Similar proportions of both groups were married, but older people with HIV in Uganda were significantly more likely to be widowed (46%) and less likely to be single or never married (0%) compared to their South African peers (25% and 22%, respectively). The older people with HIV in South Africa were more than twice as likely as older people with HIV in Uganda to report living alone (25% and 9%, respectively). Slightly less than one third of older people with HIV at both sites were living with a spouse or partner. However, older people with HIV in Uganda were significantly more likely to be living with a child or grandchild (58% and 59%, respectively) compared to their South African peers (32% and 31%, respectively). Relatively few older people with HIV lived with a parent, sibling, other family member, or friend, and there were no significant differences in this regard by site.

The vast majority of the older people with HIV in Uganda were working either full- or part-time (93%). In South Africa, while 50% of the older people with HIV were working, 19% reported being unemployed, and 31% were retired or receiving a pension. The proportion reporting being disabled and unable to work was 2% or less in both samples. There were no significant differences between the two samples in highest level of education; nearly two thirds reported attending only primary school, and about one in five had attended secondary school. Older people with HIV in Uganda were significantly more likely (70%) to be literate than those in South Africa (44%). Ninety percent of older people with HIV in South Africa owned a phone, and an additional 8% had access to a phone. Older people with HIV in Uganda were significantly less likely to own a phone (64%) and more likely to have access to someone else's phone (21%). Given the differences in study locations between the two samples, it was not surprising that nearly all participants in Uganda lived in a village or trading center (90% and 8%, respectively). In South Africa, most participants lived in urban areas such as in a city (8%) or the suburbs (76%).

Table 8.1 Demographic and health profile of older adults with HIV in South Africa and Uganda

	Total		South Africa		Uganda	
	N	%	*N*	%	*N*	%
Gender*						
Male	72	34.4	30	27.8	42	41.6
Female	137	65.6	78	72.2	59	58.4
Marital status***						
Married	51	24.5	28	26.2	23	22.8
Widowed	73	35.1	27	25.2	46	45.5
Divorced/separated	42	20.2	20	18.7	22	21.8
Cohabitating	18	8.7	8	7.5	10	9.9
Co-wife	1	0.5	1	0.9	0	0.0
Single/never married	23	11.1	23	21.5	0	0.0
Living arrangement						
Lives alone**	36	17.3	27	25.0	9	9.0
With partner/spouse	64	30.0	34	31.5	30	30.8
With child***	93	44.7	35	32.4	58	58.0
With grandchild***	92	44.2	33	30.6	59	59.0
With parent	4	1.9	4	3.7	0	0.0
With sibling	20	9.6	8	7.4	12	12.0
With other family member	11	5.3	7	6.5	4	4.0
With friend	1	0.5	0	0.0	1	1.0
Employment status***						
Working full- or part-time	146	70.5	54	50.0	92	92.9
Unemployed	22	10.6	20	18.5	2	2.0
Retired/pension	36	17.4	33	30.6	3	3.0
Disabled/unable to work	3	1.4	1	0.9	2	2.0
Education						
None	32	15.4	17	15.9	15	14.9
Primary (grades 1–7)	129	62.0	63	58.9	66	65.3
Secondary (grades 8–12)	38	18.3	24	22.4	14	13.9
Vocational/technical school	2	1.0	0	0.0	2	2.0
Tertiary	7	3.4	3	2.8	4	4.0
Literate***	118	56.7	48	44.4	70	70.0
Have phone***						
No	17	8.2	2	1.9	15	14.9
Own phone	161	77.4	96	89.7	65	64.4
Access to phone	30	14.4	9	8.4	21	20.8
Geographic location***						
City	9	4.3	9	8.3	0	0.0
Suburb	82	39.2	82	75.9	0	0.0
Town	9	4.3	7	6.5	2	2.0
Trading center	8	3.8	0	0.0	8	7.9
Village	101	48.3	10	9.3	91	90.1

(continued)

Table 8.1 (continued)

	Total		South Africa		Uganda	
	N	%	*N*	%	*N*	%
Self-rated health***						
Excellent	15	7.2	1	0.9	14	13.9
Good	79	38.2	33	31.1	46	45.5
Fair	88	42.5	62	58.5	26	25.7
Poor/very poor	25	12.1	10	9.4	15	14.9
AIDS diagnosis***	73	35.8	15	14.2	58	59.2
	M	***SD***	***M***	***SD***	***M***	***SD***
Age**	59.60	7.10	58.26	6.08	61.03	7.82
Number comorbid conditions***	3.21	3.03	1.22	1.05	5.34	3.00
CES-D depressive symptoms***	9.81	6.16	7.52	4.22	12.26	6.94

Note. Total $N = 209$, South Africa $N = 108$, Uganda $N = 101$. Chi-square tests of significance for categorical variables and one-way ANOVA for continuous variables. Percentages may not sum to 100% because of rounding
$^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$

A majority of the older people with HIV in Uganda rated their health as excellent or good (14% and 46%, respectively), significantly more than their peers in South Africa (1% and 31%, respectively). Despite their more positive evaluation of their health status, older people with HIV in Uganda were significantly more likely to report a prior AIDS diagnosis compared to those in South Africa (59% and 14%, respectively) and reported a greater number of comorbid conditions in addition to HIV on average (5.3 and 1.2, respectively). Older people with HIV in Uganda also had higher average levels of depressive symptoms (12.3) compared to those in South Africa (7.5) on the short version of the CES-D depression scale (Andersen et al., 1994; Radloff, 1977).

Social Network Composition

Approximately one third of older people with HIV in both samples reported having a partner or spouse (see Table 8.2), and nearly all had at least one child (97%). In terms of having a functional child, namely, at least one child in frequent contact, the proportions in both samples were nearly identical, with 82% of older people with HIV having this support element. However, older people with HIV in Uganda reported that they had had significantly more children and had more children who were living on average (10.0 and 7.0, respectively) compared to older people with HIV in South Africa (3.4 and 3.0, respectively). Older people with HIV in Uganda were significantly more likely to have a grandchild or great-grandchild compared to their counterparts in South Africa (96% and 84%, respectively), which is likely a result of having greater numbers of children. However, there were no significant differences in the likelihood of having a functional grandchild or great-grandchild between research sites (72% of the total sample). Regarding the number of grandchildren and great-grandchildren, older people with HIV in Uganda reported significantly greater numbers on average (10.7 ever and 9.9 still living) compared to those in South Africa (3.9 and 3.8, respectively).

Older people with HIV in South Africa were significantly more likely to report having a sibling in their social network (98%) compared to their peers in Uganda (87%), but there were no significant differences in the proportions having a functional brother or sister (53% and 46%, respectively) and no significant differences in the number of living siblings between the two sites (approximately 4 on average). Older people with HIV in Uganda were significantly more likely to have another more distant relative in their network (75%) compared to their peers in South Africa (54%), but the proportion of those with a functional other relative did not differ significantly between the two sites (40% and 49%, respectively). But congruent with other data on the number of family members, older people with HIV in Uganda reported significantly more other relatives in their networks on average (3.8) than did those in South Africa (1.1).

We also found that older people with HIV in Uganda were significantly more likely to have non-kin members in their social networks and greater numbers of such people compared with their South African peers. Three quarters of the older people with HIV in Uganda reported having a friend, and 71% had at least one functional friend, while in South Africa the proportions were 43% and 42%, respectively. However, the average number of friends did not differ between sites and was 2.8 for the combined sample. Nearly everyone in the Uganda sample reported having a neighbor whom they knew well (96%), which was a significantly greater share than those in South Africa (67%), and the average number of these neighbors was significantly greater in Uganda compared to South Africa (3.0 and 2.0, respectively). There were no significant differences between the two sites in the number of functional support elements (approximately 3.4 on average), but the size of the social network (number of individuals) was approximately twice as large on average in Uganda (28.9) as in South Africa (14.3) (Table 8.2).

Frequency of Contact and Feelings of Closeness with Family

When comparing face-to-face and telephone contact with family members, older people with HIV in Uganda tended to have higher levels of in-person contact, while older people with HIV in South Africa were more likely to stay in touch with family members by telephone (see Table 8.3). This finding is partially explained by the fact that older people with HIV in Uganda were significantly more likely to be living with children and grandchildren than their peers in South Africa and somewhat less likely to have access to a telephone. Seventy-one percent of the older people with HIV in Uganda saw a child face to face at least weekly, but only 44% were in touch by telephone at least weekly. Among older people with HIV in South Africa, the proportion of at least weekly face-to-face contact was 57%, but 72% were in at least

Table 8.2 Social network composition of older adults with HIV in South Africa and Uganda

	Total		**South Africa**		**Uganda**	
Social network components	***N***	**%**	***N***	**%**	***N***	**%**
Spouse/partner	70	33.5	37	34.3	33	32.7
Child	202	97.1	103	95.4	99	99.0
Functional child	172	82.3	90	83.3	82	81.2
Grandchild or great-grandchild**	187	89.9	91	84.3	96	96.0
Functional grandchild or great-grandchild	151	72.2	75	69.4	76	75.2
Sibling**	193	92.8	106	98.1	87	87.0
Functional sibling	103	49.3	57	52.8	46	45.5
Other relative***	131	63.9	58	53.7	73	75.3
Functional other relative	93	44.5	53	49.1	40	39.6
Friend***	121	58.5	46	43.0	75	75.0
Functional friend***	117	56.0	45	41.7	72	71.3
Neighbor known well***	161	80.9	70	67.3	91	95.8
Size of network components	***M***	***SD***	***M***	***SD***	***M***	***SD***
Children***	6.59	5.61	3.42	2.03	9.96	6.22
Living children***	5.00	4.59	3.01	1.76	7.02	5.61
Grandchildren[a] ***	7.44	6.35	3.89	2.83	10.70	6.93
Living grandchildren[a] ***	6.99	6.03	3.84	2.84	9.89	6.70
Living siblings	4.19	3.28	4.00	2.05	4.44	4.37
Other relatives***	2.39	3.68	1.10	1.41	3.81	4.75
Friends	2.76	2.51	2.61	1.97	2.85	3.24
Neighbors known well***	2.47	2.06	1.99	2.29	3.00	1.62
Number functional supports	3.38	1.27	3.31	1.28	3.46	1.27
Size of social network***	21.37	12.15	14.32	5.95	28.91	12.58

Note. Total $N = 209$, South Africa $N = 108$, Uganda $N = 101$. Chi-square tests of significance for categorical variables and one-way ANOVA for continuous variables. Percentages may not sum to 100% because of rounding

*$p < .05$, **$p < .01$, ***$p < .001$

[a] Includes grandchildren and great-grandchildren

weekly contact by telephone. A similar pattern was observed with contact with grandchildren or great-grandchildren. While the likelihood of living with siblings did not vary between groups, older people with HIV in Uganda were significantly more than twice as likely to see a sibling at least weekly than were those in South Africa (44% and 21%, respectively), while older people with HIV in South Africa were more likely than those in Uganda to be in at least weekly telephone contact (33% and 14%, respectively).

Despite different methods of maintaining contact with social network members, we did not observe any significant differences in reported closeness to family members based on research site (see Table 8.4). The vast majority of older people with HIV at both research sites felt very close to their children (85%) and grandchildren (83%). While not feeling as close to siblings as to children, approximately two thirds of older people with HIV felt very close, and one in five felt somewhat close

Table 8.3 Frequency of contact with family members among older adults with HIV in South Africa and Uganda

	Total		South Africa		Uganda	
	N	%	*N*	%	*N*	%
Children face to face***						
Once a year or less often	16	8.0	8	7.9	8	8.2
Several times a year	25	12.6	12	11.9	13	13.3
Monthly	30	15.1	23	22.8	7	7.1
Weekly	21	10.6	17	16.8	4	4.1
Daily	107	53.8	41	40.6	66	67.3
Children on telephone***						
Once a year or less often	13	6.6	6	5.9	7	7.4
Several times a year	16	8.2	3	3.0	13	13.7
Monthly	38	19.4	19	18.8	19	20.0
Weekly	85	43.4	54	53.5	31	32.6
Daily	30	15.3	19	18.8	11	11.6
Grandchildren[a] face to face**						
Once a year or less often	19	10.2	8	8.8	11	11.5
Several times a year	21	11.2	11	12.1	10	10.4
Monthly	27	14.4	21	23.1	6	6.3
Weekly	22	11.8	14	15.4	8	8.3
Daily	98	52.4	37	40.7	61	63.5
Grandchildren[a] on telephone***						
Once a year or less often	57	31.8	7	7.8	50	56.2
Several times a year	24	13.4	9	10.0	15	16.9
Monthly	33	18.4	24	26.7	9	10.1
Weekly	50	27.9	38	42.2	12	13.5
Daily	15	8.4	12	13.3	3	3.4
Sibling face to face***						
Once a year or less often	44	23.7	18	17.6	26	31.0
Several times a year	44	23.7	30	29.4	14	16.7
Monthly	40	21.5	33	32.4	7	8.3
Weekly	22	11.8	13	12.7	9	10.7
Daily	36	19.4	8	7.8	28	33.3
Sibling on telephone***						
Once a year or less often	33	18.2	7	6.9	26	32.9
Several times a year	41	22.7	19	18.6	22	27.8
Monthly	62	34.3	42	41.2	20	25.3
Weekly	37	20.4	28	27.5	9	11.4
Daily	8	4.4	6	5.9	2	2.5

Note. Total $N = 209$, South Africa $N = 108$, Uganda $N = 101$. Chi-square tests of significance. Percentages may not sum to 100% because of rounding

*$p < .05$, **$p < .01$, ***$p < .001$

[a] Includes grandchildren and great-grandchildren

Table 8.4 Feelings of closeness with family members among older adults with HIV in South Africa and Uganda

	Total		South Africa		Uganda	
	N	%	*N*	%	*N*	%
Children						
Not close at all	2	1.0	2	2.1	0	0.0
Not too close	7	3.6	4	4.1	3	3.1
Somewhat close	20	10.3	7	7.2	13	13.4
Very close	165	85.1	84	86.6	81	83.5
Grandchildren[a]						
Not close at all	4	2.2	2	2.2	2	2.2
Not too close	8	4.4	3	3.3	5	5.6
Somewhat close	18	10.0	5	5.6	13	14.4
Very close	150	83.3	80	88.9	70	77.8
Siblings						
Not close at all	11	6.0	5	5.0	6	7.1
Not too close	14	7.6	9	9.0	5	6.0
Somewhat close	39	21.2	19	19.0	20	23.8
Very close	120	65.2	67	67.0	53	63.1
Other relatives						
Not close at all	3	2.3	0	0.0	3	4.1
Not too close	5	3.8	1	1.7	4	5.4
Somewhat close	32	24.2	15	25.9	17	23.0
Very close	92	69.7	42	72.4	50	67.6

Note. Total $N = 209$, South Africa $N = 108$, Uganda $N = 101$. Chi-square tests of significance. Percentages may not sum to 100% because of rounding

$^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$

[a] Includes grandchildren and great-grandchildren

to their brothers and sisters. A similar pattern was observed regarding other relatives, with 70% of older people with HIV feeling very close and 24% feeling somewhat close to these social network members.

Frequency of Contact with Friends and Neighbors

Older people with HIV in both South Africa and Uganda were in frequent face-to-face contact with friends (see Table 8.5), although those in Uganda were significantly more likely to see friends daily compared to their South African peers (63% and 50%, respectively). Older people with HIV in South Africa were more likely to see friends on a weekly basis (46%) than older people with HIV in Uganda (23%). And while 87% of the older people with HIV in South Africa spoke to a friend on the telephone at least weekly, only 31% of their Ugandan counterparts spoke to friends on the phone with this level of frequency. Over half of older people with

Table 8.5 Frequency of contact, friends with HIV/AIDS, and mutual neighbor assistance among older adults with HIV in South Africa and Uganda

	Total		South Africa		Uganda	
	N	%	*N*	%	*N*	%
Friend face to face*						
Once a year or less often	0	0.0	0	0.0	0	0.0
Several times a year	5	4.1	1	2.2	4	5.3
Monthly	8	6.6	1	2.2	7	9.3
Weekly	38	31.4	21	45.7	17	22.7
Daily	70	57.9	23	50.0	47	62.7
Friend on telephone***						
Once a year or less often	40	34.5	0	0.0	40	57.1
Several times a year	2	1.7	0	0.0	2	2.9
Monthly	12	10.3	6	13.0	6	8.6
Weekly	45	38.8	30	65.2	15	21.4
Daily	17	14.7	10	21.7	7	10.0
Friends with HIV/AIDS*						
None	36	36.7	12	31.6	24	40.0
A few	40	40.8	14	36.8	26	43.3
About half	4	4.1	3	7.9	1	1.7
Most	5	5.1	0	0.0	5	8.3
All	13	13.3	9	23.7	4	6.7
Help from/with neighbors***						
Do not help	26	13.3	13	13.7	13	13.0
Help in emergencies	75	38.5	62	65.3	13	13.0
Help all of the time	94	48.2	20	21.1	74	74.0

Note. Total $N = 209$, South Africa $N = 108$, Uganda $N = 101$. Chi-square tests of significance. Percentages may not sum to 100% because of rounding
*$p < .05$, **$p < .01$, ***$p < .001$

HIV in Uganda reported being in telephone contact with a friend only once a year or less often. Many older Ugandans volunteered that they rarely spoke to their friends on the phone because they tended to live nearby, and they saw them in person often. Older people with HIV in South Africa were more likely to report that all of their friends also had HIV (24%), as compared to 7% of older people with HIV in Uganda. When asked about the amount of help they provided and received from their neighbors, older people with HIV in Uganda were significantly more likely to report they were involved with mutual assistance all of the time (74%) compared to older people with HIV in South Africa (21%). Among older people with HIV in South Africa, the majority were involved in helping and being helped by neighbors only in emergencies (65%), compared with 13% of older people with HIV in Uganda. There were no apparent differences between sites in the proportion who were not involved in helping relationships with neighbors (approximately 13%).

Table 8.6 Caregiving involvement among older adults with HIV in South Africa and Uganda

	Total		South Africa		Uganda	
	N	%	*N*	%	*N*	%
Currently caring for grandchild[a] or another child	88	47.3	36	40.0	52	54.2
Responsible for grandchild[a] or another child's care***						
Mainly responsible	46	51.7	10	27.8	36	67.9
Share responsibility	36	40.4	20	55.6	16	30.2
Not responsible	7	7.9	6	16.7	1	1.9
Why responsible for grandchild[a] or another child's care						
Parent working**	23	25.8	15	41.7	8	15.1
Parent died from HIV	20	22.5	11	30.6	9	17.0
Parent died from other illness**	10	11.2	0	0.0	10	18.9
Parent has HIV*	3	3.4	3	8.3	0	0.0
Parent has other illness/disabled	4	4.5	1	2.8	3	5.7
Parent unemployed or poor	14	15.6	8	21.6	6	11.3
Parents are separated/divorced	5	5.6	0	0.0	5	9.4
Grandparent request/need help*	7	7.9	0	0.0	7	13.2
Currently caring for adult relative or friend***	41	20.6	10	9.6	31	32.6
Relationship to care recipient						
Spouse or partner	3	8.1	2	20.0	1	3.7
Parent	7	18.9	2	20.0	5	18.5
Child	13	35.1	4	40.0	9	33.3
Grandchild	5	13.5	1	10.0	4	14.8
Other relative	5	13.5	1	10.0	4	14.8
Nonrelative	4	10.8	0	0.0	4	14.8
Caregiving interferes self-care	13	33.3	3	30.0	10	34.5

Note. Total *N* = 209, South Africa *N* = 108, Uganda *N* = 101. Chi-square tests of significance. Percentages may not sum to 100% because of rounding

[a]Includes grandchildren and great-grandchildren

*$p < .05$, **$p < .01$, ***$p < .001$

Providing Care to Grandchildren or Other Adults

Grandchildren We asked older people with HIV whether they were currently caring for a grandchild, great-grandchild, or another child, and nearly half (47%) were engaged in childcare (see Table 8.6). The likelihood of providing care to a child did not differ significantly by research site. However, when asked about who was responsible for the child's care, older people with HIV in Uganda were significantly more likely to say they were mainly responsible (68%) than older people with HIV in South Africa (28%). Older people with HIV in South Africa were more likely to say they shared responsibility for childcare or were not responsible (56% and 17%, respectively) compared to their peers in Uganda (30% and 2%, respectively). We asked those who indicated some responsibility for caring for a grandchild or other child the reason why they were responsible, which generated a variety of responses.

Older people with HIV in South Africa were more likely to be responsible for childcare because the parents were working (42%) compared to those in Uganda (15%). Twenty-three percent were responsible for a grandchild because the parent had died from HIV, which did not vary significantly by site, but grandparents in Uganda were significantly more likely than those in South Africa to be responsible because the parent had died from another illness (19% and 0%, respectively). Older people with HIV in South Africa were significantly more likely to be responsible because the parent had HIV (8%) compared to those in Uganda (0%), but there was no difference between sites on being responsible because the parent had another illness (5%). We also did not observe any significant differences between sites in the proportion of grandparents being responsible for childcare because the parents were unemployed or poor (16%), but grandparents in Uganda tended to be more likely to be responsible because the parents were divorced or separated compared to their counterparts in South Africa (9% and 0%, respectively). In addition, grandparents in Uganda were significantly more likely to be responsible for a grandchild because they had requested the child's help (13%) than were grandparents in South Africa (0%). This finding reflects that fostering is an important component of child socialization in Uganda and the foster child serves as a resource for emotional and instrumental support for the older adult (Kasedde et al., 2014).

Other Adults When asked whether they were currently providing care to another adult relative or friend, older people with HIV in Uganda were significantly more likely to be serving as caregivers compared to those in South Africa (33% and 10%, respectively). In terms of the relationship of the older people with HIV caregiver to the care recipient, there were no significant differences by research site. Most often care was being provided to a close relative, such as a spouse or partner (8%), parent (19%), adult child (35%), adult grandchild (14%), or other relative (14%). Eleven percent of older people with HIV were providing care to a nonrelative such as a friend or neighbor. One third of older people with HIV who were caring for an adult reported that being a caregiver interfered with taking care of themselves, and this proportion did not differ significantly between South Africa and Uganda.

Assistance and Support Received from Social Network

Need for Help and Sources of Assistance We asked participants whether they had ever needed physical, financial, or emotional help due to HIV either in the past or currently (see Table 8.7). Older people with HIV in Uganda were significantly more likely to indicate they currently needed physical help compared to their peers in South Africa (40% and 8%, respectively), while those in South Africa were more likely to say they needed such help in the past but not currently (43%) compared to older people with HIV in Uganda (16%). Regarding financial help, older people with HIV in South Africa were significantly more likely than their Ugandan counterparts to say they had never needed such help (58% and 31%, respectively). A

Table 8.7 Need for help due to HIV and sources of assistance for older adults with HIV in South Africa and Uganda

	Total		South Africa		Uganda	
	N	%	*N*	%	*N*	%
Need physical help re HIV***						
Never	97	46.6	53	49.1	44	44.0
Not now but in the past	62	29.8	46	42.6	16	16.0
Currently need help	49	23.6	9	8.3	40	40.0
Need financial help re HIV***						
Never	94	45.4	63	58.3	31	31.3
Not now but in the past	49	23.7	32	29.6	17	17.2
Currently need help	64	30.9	13	12.0	51	51.5
Need emotional help re HIV***						
Never	85	40.7	43	39.8	42	41.6
Not now but in the past	89	42.6	56	51.9	33	32.7
Currently need help	35	16.7	9	8.3	26	25.7
Who provided needed help						
Spouse/partner	24	13.3	7	8.8	17	16.8
Child	57	31.5	23	28.7	34	33.7
Sibling***	24	13.3	18	22.8	6	5.9
Other family member***	38	21.0	32	40.0	6	5.9
Friend	11	6.1	2	2.5	9	8.9
Neighbor	12	6.7	7	8.9	5	5.0

Note. Total $N = 209$, South Africa $N = 108$, Uganda $N = 101$. Chi-square tests of significance. Percentages may not sum to 100% because of rounding

$^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$

majority of older people with HIV in Uganda reported currently needing financial help (52%) compared to only 12% of their South African peers. In terms of emotional help, older people with HIV in South Africa were significantly more likely to say they had needed this help in the past (52%) than those in Uganda (33%), but less likely to currently need emotional help (8% and 26%, respectively). When asked who provided help due to HIV when needed, most older people regardless of research site indicated a child (32%), while 13% said a spouse or partner had provided help. Older people with HIV in South Africa were significantly more likely to have gotten help from a sibling or other family member (23% and 40%, respectively) compared to those in Uganda (6% and 6%, respectively). Friends (6%) and neighbors (7%) were the least likely social network members to have provided help needed because of HIV.

Help from Family Members An interesting picture emerged when analyzing differences in levels of support and assistance received from family members among older people with HIV in Uganda and South Africa. Overall, older people with HIV in Uganda were significantly more likely either to get very little help (not at all/only occasionally) or to receive help frequently (daily) with instrumental tasks. In contrast, older people with HIV in South Africa were more likely to receive help more intermittently, ranging from monthly to several times per week (see Table 8.8). To illustrate, regarding shopping or running errands, older people with HIV in Uganda were more likely to say they never or occasionally received such help (47%, com-

Table 8.8 Assistance from family members among older adults with HIV in South Africa and Uganda

		Not at all or occasionally		Once per month		Several times per month		Once per week		Several times per week		Every day	
Type of assistance		*N*	%	*N*	%	*N*	%	*N*	%	*N*	%	*N*	%
Shop or run errands***	**Total**	67	32.7	21	10.2	12	5.9	11	5.4	45	22.0	49	23.9
	South Africa	20	19.0	16	15.2	6	5.7	10	9.5	32	30.5	21	20.0
	Uganda	47	47.0	5	5.0	6	6.0	1	1.0	13	13.0	28	28.0
Housework or prepare meals**	**Total**	71	34.8	20	9.8	8	3.9	4	2.0	24	11.8	77	37.7
	South Africa	28	26.9	11	10.6	4	3.8	4	3.8	20	19.2	37	35.6
	Uganda	43	43.0	9	9.0	4	4.0	0	0.0	4	4.0	40	40.0
Take or drive you places***	**Total**	96	46.8	50	24.4	25	12.2	9	4.4	18	8.8	7	3.4
	South Africa	37	35.2	30	28.6	13	12.4	8	7.6	15	14.3	2	1.9
	Uganda	59	59.0	20	20.0	12	12.0	1	1.0	3	3.0	5	5.0
Help with mail/ correspondence*	**Total**	99	48.3	34	16.6	28	13.7	7	3.4	17	8.3	20	9.8
	South Africa	57	54.3	19	18.1	10	9.5	4	3.8	11	10.5	4	3.8
	Uganda	42	42.0	15	15.0	18	18.0	3	3.0	6	6.0	16	16.0
Manage money or pay bills**	**Total**	133	64.9	44	21.5	13	6.3	2	1.0	10	4.9	3	1.5
	South Africa	63	60.0	29	27.6	9	8.6	2	1.9	2	1.9	0	0.0
	Uganda	70	70.0	15	15.0	4	4.0	0	0.0	8	8.0	3	3.0
Give advice on big decision***	**Total**	**76**	37.1	66	32.2	36	17.6	4	2.0	14	6.8	9	4.4
	South Africa	**40**	38.1	45	42.9	15	14.3	3	2.9	1	1.0	1	1.0
	Uganda	**36**	36.0	21	21.0	21	21.0	1	1.0	13	13.0	8	8.0
Talk when feeling low***	**Total**	78	38.0	50	24.4	38	18.5	2	1.0	23	11.2	14	6.8
	South Africa	47	44.8	31	29.5	21	20.0	2	1.9	2	1.9	2	1.9
	Uganda	31	31.0	19	19.0	17	17.0	0	0.0	21	21.0	12	12.0
Talk about personal matters**	**Total**	90	44.1	59	28.9	31	15.2	2	1.0	12	5.9	10	4.9
	South Africa	55	52.9	31	29.8	13	12.5	1	1.0	3	2.9	1	1.0
	Uganda	35	35.0	28	28.0	18	18.0	1	1.0	9	9.0	9	9.0

Note. Total $N = 209$, South Africa $N = 108$, Uganda $N = 101$. Chi-square tests of significance. Percentages may not sum to 100% because of rounding
$^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$

pared with 19% of those in South Africa) or received this help daily (28%, compared with 20% in South Africa). Similarly in terms of housework or preparing meals, older people with HIV in Uganda were more likely to not receive this type of support or receive it on a daily basis (43% and 40%, respectively) compared to their South African peers (27% and 36%, respectively). Older people with HIV in South Africa were more likely to receive some assistance with getting a ride or being taken somewhere (65% at least monthly) compared to their Ugandan counterparts (41% at least monthly). But in terms of help with mail or other correspondence, it was older people with HIV in South Africa who were more likely not to receive this type of help (54%, compared with 42% of those in Uganda) while also being less likely to receive this help daily (4%, compared with 16% in Uganda). Help with managing money or paying bills was the most infrequent type of assistance provided by family members overall, with 60% of older South Africans and 70% of older Ugandans either never or occasionally receiving this type of assistance.

There were also several significant differences in emotional support provided by family members. Regarding providing advice on a big decision, older people with HIV in South Africa were significantly more likely to receive this type of help monthly compared to those in Uganda (43% and 21%, respectively), while older people with HIV in Uganda were more likely to receive such help several times a month or more often. When asked about having someone to talk to when feeling low and needing cheering up, older people with HIV in South Africa were significantly more likely to report not receiving this support or receiving it only once per month (45% and 30%, respectively) compared to their counterparts in Uganda (31% and 19%, respectively). Older people with HIV in South Africa were also significantly more likely to report not receiving emotional support in terms of talking about personal or private matters (53%) compared to their peers in Uganda (35%).

Help from Friends and Neighbors Compared to instrumental assistance received from family members, older people with HIV at both sites tended to receive lower levels of support from non-kin, although those in Uganda reported more instrumental help from friends and neighbors than did those in South Africa (see Table 8.9). Regarding shopping and running errands, older people with HIV in Uganda were significantly less likely to report not receiving this type of help and significantly more likely to receive help at least several times per week (43% and 24%, respectively) compared to their South African counterparts (60% and 2%, respectively). Only 16% of the older people with HIV in South Africa got at least some help from friends with housework or preparing meals, compared to 34% of those in Uganda. Similarly, just 22% of older people with HIV in South Africa received a ride or an escort from a friend at least once a month, compared to 53% of older Ugandans. Most older people with HIV in Uganda received help with mail or correspondence from their friends at least once a month (59%), with 23% receiving such help at least several times per week; this was much less common among their counterparts in South Africa (13% and 1%, respectively). Friends rarely provided help in managing money or paying bills, but older people with HIV in Uganda were significantly

Table 8.9 Assistance from friends and neighbors among older adults with HIV in South Africa and Uganda

		Not at all or occasionally		Once per month		Several times per month		Once per week		Several times per week		Every day	
Type of assistance		*N*	%	*N*	%	*N*	%	*N*	%	*N*	%	*N*	%
Shop or run errands***	**Total**	102	51.3	36	18.1	24	12.1	11	5.5	21	10.6	5	2.5
	South Africa	59	59.6	18	18.2	10	10.1	10	10.1	2	2.0	0	0.0
	Uganda	43	43.0	18	18.0	14	14.0	1	1.0	19	19.0	5	5.0
Housework or prepare meals**	**Total**	149	74.9	26	13.1	8	4.0	8	4.0	4	2.0	4	2.0
	South Africa	83	83.8	7	7.1	4	4.0	5	5.1	0	0.0	0	0.0
	Uganda	66	66.0	19	19.0	4	4.0	3	3.0	4	4.0	4	4.0
Take or drive you places***	**Total**	124	62.3	33	16.6	28	14.1	5	2.5	8	4.0	1	0.5
	South Africa	77	77.8	16	16.2	3	3.0	2	2.0	1	1.0	0	0.0
	Uganda	47	47.0	17	17.0	25	25.0	3	3.0	7	7.0	1	1.0
Help with mail/ correspondence***	**Total**	127	63.8	29	14.6	17	8.5	2	1.0	12	6.0	12	6.0
	South Africa	86	86.9	10	10.1	1	1.0	1	1.0	1	1.0	0	0.0
	Uganda	41	41.0	19	19.0	16	16.0	1	1.0	11	11.0	12	12.0
Manage money or pay bills***	**Total**	167	84.8	15	7.6	5	2.5	4	2.0	5	2.5	1	0.5
	South Africa	95	96.9	2	2.0	1	1.0	0	0.0	0	0.0	0	0.0
	Uganda	72	72.7	13	13.1	4	4.0	4	4.0	5	5.1	1	1.0
Give advice on big decision**	**Total**	96	48.2	60	30.2	27	13.6	1	0.5	11	5.5	4	2.0
	South Africa	51	51.5	37	37.4	10	10.1	0	0.0	1	1.0	0	0.0
	Uganda	45	45.0	23	23.0	17	17.0	1	1.0	10	10.0	4	4.0
Talk when feeling low***	**Total**	83	43.9	52	27.5	28	14.8	1	0.5	17	9.0	8	4.2
	South Africa	48	48.5	36	36.4	12	12.1	0	0.0	1	1.0	2	2.0
	Uganda	35	38.9	16	17.8	16	17.8	1	1.1	16	17.8	6	6.7
Talk about personal matters**	**Total**	105	56.8	42	22.7	18	9.7	4	2.2	10	5.4	6	3.2
	South Africa	58	59.8	28	28.9	9	9.3	1	1.0	0	0.0	1	1.0
	Uganda	47	53.4	14	15.9	9	10.2	3	3.4	10	11.4	5	5.7

Note. Total $N = 209$, South Africa $N = 108$, Uganda $N = 101$. Chi-square tests of significance. Percentages may not sum to 100% because of rounding

$^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$

more likely to receive this type of assistance compared to those in South Africa (27% and 3%, respectively).

Compared to instrumental help, older people with HIV were more likely to report receiving emotional support and advice from friends, but at a lower frequency than they received emotional support from family members. Older people with HIV in South Africa were more likely to report not receiving support in terms of advice on a big decision or receiving such support only monthly (52% and 37%, respectively) compared to those in Uganda (45% and 23%, respectively). A similar pattern was observed with older people with HIV in South Africa not receiving support or receiving it only monthly when they were feeling low and wanted to talk (49% and 36%, respectively) compared to their Ugandan counterparts (39% and 18%, respectively). Fewer than half of older people with HIV received emotional support by discussing personal or private matters with friends, and the proportion who received this type of help more than once a month was significantly lower in South Africa (11%) than in Uganda (31%).

Negative Support from Family and Friends Negative social support from family and friends tended to be low overall, but older people with HIV in South Africa experienced significantly more frequent negative interactions with their social networks in several domains compared to their Ugandan counterparts (see Table 8.10). Only 11% of participants in Uganda reported that family members expressed reluctance to talk to them once per month or more often, compared with 32% of participants in South Africa. Older people with HIV in South Africa were also more likely to say that at least once per month friends were reluctant to talk (21%), compared to 13% of those in Uganda. Older people with HIV in South Africa were twice as likely to report that their family members upset them or hurt their feelings (43%) in comparison to older Ugandans (20%). However, there were no significant differences by research site in the likelihood of friends upsetting the older people with HIV and hurting their feelings on at least a monthly basis (26% overall). There were also no significant differences by research site in the proportions of older people with HIV who said that family members or friends refused to provide help at least once per month or more often (20% and 14%, respectively, for the combined samples).

Levels of Social Support and Perceptions of Support Sufficiency While older people with HIV in Uganda tended to report a greater intensity of social support from family compared to those in South Africa, the two groups did not differ significantly in the number of ways that family provided help and on average received four types of support (see Table 8.11). But in the case of help from friends, older people with HIV in Uganda reported significantly more types of support on average (3.8) compared to those in South Africa (2.2). Older people with HIV in South Africa reported a significantly greater number of types of negative support from family on average (0.9) compared to their Ugandan counterparts (0.5), but the number of types of negative support from friends was not significantly different by site ($M = 0.5$).

Table 8.10 Negative support from family members and friends/neighbors among older adults with HIV in South Africa and Uganda

Type of assistance		Not at all or occasionally		Once per month		Several times per month		Once per week		Several times per week		Every day	
		N	%	*N*	%	*N*	%	*N*	%	*N*	%	*N*	%
Family reluctant to talk**	**Total**	160	78.4	24	11.8	13	6.4	1	0.5	3	1.5	3	1.5
	South Africa	71	68.3	18	17.3	11	10.6	1	1.0	2	1.9	1	1.0
	Uganda	89	89.0	6	6.0	2	2.0	0	0.0	1	1.0	2	2.0
Friends reluctant to talk*	**Total**	164	83.2	17	8.6	10	5.1	0	0.0	6	3.0	0	0.0
	South Africa	77	79.4	13	13.4	6	6.2	0	0.0	1	1.0	0	0.0
	Uganda	87	87.0	4	4.0	4	4.0	0	0.0	5	5.0	0	0.0
Family upset you or hurt your feelings**	**Total**	139	68.1	39	19.1	20	9.8	2	1.0	3	1.5	1	0.5
	South Africa	59	56.7	25	24.0	17	16.3	1	1.0	2	1.9	0	0.0
	Uganda	80	80.0	14	14.0	3	3.0	1	1.0	1	1.0	1	1.0
Friends upset you or hurt your feelings	**Total**	145	73.6	28	14.2	18	9.1	1	0.5	4	2.0	1	0.5
	South Africa	76	78.4	13	13.4	8	8.2	0	0.0	0	0.0	0	0.0
	Uganda	69	69.0	15	15.0	10	10.0	1	1.0	4	4.0	1	1.0
Family refused to help when asked	**Total**	164	80.4	24	11.8	12	5.9	2	1.0	1	0.5	1	0.5
	South Africa	80	76.9	11	10.6	10	9.6	2	1.9	1	1.0	0	0.0
	Uganda	84	84.0	13	13.0	2	2.0	0	0.0	0	0.0	1	1.0
Friends refused to help when asked	**Total**	168	85.7	18	9.2	2	1.0	2	1.0	5	2.6	1	0.5
	South Africa	84	87.5	9	9.4	2	2.1	0	0.0	1	1.0	0	0.0
	Uganda	84	84.0	9	9.0	0	0.0	2	2.0	4	4.0	1	1.0

Note. Total N = 209, South Africa N = 108, Uganda N = 101. Chi-square tests of significance. Percentages may not sum to 100% because of rounding
*$p < .05$, **$p < .01$, ***$p < .001$

When asked about perceptions of the availability of instrumental help with tasks of daily living, a majority of older people with HIV in both groups felt such help was available at least some of the time (57%). Nearly one third (29%) reported that instrumental help was not available to them, and there were no significant differences between groups in this regard. However, there were significant group differences in the perceptions of instrumental support adequacy. The proportion of older people with HIV in South Africa who felt they had received all the instrumental help they needed (67%) was more than double the proportion of older Ugandans who felt their needs had been met (32%), and over one third of older people with HIV in Uganda reported needing a lot more instrumental help, compared with only 4% of older South Africans. Older people with HIV in Uganda were significantly more likely to say that emotional support was available to them all or most of the time

Table 8.11 Levels of social support and perceptions of support among older adults with HIV in South Africa and Uganda

	Total		**South Africa**		**Uganda**	
	M	***SD***	***M***	***SD***	***M***	***SD***
Number ways family helps	4.44	2.78	4.55	2.73	4.33	2.84
Number ways friends help* **	2.93	2.44	2.15	2.13	3.77	2.49
Number family negative support* **	0.72	1.06	0.94	1.17	0.47	0.88
Number friend negative support	0.54	0.94	0.49	0.93	0.59	0.94
	N	*%*	***N***	*%*	***N***	*%*
Instrumental help available						
All/most of the time	80	38.8	40	38.1	40	39.6
Some of the time	38	18.4	20	19.0	18	17.8
Only occasionally	28	13.6	19	18.1	9	8.9
Not at all	60	29.1	26	24.8	34	33.7
Instrumental help adequacy* **						
Got all needed	98	51.0	70	66.7	28	32.2
Need a little more	43	22.4	27	25.7	16	18.4
Need some more	17	8.9	4	3.8	13	14.9
Need a lot more	34	17.7	4	3.8	30	34.5
Emotional support available* **						
All /most of the time	74	35.9	10	9.4	64	64.0
Some of the time	28	13.6	14	13.2	14	14.0
Only occasionally	56	27.2	45	42.5	11	11.0
Not at all	48	23.3	37	34.9	11	11.0
Emotional support adequacy* **						
Got all needed	114	56.7	71	67.0	43	45.3
Need a little more	40	19.9	24	22.6	16	16.8
Need some more	18	9.0	6	5.7	12	12.6
Need a lot more	29	14.4	5	4.7	24	25.3
	M	***SD***	***M***	***SD***	***M***	***SD***
Instrumental support index* **	5.77	1.55	6.26	1.25	5.17	1.67
Emotional support index* **	5.81	1.32	5.49	1.04	6.16	1.50

Note. Total *N* = 209, South Africa *N* = 108, Uganda *N* = 101. Chi-square tests of significance for categorical variables and one-way ANOVA for continuous variables. Percentages may not sum to 100% because of rounding

**p* < .05, ***p* < .01, ****p* < .001

(64%) as compared to older South Africans (9%). The majority of older people with HIV in South Africa felt that emotional support was available only occasionally (43%) or not at all (35%), which was significantly higher than among older Ugandans (11% and 11%, respectively). Despite reporting a greater availability of emotional support, older people with HIV in Uganda were significantly more likely to say that they needed some more (13%) or a lot more (25%) emotional support than were their South African peers (6% and 5%, respectively). Looking at overall perceptions of support sufficiency, older South African people with HIV had significantly higher average scores on the instrumental support index compared to those in Uganda (6.3 and 5.2, respectively). The reverse pattern was observed on the emotional support index, with older Ugandan people with HIV having higher average index scores than their South African counterparts (6.2 and 5.5, respectively).

Regression Analyses of Instrumental and Emotional Support Sufficiency

Following the descriptive comparisons of findings from the two research sites, we performed multiple regression analyses to investigate which combination of factors was associated with perceptions of sufficient instrumental and emotional support given their important role in buffering HIV-related stressors. We retained the following independent variables based on our correlational analysis of factors related to greater perceptions of instrumental and emotional support sufficiency: lives alone, level of education, literacy, access to a telephone, self-rated health, prior AIDS diagnosis, number of comorbid health conditions, CES-D depressive symptoms, having a partner or spouse, number of functional support elements, number of ways that family helps, number of ways that friends help, family negative support, and research site (South Africa = 1, Uganda = 2).

In the regression analysis on instrumental support sufficiency, having a prior AIDS diagnosis had a negative association with this index ($\beta = -0.18$). The number of ways family members provided help was positively associated with higher levels of perceived instrumental support ($\beta = 0.27$). However, the number of ways that friends provided help was negatively associated with perceptions of instrumental support sufficiency ($\beta = -0.17$). Research site was not related to this dependent variable after controlling for other factors (see Table 8.12). This regression model was statistically significant ($p < .001$) and accounted for 31% of the variance in perceptions of instrumental support.

For the regression analysis of perceptions of emotional support sufficiency, higher levels of depressive symptoms were negatively associated with the availability and adequacy of emotional support ($\beta = -0.18$). Like perceptions of instrumental support, the number of ways family members provided help was positively associated with higher perceptions of emotional support ($\beta = 0.21$). After controlling for the other factors in the equation, research site was positively associated with greater perceptions of emotional support sufficiency ($\beta = 0.47$), indicating that older people with HIV in Uganda tended to evaluate emotional support more positively compared to those in South Africa. The regression model was statistically significant ($p < .001$) and explained 23% of the variance on emotional support perceptions (see Table 8.13).

Table 8.12 Multiple regression on instrumental support sufficiency index: older adults with HIV in South Africa and Uganda

Variable	*B*	*SE*	β	*t*	*p*	95% CI
Lives alone	−.088	.334	−.021	−0.27	.791	[−.747, .570]
Education	−.205	.140	−.108	−1.46	.146	[−.482, .072]
Literate	−.135	.247	−.043	−0.55	.586	[−.623, .353]
Phone	.827	.457	.122	1.81	.072	[−.075, 1.729]
Self-rated health	.191	.150	.097	1.27	.205	[−.105, .487]
AIDS diagnosis	−.579	.244	−.178	−2.38	.019	[−1.059, −.098]
Number comorbidities	−.032	.057	−.060	−0.56	.576	[−.143, .080]
CES-D scale	−.037	.022	−.144	−1.71	.090	[−.080, .006]
Has partner/spouse	.129	.233	.039	0.55	.580	[−.331, .589]
Number functional supports	−.010	.091	−.008	−0.11	.915	[−.190, .170]
Number ways family help	.158	.047	.274	3.35	.001	[.065, .252]
Number ways friends help	−.108	.048	−.170	−2.27	.024	[−.202, −.014]
Family negative support	.008	.105	.006	0.08	.938	[−.200, .216]
Research site	−.300	.349	−.097	−0.86	.391	[−.989, .388]

Note. Listwise $N = 182$. F (14, 167) = 5.46, $p < .001$. Model $R^2 = .314$

Table 8.13 Multiple regression on emotional support sufficiency index: older adults with HIV in South Africa and Uganda

Variable	*B*	*SE*	β	*t*	*p*	95% CI
Lives alone	−.100	.295	−.028	−.338	.736	[−.681, .482]
Education	.139	.124	.085	1.118	.265	[−.106, .383]
Literate	−.155	.219	−.059	−.709	.479	[−.587, .277]
Phone	.630	.358	.129	1.759	.080	[−.077, 1.337]
Self-rated health	.134	.134	.079	1.001	.318	[−.130, .397]
AIDS diagnosis	.092	.210	.034	.439	.661	[−.323, .507]
Number comorbidities	−.066	.048	−.150	−1.371	.172	[−.162, .029]
CES-D scale	−.039	.019	−.184	−2.097	.037	[−.076, −.002]
Has partner/spouse	.089	.203	.032	.438	.662	[−.312, .490]
Number functional supports	−.004	.079	−.004	−.049	.961	[−.159, .152]
Number ways family help	.100	.040	.207	2.490	.014	[.021, .179]
Number ways friends help	−.031	.042	−.056	−.737	.462	[−.114, .052]
Family negative support	−.028	.092	−.023	−.305	.761	[−.209, .153]
Research site	1.241	.313	.472	3.958	.000	[.622, 1.859]

Note. Listwise $N = 192$. F (14, 177) = 3.722, $p < .001$. Model $R^2 = .227$

Discussion

This study presents an in-depth look at social support among older adults living with HIV in urban or suburban South Africa and in rural Uganda. Our findings indicate that the older people with HIV in these two sites have much in common, but they differ substantially in their social networks, caregiving involvement, and need for and receipt of social support. Specifically, older people with HIV in Uganda had larger families and social networks and tended to receive more emotional support than older people with HIV in South Africa in this sample, yet they also reported needing more emotional and instrumental support than they received. The composition of the two samples undoubtedly affected our findings. While 90% of participants in Uganda lived in rural areas, those in South Africa overwhelmingly lived in periurban or urban areas. Participants in Uganda were 3 years older than those in South Africa, on average, and women made up a substantially greater share of the South Africa group. In both groups, HIV has taken a toll on their health. In South Africa, only one third rated their health excellent or good. The Uganda sample was twice as likely to rate their health excellent or good, but 59% had received a diagnosis of AIDS, and older people with HIV in Uganda had more comorbid conditions and substantially more depressive symptoms on average than their counterparts in South Africa.

Social Networks

Participants in both samples were close to their families. Feelings of closeness to children and grandchildren were strong, and most participants felt very close to siblings and to other family members, as in other research (Moore et al., 2018). However, participants in Uganda had larger families and had social networks about twice the size of older people with HIV in South Africa. The Uganda group had more children and more grandchildren and were about twice as likely to be living with them. In the South Africa sample, older people with HIV were more likely to live alone and never to have been married.

Non-kin networks differed substantially between the two sites. Older people with HIV in South Africa were much less likely to have a friend or a functional friend in their social network or to know a neighbor well compared to their Ugandan peers. While three quarters of participants in Uganda said they had at least one friend, fewer than half of those in South Africa did. Of those who did, in both samples, nearly all had at least weekly in-person contact with a friend. In South Africa where telephone access was more common, older people with HIV had more phone contact with family and friends. The difference in phone contact may be more a function of suburban versus rural residence, as recent research has found much lower frequency of phone/text/email contacts than in-person contacts for older adults in rural South Africa compared to what we observed in the present study (Harling et al., 2020).

Caregiving and Other Support

Older people with HIV are not only recipients but providers of care. Almost half the combined sample provided care for children, reflecting a well-established pattern of caregiving among older adults in sub-Saharan Africa (Schatz et al., 2015). While this proportion may be decreasing as the availability of antiretroviral therapy has greatly reduced the number of deaths from AIDS (Schatz et al., 2015; Mathambo & Gibbs, 2009), it is likely that older people in this region will continue to provide a substantial amount of care for children due to parents' migration for work opportunities. Older people with HIV in Uganda were more than twice as likely as their counterparts in South Africa to say they had primary responsibility for a child, despite the greater proportion of women in the South Africa sample and the strong tendency for women to take on childcare responsibilities (Hatch & Posel, 2018). The reasons for providing care to grandchildren included a parent's death from HIV or another illness—the latter was the most common reason in Uganda—or a parent's need to work. In South Africa, parents' poverty was another common reason. In Uganda, several older people with HIV requested a grandchild as a companion or helper. Such "bidirectional care" has often been reported in sub-Saharan Africa (Small et al., 2019). In addition, almost one third of older people with HIV in Uganda were caring for an adult relative or friend, compared with one tenth in South Africa.

Especially in rural areas, older people with HIV contribute to their communities. Three out of four participants in Uganda said they were "involved in mutual assistance all of the time," compared with one in five in South Africa, though most in South Africa did exchange help with neighbors in emergencies. Ugandans' larger and more active social networks may reflect the greater community interdependence previously found in rural areas (Moore et al., 2018; Tsai et al., 2012), as well as a lack of emergency services (Moore & Prybutok, 2014). Research has also underscored the importance in sub-Saharan Africa of maintaining one's usefulness in the community (Freeman, 2016; Mugisha et al., 2018; Ouedrago et al., 2019).

Social Factors and Social Support

Impact of Apartheid Families and communities in South Africa have had to contend with the serious consequences of apartheid and unemployment concurrent with the HIV epidemic (Schatz et al., 2015). The apartheid system in South Africa upended the traditional household structure, in which adult children would take care of aging parents, by compelling younger generations to migrate for work; after apartheid, high unemployment in rural areas maintained the practice of labor migration (Schatz et al., 2015; Cohen & Menken, 2006). Still, the social expectation that the younger generation would care for the older relatives seems to retain its importance in South Africa (Madhavan et al., 2017).

Economic Development South Africa has more economic development than Uganda, with a less agrarian, more formal labor market, which could be expected to affect the kind of resources available (Hove et al., 2013). Nearly all participants in Uganda continued to work, while in South Africa, half were employed, and one third were retired and/or receiving a pension; one in five was unemployed. Older people with HIV in Uganda were more likely to need financial help because of HIV; most participants in South Africa said they had never needed financial help because of HIV. This does not necessarily mean they did not have financial challenges, especially if they were caring for children or other adults (Small et al., 2019). While pensions are an important source of income, they may be stretched to support other household members (Schatz et al., 2015; Schatz & Ogunmefun, 2007).

Sources of Social Support

In both Uganda and South Africa, older people with HIV received more instrumental and emotional help from family than from friends and neighbors, consistent with previous research (Moore et al., 2018). Older people with HIV in Uganda reported receiving more emotional help than instrumental help from friends and neighbors, but they received more of both types of assistance than from non-kin than did their counterparts in South Africa. When asked specifically about who provided help if needed due to HIV, respondents in Uganda most often named close family (spouse/partner or children). In South Africa, the most cited source of help was distant family members. The reliance on distant family members could be, in part, because adult children have migrated elsewhere or have died from HIV/AIDS or another cause and are not available to provide care, in line with Cantor's Hierarchical Compensatory Model (Cantor, 1979; Harling et al., 2020; Mathambo & Gibbs, 2009; Schatz & Seeley, 2015; Small et al., 2019).

Sufficiency of Support

While the availability of instrumental support was similar across the two sites, perceptions of the adequacy of support differed. In South Africa, older people with HIV were more than twice as likely as those in Uganda to say their instrumental needs were met; more than one third of those in Uganda said they needed a lot more help. This could be related to the poorer health of older people with HIV in Uganda and their high rates of having an AIDS diagnosis; a diagnosis of AIDS was significantly associated with a lower level of instrumental support sufficiency. While the number of ways that family members provided help was positively associated with greater perceived instrumental support sufficiency, greater assistance from friends was *negatively* associated with perceived instrumental support. It may be that older people with HIV were dissatisfied that their family members could not provide all the help they needed, given cultural expectations that older people should rely on the family for care (Cohen & Menken, 2006; Mathambo & Gibbs, 2009).

Regarding emotional support, older people with HIV in Uganda evaluated their emotional support more positively than those in South Africa. Negative support was not common, but it was notably more common for participants in South Africa, who reported family members who were reluctant to talk or who hurt their feelings. This may reflect their closer relationships with family members (Moore et al., 2018). But paradoxically, despite perceiving emotional support as being more available, older people with HIV in Uganda were much more likely to say they needed more support. Emotional support sufficiency was associated with fewer depressive symptoms. The importance of *perceived* social support for mental health echoes findings outside of Africa. While different cultures may have different expectations of help from family and friends, meeting those expectations remains essential (Cohen & Wills, 1985; McDowell & Serovich, 2007; Ogletree et al., 2019).

Limitations

Due to the cross-sectional nature of these data, we cannot make causal inferences regarding associations of independent factors and the perceptions of social support sufficiency described in this chapter. The samples that provided data for the current analysis represent only two countries in sub-Saharan Africa, and these findings may not be generalizable to all older people with HIV living in this region. In addition, differences noted between Ugandan and South African older people with HIV are at least partially attributable to differences in geographic location (rural, periurban, urban) and/or the level of economic development in these two countries and may not reflect differences due to country and culture as much as may be implied by our analyses. In addition, due to space limitations, we did not examine gender differences in social network composition and dynamics (such as receipt of assistance from family and friends) in our current analyses. Such differences have been highlighted in other research (Harling et al., 2020), and this should be addressed in future work.

Conclusions and Implications

Older adults living with HIV in rural Uganda and suburban South Africa are not isolated. Their family members and, to a lesser degree, friends and neighbors provide a substantial amount of support. But with limited resources and confronted with the challenges of managing HIV and often caring for others, a sizable share of older people with HIV need more help than they currently receive from their informal networks. Trends in both nations toward increasing urbanization and economic development may have the unintended consequences of weakening the social support networks of older people in sub-Saharan Africa, including those living with HIV. As suggested by Cantor's Hierarchical Compensatory Model (Cantor, 1979), these older people may increasingly need to seek support from government and community-based organizations to meet the challenges of aging. However, for the vast majority of older people in this region, these services are few and far between, despite the development of policy frameworks to address the needs of older individuals. A focused effort is needed to implement those policy frameworks under consideration and to develop sustainable funding streams to support older people living with HIV in sub-Saharan Africa.

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Chapter 9
Reprogramming HIV Prevention and Service Provision for Older Adults in Western Kenya

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Contents

Introduction

The Centers for Disease Control and Prevention (CDC) documents that during the early years of HIV and AIDS, the symptoms of the disease had been reported on five continents: Europe, Africa, North America, South America, and Australia (Mann, 1989). In Africa, the disease was first described by Ugandan doctors as a wasting

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disease that was fatal in nature and was called “slim” by locals (Serwadda et al., 1985). In that period, the disease was described only among men who had sex with men, but as female counterparts of infected men began developing similar symptoms, heterosexual transmission was described (CDC, 1983). Soon after, children born of pregnant infected women were also diagnosed, indicating vertical transmission. As they observed the growth in reported cases, countries globally began setting up surveillance systems for the disease.

For several decades after its discovery, HIV was considered a disease of the young, since sexual contact constitutes the main form of transmission; it was largely considered an uncommon risk in older adults (Negin, 2012). Recently, however, the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) reports have indicated a shift in the epidemiology of HIV, with increasing numbers of older people living with HIV (UNAIDS, 2013, 2014b). This epidemiologic transition has manifested in both developing and developed countries. In the United States, for example, the CDC (2020) estimated that over 50% of all people living with HIV in 2018 were older adults, that is, aged 50 years and older. In the last decade, the number of older adults living with HIV has nearly doubled globally (Mahy et al., 2014). In sub-Saharan Africa, the region that is worst hit by the pandemic, home to over 70% of people living with HIV, estimates stand at 3.6 million older adults with HIV (UNAIDS, 2016), with the numbers expected to increase nearly threefold to 9.1 million by the year 2040 (Tweya et al., 2017).

Two main factors account for the shift in the epidemiology of HIV. First, widespread access and availability of antiretroviral therapy (ART) globally has enabled those infected with HIV to live longer, turning HIV from a known death sentence to a chronic and manageable disease (Deeks et al., 2013).

Second, an increasing number of persons aged 50 years and above are newly diagnosed with HIV (UNAIDS, 2014b). This group includes people who have been living with HIV but are diagnosed only at a late stage of infection and older adults with new infections (UNAIDS, 2014b). In 2018, UNAIDS estimated that 7.5 million people (3.3 million women and 4.2 million men) living with HIV were aged 50 years or older, with nearly 110,000 annual incident infections—of which 74% were occurring in sub-Saharan Africa (UNAIDS, 2019). Contrary to common perceptions, a significant number of persons are infected at an older age because older adults exhibit sexual risk behaviors similar to those of younger persons (UNAIDS, 2014b). They engage in multiple sexual encounters with other older adults in addition to engaging in intergenerational sex, often through transactional sex, referred to in different contexts as “sugar daddies/mummies” or “sponsor” relationships (Shisana et al., 2016). In addition, older persons are more susceptible to HIV infection. For example, due to biological changes with menopause, older women are more vulnerable to HIV infection than younger women (Mahy et al., 2014).

Decreased immunity associated with increasing age is worsened by HIV, such that compared to those below 50, older adults with HIV face worse health outcomes and bear a greater burden of both HIV-related and nonrelated comorbidities (Negin et al., 2012a; Schouten et al., 2014). Older adults with HIV also bear a higher pill burden and greater treatment side effects (Back & Marzolini, 2020) that may increase the risk of treatment nonadherence.

In spite of the shift in the epidemiology of HIV, and in spite of older adults' risk of worse outcomes from HIV, programming for HIV prevention and service provision continues to focus on populations younger than 50. For example, most HIV-related information and prevention messaging is targeted at younger people, leading to lower levels of HIV-related knowledge among older adults, more risky sexual behavior, poor access to and uptake of HIV testing services (Negin et al., 2012c; UNAIDS, 2014b), diagnostic delays, and late presentation for HIV care (Kiplagat et al., 2018; Smith et al., 2010).

Globally, HIV among older adults has not received much attention, with inadequate surveillance data. As a result, significant evidence and policy gaps persist in the global HIV response concerning older adults (Negin et al., 2012b). The situation is worse in sub-Saharan Africa not only because the region has the world's highest HIV incidence and prevalence but also because resource limitations serve as a barrier to optimal HIV care.

Kenya is experiencing one of the largest HIV epidemics in the world (Avert, 2020) and has an estimated HIV prevalence rate of 5.6% among older adults, slightly higher than that among the general adult population (5.4%) (UNAIDS, 2017; NASCOP, 2015). A study in western Kenya found that 12% of adults living with HIV are older adults (Kiplagat et al., 2018), yet they continue to be neglected and face obstacles in HIV prevention, diagnosis, access to care, and quality of care. For example, while national HIV testing guidelines provide for improved access to testing services for all persons, special focus is paid to young people and those in their reproductive years, leaving out older adults (Kenyan MOH/NACC, 2016). Older adults with HIV also suffer environmental challenges, such as social isolation and food insecurity.

To achieve the UNAIDS 90-90-90 targets (UNAIDS, 2014a)—that 90% of all people living with HIV will know their HIV status, 90% of those who know their status will be receiving ART, and 90% of those on ART will achieve viral suppression—and Kenya's goal of reducing infections by 75% (Kenya MOH, 2014), there is an urgent need to tailor HIV prevention and service provision, including HIV messaging and testing services, to be more inclusive of older adults. This calls for changes in policy, in healthcare services, and in how societies are organized to meet the needs of older adults with HIV. This chapter specifically highlights how HIV prevention and service provision can be reprogrammed to accomplish these goals and provides some recommendations specific to western Kenya.

HIV Prevention and Service Provision in Kenya

HIV Prevention Among Older Adults

As with all diseases, the best strategy in dealing with HIV and AIDS is prevention. The first step in prevention is creating awareness, followed by education, testing, and promotion of safe (or safer) sex practices. Kenya is regarded as an HIV prevention success story, with reports indicating that incidence of HIV in 2010 was less than one third of incidence in 1993, when the country's HIV infection was at its peak (UNAIDS, 2013). Using the Prevention Revolution Roadmap to End HIV by 2030, developed by Kenya's National AIDS Control Council and National AIDS and STIs Control Programme in 2013, the country has outlined its strategy to reduce new infections by 75% (Kenya MOH, 2014). A combination of prevention approaches targeting behavior, biomedical factors, and organizational structure is outlined in the Kenya AIDS Strategic Framework 2014/2015–2018/2019 (Maisha NACC, 2014).

Prevention messaging and initiatives promoting abstinence, being faithful to one partner, and using condoms have been implemented. In 2003, Kenya introduced HIV education into its school curriculum. In 2013, a policy was developed that provided education on HIV prevention, care, and support for learners and teachers. These efforts have increased HIV awareness among young people. Additionally, Kenya has continued to increase availability of condoms, although condom use remains low. UNAIDS (2017) reported that only three quarters of men and about 55% of women used a condom when they last engaged in sex with a casual partner.

Other HIV prevention strategies, such as access and use of pre-exposure prophylaxis, prevention of mother-to-child transmission, voluntary medical male circumcision, harm reduction, screening for HIV, initiation of free ART, and "prevention with positives" (secondary HIV prevention efforts), have been implemented in Kenya (Maisha NACC, 2014). All these approaches have focused on specific populations, such as younger adults, pregnant women, children born to mothers with HIV, key populations (female sex workers, men who have sex with men, injection drug users), and, recently, adolescents (Murphy et al., 2006). Decades later, these prevention strategies have continued to deprioritize older persons.

HIV Screening and Testing in Older Adults

Almost half (47%) of Kenyans living with HIV know their status (Avert, 2020). Numerous testing approaches have been adopted by the Kenyan government, including voluntary counseling and testing, provider-initiated testing and counseling, diagnostic testing and counseling, door-to-door or home-based testing and counseling, and self-testing (WHO, 2016b). Despite these efforts, access to testing services for older adults still lags, due to both low levels of HIV knowledge among older adults (Negin et al., 2012c) and healthcare providers being less likely to offer them testing because they deem older adults to be at a lower risk for infection (Johnson et al., 2015). This lack of access to testing means that older adults are less likely than younger adults to enjoy the benefits of early diagnosis and treatment initiation (Kiplagat et al., 2018). Late testing and diagnosis subsequently predisposes older adults to worse outcomes.

HIV Treatment and Care for Older Adults Living with HIV

Though UNAIDS and the WHO have provided guiding principles to testing and treatment of all people infected with HIV (WHO, 2015a, 2016a), there is a lack of specific guidelines that focus on older persons. The fact that older adults are at a higher risk of multimorbidity leads to their exclusion from clinical trials that guide HIV prevention and treatment (Levy et al., 2007). No policies and guidelines have been formulated to target older adults with HIV, likely because little is known about their needs and experiences (Patel et al., 2016). In Kenya, laws and policies have ignored the plight of older adults with HIV. To develop inclusive policies guiding HIV care, we must outline the needs and document the challenges this population faces in seeking HIV care services.

Early development of comorbid conditions is common among people living with HIV, with studies estimating a higher prevalence when compared to their HIV-negative counterparts (Back & Marzolini, 2020). These comorbid conditions include hypertension, diabetes, cancer, liver cirrhosis, neurocognitive disorders or impairment, and depression, with older age being a significant independent risk factor for some of them. Older adults with HIV have a higher risk for multimorbidity and are more likely to require care for multiple disease states, but healthcare providers in sub-Saharan Africa are not trained to provide this specialized care. Most healthcare settings provide separate healthcare services for HIV and for various chronic conditions (diabetes, hypertension, depression, cancer, chronic pain, arthritis) (Rabkin et al., 2012; Zakumumpa et al., 2018), so older patients not only will have to queue to be seen by an HIV clinician but also may be referred to multiple clinicians to seek care for comorbidities (Negin et al., 2012a; Brennan-Ing et al., 2017; Kuteesa et al., 2014; Kiplagat et al., 2019). Time taken to access care at the various points may have a negative impact on the health of the already sick older adults (Kelly et al., 2019).

In addition, older adults living with HIV may experience social issues, including stigma related to HIV (Kuteesa et al., 2014); ageism, or “prejudice and discrimination against older people” (Emlet, 2006; Kiplagat & Huschke, 2018); loneliness and depression (Fakoya et al., 2020; Berg-Weger & Morley, 2020); and neglect. Discrimination against people with HIV makes coping with the illness difficult (Pindani et al., 2014), resulting in negative health outcomes. Studies have suggested that such issues are a result of societal attitudes that reflect a lack of awareness and understanding of older adults’ challenges and needs, as well as inadequate policies to address HIV in the aging population (Brennan et al., 2011; Siegler & Brennan-Ing, 2017). Furthermore, food insecurity in people living with HIV is high, estimated at 20–50% in Kenya (Wakibi et al., 2011), impacting adherence and health outcomes, including those of older people (Kalichman et al., 2014).

Suggestions for HIV Reprogramming

Older adults face obstacles in HIV prevention, diagnosis, access to care, and quality of care, as well as environmental challenges such as social isolation and food insecurity. There is therefore a need for changes in policy, healthcare service provision, and the ways societies are organized to meet the needs of older adults living with HIV. To transform HIV programming in western Kenya and other resource-limited settings to meet the needs of older adults, we make various suggestions based on the foregoing discussion.

Creating HIV Awareness Among Older Adults

Provide Education on Prevention and Control of Sexually Transmitted Infections (STIs) Sexual activity among adults continues into their old age (Negin et al., 2015). Despite this, little HIV prevention messaging targets older persons. The misconception that sexually transmitted infections (STIs), including HIV, affect only younger people persists, and assumptions that older adults are not sexually active perpetuate the notion that they do not need sexual education. Older persons often do not perceive themselves to be at risk of HIV and other STIs and may not use any protection during sexual intercourse, even when engaging with multiple partners. Older persons who have lost their partners re-enter into dating, and some older adults engage in transgenerational relationships (Adegbenro et al., 2011; Clüver et al., 2013; Potgieter et al., 2012). Biological changes during menopause (Brooks et al., 2012) coupled with differences in power relations that hamper safe sexual practices (Beaulaurier et al., 2014) place older women at higher risk of HIV. Older men may have difficulty using condoms due to age-related erectile dysfunction (Karpiak & Lunievicz, 2017). Additionally, older adults have low levels of HIV-related knowledge and awareness when compared to younger adults (Anokye et al., 2019; Davis & Elder, 2020; Gedin & Resnick, 2014; Lekalakala-Mokgele, 2014). Providers, therefore, need to be educated about sexuality in later life and the importance of taking sexual histories of older people and incorporating sexual health in clinical practice (Brennan-Ing et al., 2018).

Using images of older adults in messages promoting STI/HIV testing and prevention and reproductive health services may help to dispel the misconceptions that older adults are not at risk of HIV and other STIs. Older adults should also be encouraged to be open to learning—asking questions related to their sexuality and looking out for information about HIV—and to read HIV-related printed information (newspapers, magazines, posters, flyers) and listen to informational advertisements on the radio and TV and in movies, among other information.

Multistakeholder approaches may be important in the process of increasing HIV knowledge and promoting screening uptake among older people. The involvement and leadership of community-based organizations and faith-based organizations have been shown to increase HIV knowledge and promote HIV screening in western Kenya (Kamaara et al., 2019). There is, therefore, a need to formulate policies that engage these stakeholders and target older persons for education and screening. The focus should be on policies that influence health-seeking behavior among older adults; information that increases correct and comprehensive knowledge about HIV among older adults; and ways to increase awareness of and access to HIV screening for older persons.

HIV Screening and Testing Focusing on Older Adults

Target HIV Counseling and Testing Services for Older Adults HIV testing is the gateway to prevention, treatment, and care. HIV testing policies and guidelines should include older adults as a key target, as they not only may underutilize the service for lack of knowledge (Kiplagat & Huschke, 2018) but also may be excluded by service providers who believe older adults are not at risk of HIV infection (Negin et al., 2012c). HIV testing services offered in home settings by community health workers and trained counselors has shown tremendous success in the uptake of HIV testing, but they rarely target older adults (Sharma et al., 2016; Kimaiyo et al., 2010; Dalal et al., 2013; Waruiru et al., 2014).

Build Capacity Among Healthcare Providers to Understand and Manage Older Adults Perceived stigma concerning HIV in older people, the belief that older persons are no longer sexually active, and comorbidities in old age make HIV diagnosis difficult (Negin et al., 2012c). Prejudice against older people in relation to sexuality has been described widely in the literature (Emlet et al., 2015; Chepngeno-Langat & Hosegood, 2012; DeMarco et al., 2017). Owing to ageist attitudes by care providers and the wider community (Beard et al., 2016; Schatz et al., 2018), older persons may not seek or receive HIV testing services and are thus often diagnosed at a late stage of infection (DeMarco et al., 2017; Kuteesa et al., 2014; Negin et al., 2012c; Kiplagat & Huschke, 2018). Training healthcare providers on approaches to providing HIV testing services for older adults will improve not only the experiences of older adults but also the care provided to older adults with HIV.

Training healthcare providers in patient-centered case management (M. L. Greene et al., 2018) is important to address HIV care in the context of numerous factors affecting the patient's ability to adhere to treatment or stay healthy. Specific areas of need for older adults include but are not limited to healthy sexuality, social isolation, substance use, retention in care, comorbidities, and health promotion (Chepngeno-Langat & Hosegood, 2012; Kiplagat et al., 2018; Edelman et al., 2014). Providers need to be trained to be continuously cognizant of older adults' needs and to initiate conversations that may seem difficult for older persons to raise.

Comprehensive Care and Management for Older Adults Living with HIV

Screen for Comorbid Conditions in Older Adults with HIV The ability to metabolize HIV medication is reduced in older adults, predisposing them to potential ART-related toxicities. Long-term use of specific ART groups has been associated with increased risk of heart disease, bone fractures, liver toxicity, lipodystrophy, peripheral neuropathy, and pancreatitis (Greene et al., 2014; Back & Marzolini, 2020). Although new ART formulations have a more favorable side effect profile, these new formulations are not widely accessible in low- and middle-income countries, including Kenya. If not screened for and identified early, these common comorbid conditions increase morbidity and mortality in older adults with HIV. Kenya's HIV care guidelines need to include recommendations that older adults receive continuous screening and testing for common comorbid conditions. The implementation of these guidelines may require training HIV clinicians on the tools to assess the comorbidities and other geriatric syndromes.

Manage Polypharmacy in Older Adults The multimorbidity common in older adults living with HIV may result in polypharmacy—the use of multiple medications concurrently. Comorbid disease and high pill burden in older adults with HIV are associated with adverse health outcomes (Back & Marzolini, 2020). Interactions among the medications may result in some drugs losing their efficacy and may increase the potential for toxicity in others (Richterman & Sax, 2020). Because the majority of care for HIV is provided in specialized clinics separate from care for other chronic diseases, reconciling prescriptions can be challenging. We therefore suggest that healthcare providers for older adults with HIV conduct a thorough review of medication during clinic visits, asking patients to bring along all the medications they are using, and de-prescribing where appropriate.

Promote Multidisciplinary Care—Integrate Services and Information Sharing Among Providers Having to seek fragmented and disconnected services for multiple conditions not only is costly but also has an impact on retention. For example, an older adult with HIV and one or more comorbid conditions may be required to visit several healthcare providers to receive care for those conditions. Accordingly, health facilities need to be transformed to integrate services (WHO, 2015b) for older adults with HIV and to share information (Ball, 2014), an approach that has been encouraged for the general population as well (Njuguna et al., 2018). Integration of care will require a multidisciplinary team (HIV clinician, specific disease specialists, pharmacists, social workers, and dietician) working together to provide services for older adults with HIV.

Additionally, integration of health information management systems developed for various conditions could bring together data that would be useful in decision-making and management of older patients. Information from these databases could promote communication among healthcare providers to improve treatment outcomes (Araujo de Carvalho et al., 2017). For example, pharmacists and other care specialists could use the data to inform prescription streamlining and dispensing of medication to reduce pill burden.

Promote Patient-Provider Communication, such as by Engaging Older Care Providers in the Management of Older Adults with HIV A study conducted in western Kenya (Kiplagat & Huschke, 2018) found that older adults desire to have older healthcare providers, as they perceive that they would relate better and the older providers would have better understanding of their needs. Some studies have highlighted healthcare providers' challenges when discussing sexual issues (Mutevedzi & Newell, 2011; Negin & Cumming, 2010), with some suggesting that older adults are comfortable with providers of the same gender when discussing issues related to sex (Pascoal et al., 2017). In any case, individual patient preference may be taken into account to maximize comfort and promote open communication. The need for quality patient-provider communication (Hurley et al., 2017; Wachira et al., 2014) is also emphasized to improve the experiences of older adults seeking HIV care services. We suggest introduction of "older adult-friendly clinics" within the HIV care setting, staffed with older healthcare providers and dedicated to older adults living with HIV.

Expand HIV Service Provision to Community Settings The one-size-fits-all model, or what is commonly known as clinic-based service provision, is common in most countries that provide free HIV care services (Duncombe et al., 2015). Yet healthcare settings face challenges when providing HIV services that make them off-putting to older adults. Healthcare providers spend less time with each patient because of high workloads and the large numbers of patients that generally characterize the hospital setting (Burmen et al., 2017; Abdurahman et al., 2015; Ahmed et al., 2015).

Community ART groups, a model that uses a support-group structure led by a peer or healthcare worker who collects and distributes prepacked ART for group members, have been utilized (Prust et al., 2017). To mitigate facility-related barriers, we suggest promoting ART groups among older adults with HIV. We foresee that this community-based service provision will not only reduce the cost of travel to the facility but also improve access to frail patients, promote medication adherence, and improve health outcomes. Optimal use of other facilities in the community, including faith-based and community-based organizations and mobile HIV facilities, may promote engagement of older adults in HIV care.

Provide Better Amenities in the Healthcare Environment While emphasis is placed on access to HIV care (Yakob & Ncama, 2016; Hardon et al., 2006; Knight et al., 2018), the quality of healthcare facilities in which these services are provided plays a key role in their use. Facilities should consider older people's limited physical capacity. Factors to consider include physical barriers that may be present, limited capacity, and communication barriers due to written signage that may be challenging to older persons who are unable to read or have poor eyesight (WHO, 2015b). Healthcare facilities fall short in providing clean drinking water, sanitary facilities (clean and accessible toilets), and amenities for persons with disability (Kiplagat et al., 2019). For example, a HIV healthcare facility on the second floor of a building that has no elevators or ramps is problematic for older people. Older adults visit washrooms frequently and use lifts more than young persons, and although these amenities are nonclinical features, they influence older adults' use of and continuous engagement in HIV care services (Rachlis et al., 2016a; Yakob & Ncama, 2016). Healthcare facilities, therefore, need to be redesigned to provide age-friendly and integrated services to improve experiences of older adults and achieve retention in care.

Reduce Social Isolation and Strengthen Social Support Services for Older Adults Social isolation/living alone is common among older people living with HIV compared to their younger counterparts (Kuteesa et al., 2014). Older adults have voiced what they perceive to be barriers to receiving emotional and social support from relatives and those close to them. These barriers include nondisclosure or taking longer periods to disclose their HIV-positive status, the desire to be independent and not wanting to be a burden to others, ageism, and others' fear of HIV (Kiplagat et al., 2019; Emlet, 2006). Strengthening peer groups for older adults living with HIV may help increase the social support systems (Brennan-Ing et al., 2017; Cox & Brennan-Ing, 2017) available for older persons—hosting frequent peer group meetings within communities or faith-based organizations. Issues related to managing medication adherence, disclosure and how to deal with stigma (perceived and enacted), health insurance and financial issues, and management of comorbid conditions may be discussed, giving an opportunity for older adults to relate with others who are facing similar challenges.

Improve Food and Nutritional Security Food security and nutrition are often neglected as provision of ART is prioritized, yet they promote ART adherence, reduce ART side effects, and help with regaining strength (Byron et al., 2008). In 2006, all United Nations member states recognized that HIV is interlinked with food and nutrition and committed to addressing nutrition and food security as an aspect of universal health coverage for HIV prevention and treatment; they reaffirmed this position in 2011 (United Nations General Assembly, 2012). Most of these states, including Kenya, have also endorsed the sustainable development goal (SDG 2) to "end hunger, achieve food security and improve nutrition and promote sustainable agriculture" (Griggs et al., 2013). This goal requires that governments adequately invest to ensure sustainable access, availability, and utilization of nutritious foods for their people, including those infected with HIV, by setting up social protection mechanisms (Mall, 2005; Rachlis et al., 2016b) to alleviate financial burden and food insecurity among older adults (Tiyou et al., 2012; Boyer et al., 2009; Hessol et al., 2017). Integrating HIV into programs that focus on agricultural extension to improve food security in communities (Mamlin et al., 2009) will support older adults whose immunity is compromised not only by HIV but also by old age.

Include Older Adults in Clinical Trials Finally, studies have pointed out the unjustifiable exclusion of older adults from clinical trials for reasons such as negative stereotypes, perceived lack of competence, complications in obtaining consent, and the additional time needed to include them as participants (Arrant, 2020; Konrat et al., 2012). If prescriptions will be used among older persons, we suggest proactive inclusion of them as much as possible in the clinical trials testing these medications (Cherubini et al., 2010), which is likely to result in specific treatment guidelines.

Conclusions

In this chapter, we conduct a situational analysis of HIV prevention and service provision in Kenya and identified gaps specific to older adults. Older adults living with HIV face unique challenges that include, but are not limited to, low levels of HIV knowledge, likely to result in limited utilization of HIV testing services, combined with limited access to testing services; multimorbidity and issues with polypharmacy; and inadequate social support. These challenges require a transformed care system that is responsive to older adults. Key to this transformation are greater awareness and education about HIV and STI prevention and control among older adults; training of healthcare providers in geriatric care and the management of an aging HIV population; assurance that older adults have access to social support and are food secure; and proactive inclusion of older adults in clinical trials that evaluate efficacy and safety of HIV medications. The use of community resources like faith leaders in promoting HIV awareness, screening, and linkage to care—perhaps by training faith-based leaders to offer testing and counseling services—may be a potential area to explore.

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Chapter 10
Beyond Policy Fixes to a New Politics of Care: The Case of Older People Living with HIV in Sub-Saharan Africa

Ruth K. Finkelstein, Gregg S. Gonsalves, and Mark Brennan-Ing

Contents

As the population of older people living with HIV approaches four million in sub-Saharan Africa, with numbers continuing to grow for the foreseeable future, it is critical that we develop a policy response to support them in their quest for healthy aging. The aging of people living with HIV in sub-Saharan Africa and elsewhere represents a success story for antiretroviral therapy (ART), but this success also brings challenges (High et al., 2012). Older people living with HIV have increasing needs for health and social care due to multiple health challenges resulting from HIV and age-related chronic conditions, along with other common circumstances of

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growing old (Brennan-Ing et al., 2021). The well-being of older people living with HIV in this region is complicated by the lack of financial, health-care, and community-based resources that support well-being across the life course, such as those available in high-income countries (Hove et al., 2013; Mokomane, 2013; Strydom, 2008; Zekeng, 2016). Our recent experience with the COVID-19 pandemic has brought into sharp relief the interconnected nature of our world and reminded us again that until we address the structural factors that have hampered our efforts to address the needs of older people living with HIV, those same factors will trigger further hardship during each new health crisis.

Older people living with HIV in sub-Saharan Africa are survivors of both HIV-related and non-HIV-related challenges they have faced over the life course, which is a testament to their resilience and grit. However, the chapters in this volume have illustrated that the situation for many of these people remains tenuous, with unmet needs for support in several domains:

- High rates of comorbid health conditions such as hypertension, diabetes, and tuberculosis in addition to HIV and the experience and difficulty of managing multiple comorbid conditions (i.e., multimorbidity)
- A high prevalence of depression and HIV-associated neurocognitive disorders (HAND), which negatively impact engagement in care, ART adherence, clinical outcomes, and quality of life for older people living with HIV
- The lasting impact of an HIV diagnosis on one's ability to adjust and adapt to new health challenges, such as the COVID-19 pandemic
- The recognition that many older people living with HIV remain sexually active but may place sexual partners at risk by failing to engage in safer sex practices like condom use, resulting in new HIV infections
- The negative impact on psychological well-being of comorbid conditions and financial strain among older people living with HIV who care for grandchildren
- The critical role of informal social support from family, which is often outstripped by needs associated with HIV and aging, and the ongoing responsibility of older people living with HIV, particularly women, to provide care and financial assistance to their families
- The lack of financial support to meet basic needs for people living with HIV, particularly for those who cannot work or engage in subsistence activities (e.g., farming)
- The invisibility of older people living with HIV in policy and programmatic efforts regarding HIV prevention and testing and the fragmentation and inadequacy of supportive health-care services

The chapters in this volume underscore the need for policy innovations to support older people living with HIV in sub-Saharan Africa to improve their available health-care and social care resources. However, to develop successful policy initiatives for this population, it is important to grasp the political, economic, and sociocultural context in which aging with HIV occurs. The challenges faced by older people living with HIV are an exacerbation of the lack of assistance generally experienced by older adults in this region (Aboderin & Beard, 2015; Mokomane, 2013; Strydom, 2008).

In this chapter, we review the context of aging in sub-Saharan Africa and explore reasons for the current state of the social care infrastructure in this region. Next, we explore specific issues affecting older people living with HIV in sub-Saharan Africa. To tap into the local knowledge, we consulted with our personal contacts from across the region (Nigeria, Kenya, Tanzania, and Uganda) and asked them about challenges facing older people living with HIV and the responses needed to address these issues. These contacts included program managers, advocates, policy makers, and providers, some of whom are also older people living with HIV. We have used these conversations as a backdrop to provide a more grounded view of the critical issues facing older people living with HIV that reflect larger issues of population aging in this region. We conclude with a discussion of initiatives necessary to support older people living with HIV in sub-Saharan Africa.

The Context of Aging in Sub-Saharan Africa

Population Aging

The global phenomenon of population aging has begun in sub-Saharan Africa, though it was the last region in the world to reach this stage. There were 46 million older adults in sub-Saharan Africa in 2015, with this number projected to increase to 157 million in 2050, the fastest rate of any global region (World Health Organization, 2015). The median age in sub-Saharan Africa is still 18; however, the combination of decreases in fertility rates and increases in life expectancy results in an ever-growing proportion of the population who are aged. Despite the region having the world's lowest life expectancy, on average, a woman in sub-Saharan Africa who lives to age 60 can expect to live for another 16 years (World Health Organization, 2015). The result is that there is a new, expanding group of older people who cannot reasonably meet their basic needs, let alone live in dignity and health, maintained by the small-scale agriculture, trading, and informal sector work that continues to represent the bulk of employment in this region, despite increased urbanization (Golub & Hayat, 2015; Hjort & Poulsen, 2019; Saghir & Santoro, 2018). The policy, institutional, and financial frameworks that support healthy aging in high-income countries are significantly more limited in sub-Saharan Africa.

State of the Region

Any discussion of HIV-specific policy and programmatic approaches to the needs of older people living with HIV must acknowledge and confront the wider social, economic, and political context in the region, which will hamper any HIV-specific initiatives in the long run. For example, the 2020 United Nations Sustainable Development Goals (SDGs) identify the 46 "sub-Saharan" countries (as defined by the United Nations Development Programme) as the region with the lowest baseline metrics on the indicators of progress and, therefore, as the place where the most work is needed to achieve these goals (United Nations, 2020b). The SDG indicators are not the first to identify significant challenges in this region resulting from patterns of low income, high morbidity, high birth rate, rising (but still shorter) life expectancy, and population growth (Hove et al., 2013; Liou et al., 2020; Saghir & Santoro, 2018; Shahbaz et al., 2019).

HIV-specific policy interventions for older people are built upon a bedrock of the rights of older people to social security and to an adequate standard of living as laid out in the major international human rights instruments, beginning with the Universal Declaration of Human Rights (UDHR) in 1948 (International Labour Office, 2021). However, declaration of rights does not guarantee their achievement. Therefore, universal access to social protection for those who cannot work and to health care remain key components in the UN's first and third SDGs, respectively. According to the International Labour Office (ILO) World Social Protection Database, the region has the lowest levels of income support and universal health coverage in the world. Legally, 40% of older people in sub-Saharan Africa are entitled to old-age income protection, but effective coverage is less than 20% of the older population. Similarly, just over 15% of people in the region have effective coverage by a universal health system (International Labour Office, 2021). Consequently, consideration of policy for older adults living with HIV in sub-Saharan Africa begins with addressing the barriers to these fundamental social protections.

Structural Barriers to Social Protection

The Nobel Prize winning development economist Amartya Sen once said: "No famine has ever taken place in the history of the world in a functioning democracy." Democratic governments, he said, "have to win elections and face public criticism, and have strong incentive to undertake measures to avert famines and other catastrophes" (Sen, 1999, p. 16). Sen's thesis has its supporters and detractors, but it is clear that in the case of famines, a measure of human complicity is required. In responding to a report by USAID's Famine Early Warning Systems Network on the 2011–2012 famine in Somalia, Oxfam's local in-country director said, "Famines are not natural phenomena, they are catastrophic political failures. ... The world was too slow to respond to stark warnings of drought, exacerbated by conflict in Somalia, and people paid with their lives" (AJ Correspondents, 2013).

The situation of older people living with HIV in sub-Saharan Africa, and the associated larger struggle for dignity and support for older adults on the continent, must also be seen as a human creation, the result of policy choices made domestically and internationally to keep older people in poverty. As economists Daron Acemoglu and James Robinson argue in their book *Why Nations Fail: The Origins of Power, Prosperity and Poverty*, "... poor countries are poor because those who have power make choices that create poverty. They get it wrong not by mistake or ignorance but on purpose" (Acemoglu & Robinson, 2012, p. 68). Thus, as we confront the fact that there is little support for older people living with HIV in most, if not all, countries in Africa, we must realize that this is a larger problem of social protections and economic organization and one that can only be seen through the lens of the political economy on the continent.

Acemoglu and Robinson, the authors of the *Palgrave Handbook of African Political Economy* (Oloruntoba & Falola, 2020), and many other experts describe the extractive nature of the global economy, which strips African countries of their natural resources. Meanwhile, local political elites amass wealth at the expense of the rest of their countries' residents, resulting in the engine of economic exploitation that reigns on the continent. International institutions and the high-income countries that control them have their own role. For example, the Bretton Woods system-imposed structural adjustment policies of the 1980s threw countries on the mercy of the market and pushed privatization, trade liberalization, and shrinking budget deficits at the expense of expanding government services, including social protections (Elson, 1994). It is no surprise that this one-two punch, an extractive, exploitative run on African economies and the discouragement of social welfare expansion, has left older people, and practically everyone else on the continent, without safety or succor.

What is less well recognized and discussed is the role of the HIV/AIDS response in perpetuating the status quo. Alex de Waal, in his 1997 *Famine Crimes: Politics and the Disaster Relief Industry in Africa* and his more recent 2018 book, *Mass Starvation: The History and Future of Famine,* builds on Sen's insights about the political roots of famine and points to the role of what he calls the *humanitarian international* in perpetuating food crises (de Waal & de Waal, 1997; de Waal, 2018). In de Waal's analysis, international humanitarian agencies depend on famines for self-perpetuation, organizational survival, and growth and so ignore the political roots of famine and direct focus on the role of charity—their own—in addressing crisis after crisis. The same critique can be made of the *AIDS international* in perpetuating its own needs in the context of the HIV epidemic (de Waal, 2006, 2021; Gonsalves, 2006a, 2006b). Like de Waal's humanitarian international, the AIDS international, composed of large institutions like the Global Fund, the President's Emergency Plan for AIDS Relief (PEPFAR), and the nongovernmental organizations (NGOs) that spend their money, remain largely unaccountable. These bodies are self-justifying, pursuing organizational survival and expansion; serving as proxies for policies of the major industrialized countries; privileging generalized international responsibility instead of specific local political accountability; privileging technical skill and experience over local knowledge; and promoting demonstrations or assistance instead of sustainable social change (Bukenya, 2018; Olakunde et al., 2019).

The cumulative effects of the policy choices that have been made at the expense of the well-being of people both young and old in sub-Saharan Africa, and the unintended consequences of the well-intentioned yet self-serving nature of AIDS international, have left older people in the region, including those with HIV, vulnerable in three domains critical to healthy aging: economic well-being, accessible health care, and an adequate system of social care.

Economic Well-being

Lack of Pensions and Other Income Support

Ironically, while at least some form of old-age pension exists on paper for every country in sub-Saharan Africa, the effective coverage is shockingly low (International Labour Office, 2021). Exceptions are countries with universal noncontributory plans (so retirement income does not depend on employer or individual contributions during work years) or places where the government or an NGO makes contributions for some working people. Eight of the 46 countries in the region have between 85% and 100% effective pension coverage (International Labour Office, 2021). These include South Africa, Eswatini, Seychelles, Namibia, Mauritius, Lesotho, Cabo Verde, and Botswana. Thirty-four countries, on the other hand, have effective coverage below 20%. The single biggest reason for the gap between the legal frameworks for the old-age social protection programs and their covered populations is the prevalence of informal sector work, estimated at or above 85% for the region (International Labour Office, 2017).

Most countries affirm the right to an old-age pension and are piloting small demonstration programs for their provision in specific areas and/or with specific populations. In Africa, contributory social security programs are widespread but often limited to the narrow sector of people engaged in formal employment, while noncontributory and means-tested financial safety net programs are less commonplace (Mthethwa, 2014). A further significant limitation to the existing old-age pensions is that the amount paid is extremely low. Only four countries (Mauritius, Seychelles, one state in Nigeria, and Uganda) pay pensions that are more than 50% of the minimum wage. Yet Uganda pays this potentially adequate pension to less than 7% of the people who are income- and age-eligible to receive it. Income support for disability benefits effectively exists for less than 1% of the estimated eligible population, except in South Africa (International Labour Office, 2017). Thus, the context of older people living with HIV receiving minimal and inadequate income support is ubiquitous among most older adults in the region.

The result of the limited receipt of pensions and their inadequacy is that the labor force participation rates for people over 65 years in these 46 countries, per the ILO, are the highest in the world, topping out at 96% in Malawi (Staudinger et al., 2016). Older people must work until they literally drop dead. Obviously, this is an unacceptable condition for anyone, but even worse for people managing their own illnesses and those who are simultaneously caretakers for others, as are many older people living with HIV.

Financial Strain Among Older People Living with HIV: Local Perspectives

Economic deprivation is a persistent problem in sub-Saharan Africa regardless of age or HIV serostatus. Our contacts reported that few older adults in the region have access to pensions and most rely on their families for financial support in old age. However, these families are often of limited means, and for many older people living with HIV, such family support is unavailable. This group includes single women without children, parents who have lost children due to AIDS, and childless widows when their husbands' families shirk their responsibility to provide financial support. In some cultures, women do not inherit familial wealth when their husbands die, leading to an impoverished old age.

Our contacts confirmed that direct financial support in the form of cash transfers for older people in general or for older people living with HIV is uncommon. When present, such assistance is typically provided by NGOs and at levels inadequate to meet basic survival needs. Many described older people living with HIV outside of urban areas as typically engaging in small-scale farming or petty trading to stretch limited means. There has been interest in promoting income-generating activities, such as engaging in commercial farming or teaching others how to produce and sell crafts like beadwork. Other schemes to address financial need involve pooling monetary resources, situations where community members contribute to a specific cause to help a neighbor or contribute to a collective fund that is later distributed by lottery. While these proposals have the potential to alleviate financial hardship for a few individuals, they do not provide a social safety net designed to support people living with HIV and other individuals in later life, nor can they conceivably be construed as contributing to the structural reform necessary to address poverty in the region.

Health Care

Access to Health Care

Universal health care is an urgent priority for people of all ages and the subject of repeated unrealized international and regional commitments and plans (Boerma et al., 2014). Only Kenya has universal national health insurance on the books for people aged 70 and older, though implementation remains “in process.” Other countries, like South Africa, are attempting to launch such insurance schemes but face obstacles such as corruption, lack of political will, and competing interests from stakeholders (Michel et al., 2020). Most countries offer some specific services, often designed and funded by international aid groups, including significant provision of HIV treatment. Much of the available health care has been created by de Waal’s humanitarian international and is, therefore, responsive to priorities set far from the affected countries. While older adults can potentially receive care in systems designed with different needs in mind, access, quality, and adequacy of care all suffer. Obviously, if there is no care designed for older adults, it is axiomatic that there is no care for older adults living with HIV.

While most HIV treatment services are provided at no cost, there is current talk of implementing user fees for PEPFAR-supported programs that would create additional barriers for older people living with HIV in poverty or near poverty (Banigbe et al., 2019). Beyond PEPFAR or Global Fund-supported programs for HIV care, there is a scarcity of health-care resources and of subsidy or coverage for care. In 2020, sub-Saharan Africa had 12.6 skilled health-care workers per 100,000 population. Estimates of an adequate ratio vary, but WHO suggests 59.4 per 100,000. The dearth of services and travel times are greater in rural areas (International Labour Office, 2021). While there have been expansions in coverage of essential health services for specific populations in a few countries in recent years (notably, Kenya and Rwanda), effective coverage of essential health services remains at 15.7% of the population (International Labour Office, 2021). There are few or no free health services in many places on the continent. This means that in the context of financial burdens on older people living with HIV, for them to receive care for anything other than HIV (or TB) requires the mobilization of resources to pay for it in most of the region.

Structural and Psychosocial Barriers to Health Care: Local Perspectives

Our local contacts, as well as several authors in this volume, identified fragmentation of health services as a barrier to adequate medical care. Because they are most commonly individual projects of international aid organizations, HIV care, general medical care, sexual and reproductive health care, and mental health services are often delivered in separate locations by different entities, making the provision of integrated care impossible. This situation exacerbates the problem of accessing services for many older people living with HIV who face transportation barriers. Transportation barriers exist not only for older people living in rural areas far from health-care providers, which tend to be located in urban areas, but also for those who live in urban areas and cannot afford transport or have limited mobility. One person spoke about transportation barriers newly faced by people living with HIV who return to rural areas upon retirement. For older people living with HIV in rural areas, there are programs that rely on community health centers and health outreach workers, nurses, and physicians to bring health care to those who live far from facilities. However, this model does not work well for those newly diagnosed with HIV or those with unstable health conditions. Recently, shutdowns due to the COVID-19 pandemic have prevented many older people living with HIV from accessing the health care they need, according to our local contacts.

Our contacts also identified significant economic barriers to health care in addition to the cost of transportation. They noted that the vast majority of older people living with HIV have never had the benefit of health-care coverage outside of HIV care. In most parts of sub-Saharan Africa, economic deprivation also results in barriers to accessing medication. People may not be able to afford to purchase the full prescription and may take medications for only a few days rather than the full course prescribed, which can lead to drug resistance or renewed symptoms. This situation seems particularly dangerous for older people living with HIV and with chronic conditions that require daily medication, such as hypertension or diabetes.

HIV stigma emerged as a recurrent theme in the realm of psychosocial barriers to care. Older people living with HIV may avoid accessing HIV care at public clinics because it results in inadvertent disclosure of their serostatus. They may also have difficulty speaking with younger health-care providers in clinical settings because they are ashamed that they are HIV positive. It was also mentioned how other stigmatized identities, such as being formerly incarcerated or being MSM (a man who has sex with men), intersect with HIV stigma and present additional barriers to care. Women who bear the brunt of family responsibilities face particular barriers to care because of long wait times for services, long lines, and concomitant childcare responsibilities. Violence against women, particularly intimate partner violence, was also mentioned as a barrier for women seeking HIV treatment services.

Difficulty in Addressing Comorbidities: Local Perspectives

Our local contacts identified several other issues around screening and treatment of HIV-related and age-related comorbid conditions, in addition to care fragmentation and lack of insurance coverage. As in high-income countries, older people living with HIV in sub-Saharan Africa have difficulty managing multiple comorbidities in addition to HIV—for example, having to take multiple medications in addition to ART, with resultant polypharmacy and potentially dangerous drug-drug interactions. One person described difficulty in accessing a form of ART that would not further complicate her diabetes. There was also concern about the lack of research on the long-term effects of ART and potential side effects of ART that can result in comorbid conditions (e.g., liver or renal toxicity). This problem is exacerbated by the lack of infrastructure in many places to provide laboratory tests for common side effects of ART and to diagnose and manage key comorbidities such as diabetes and hypertension. Health-care workers, particularly health aides and community outreach workers, lack standards of care to guide the treatment of multiple comorbid conditions among older people living with HIV and require additional training.

Systems of Social Care

Adequacy of Informal and Formal Social Supports

Another need for older adults everywhere is social support, including both the informal caregiving and assistance with housing and other material needs that families and neighbors provide, and the public and private institutions that turn those same functions into services delivered by paid personnel for people whose families are unable to do so. In sub-Saharan Africa, in addition to the barrier of underinvestment in human capital, there is the dominant pan-African myth that “families care for their own.” Some scholars question the extent to which such “filial piety” was ever as ubiquitous as claimed (Aboderin & Hoffman, 2015), but existing trends of globalization, urbanization, migration for work, and the increase in number and proportion of women in the wage workforce have made care of older people by families and neighbors more difficult. Further, the role of older people as carers for widows and orphans of the HIV/AIDS epidemic is well documented (Small et al., 2017). Therefore, the need for paid social services for older adults (and others with disabilities) is increasing. This presents another need made more imperative by having an aging population, a reality that has not yet been addressed by governments in this region. And this is yet another instance where the dearth of social care designed for older people living with HIV is but a subset of the limited social support available for people beyond what is provided informally. With these structural deficiencies in health care and social protection generally across the continent, addressing the situation of older people living with HIV requires looking toward more structural reforms, as small, piecemeal initiatives through PEPFAR or the Global Fund will never meet the needs of older people in Africa.

The Invisibility of Older People Living with HIV in Service Provision: Local Perspectives

Our contacts shared that while the situation has improved over the last decade, HIV is still overwhelmingly viewed as a disease that primarily affects young people, rendering older people living with HIV and their needs for support invisible. Many people with HIV who advocated for the needs of this population have grown older and have become less engaged in activism. Our contacts confirmed that there are few social service programs supporting older people in general or older people living with HIV. To compound the problem, funding for specialized programs to support people living with HIV is being reduced, and this type of support is shrinking rather than being expanded. Thus, this group is largely forgotten.

Others mentioned that older people are not perceived as being sexually active, and thus there is a lack of HIV testing for older people in the general context of ignoring the sexual health needs of older adults. HIV tests are rarely administered to older people unless it is part of a general medical work-up focused on other comorbid conditions. Because of this perspective, adults who seroconvert in later life are even more invisible in HIV treatment and care services. In addition, the idea that most people living with HIV would not survive to old age has hampered efforts to develop services to support aging with HIV.

A prominent theme in the conversations with our local contacts was that existing services and interventions for people living with HIV, including education and information campaigns, largely target younger people such as adolescents and young women. This focus is due in part to a failure to consider the needs of older people in policy frameworks, including those focused on HIV. One person noted that because only 10% of the people in her country are 65 and older, they are a neglected and forgotten group in society. When policy discussions do not address the needs of older people living with HIV, opportunities to advocate for funding to support them are lost.

Our contacts noted that some countries, like Kenya, have begun to include older people living with HIV in the development of policy frameworks, but the benefits of this approach have yet to be realized. There have also been some positive developments in providing services for older people living with HIV that have germinated out of private NGOs specifically focused on older people. There was a suggestion that successful programs for younger people living with HIV could be recalibrated to meet the needs of older adults.

Our local contacts offered two solutions to combat ageism as it relates to HIV in sub-Saharan Africa. The first is to mount public education campaigns to raise awareness of the growing number of older people living with HIV in the region and their need for specialized services. These campaigns should feature the lived experience of older adults themselves, including the fact that many remain sexually active and are still at risk for acquiring HIV or, if seropositive and not virally suppressed, infecting others. The second suggestion is to strengthen advocacy efforts around aging with HIV. This initiative would involve forming coalitions of existing advocacy groups as well as enlisting older people living with HIV to mobilize and articulate their need for a greater level of services and support.

Policy or Politics?

What if the situation we have described here, in which older people living with HIV in sub-Saharan Africa—and older adults in general—are left to fend for themselves, requires a political solution, not a technical one or simply larger grants from the Global Fund or a larger tranche of aid from the Department for International Development? What if the focus on these international agencies is distracting from the local political work needed on the continent to address the structural barriers to care and support? What might a transition from economies of exploitation to economies of care entail (Ndlovu-Gatsheni & Oloruntoba, 2020)? How might it be achieved in the context of work on the AIDS epidemic?

The Political Economy of Care

It is another pandemic, COVID-19, that has started a conversation about a new politics of care in both the Global North and South. A full-scale realignment of political and economic priorities is needed to avoid catastrophes like those the new pandemic has wrought all across the globe (Ndlovu-Gatsheni & Oloruntoba, 2020). Increasingly, activists are calling for a commitment to universal provision for human needs, eschewing an economy of abandonment and ensuring that new kinds of threats are dealt with by addressing the root causes of the disparities glaringly apparent in what we have all faced since 2020 (Dowling, 2020; Gonsalves & Kapczynski, 2020). If the AIDS epidemic was unable to set the stage for such a realignment, new political opportunities may be opening up now.

In July 2020, the Committee for Development Policy, a subsidiary body of the United Nations Economic and Social Council, called for a new multilateralism where "global rules should be calibrated towards the overarching goals of social and economic stability, shared prosperity and environmental sustainability and protected against capture by the most powerful players" (Committee for Development Policy, 2020, p. 5). At the end of 2020, UN Secretary General António Guterres expanded on these ideas in a speech to commemorate the 25th anniversary of the World Summit for Social Development: "The pandemic brings new awareness of the social and economic risks that arise from inadequate social protection systems, unequal access to health care and other public services and high levels of inequality, including gender, race inequality, and all the other forms we witness in the world. It can therefore open the door to the transformational changes needed to build a New Social Contract at the national level that is fit for the challenges of the 21st century" (United Nations, 2020a).

Reorganizing the AIDS Response Around a Politics of Care

All of the structural issues called out as the root causes of the inadequate global response to the COVID pandemic have also been named as barriers to the adequacy of response to care for older people living with HIV in Africa. If both are determined by structural issues that keep social protections out of the reach of most people on the planet—not just the aging population or those in Africa—then part of the HIV/AIDS response must address root causes of this predicament. Of course, the provision of HIV treatment and other services cannot wait for these structural reforms to happen, and support for older people living with HIV through programs like the Global Fund and PEPFAR is necessary. However, the current structure will always be insufficient and, in a climate of shifting global health and development priorities, subject to the whims of the moment and of donor nations. Thus, while advocacy is often not the purview of service providers and NGOs involved in HIV care, or is only a minor part of their remit, new efforts on these broader issues in collaboration with organizations working in other areas of health and human development are vital to pave the way for long-term sustainable solutions on the continent. In fact, reorganizing the HIV response to prepare for the post-HIV/AIDS era, when dedicated funds for the disease disappear, is an unavoidable responsibility; there is no question about whether there will be a transition from HIV-specific funding to general local, domestic support. The only question is when this will occur and how long the transition will take.

Despite this imperative, the short-term incentive for AIDS organizations is survival. It is common for NGOs to prioritize donors' needs, particularly in countries in which democratic governance is weaker and the independence of these organizations is in question (Oberth et al., 2016). In addition, these same settings make it difficult for NGOs that prioritize advocacy to themselves survive and to influence the local political process (Parks, 2008). If de Waal maintains that humanitarian organizations perpetuate a cycle of famine and food crises, the architecture of the HIV/AIDS response may similarly be partly responsible for perpetuating the precarity and inadequacies of the response to the HIV pandemic itself, by creating a situation in which the root causes of these problems are obscured by the short-term imperatives for NGOs.

The lack of services for aging populations living with HIV is a political crisis tied to local and global political economies that do not prioritize human needs. Facing this fact head-on, rather than simply calling for more donor investment or calling to redirect existing resources toward the older population, is the start of working toward a solution.

If de Waal remains a critic of the bureaucracy of humanitarianism in *Famine Crimes*, in his later work on AIDS and current work on COVID-19, he speaks encouragingly of the response to the AIDS epidemic—not the vast infrastructure of NGOs that has sprung up around the world following the Global Fund and PEPFAR, but the political work in countries around the world to challenge governments to respond to the epidemic. In this more recent work, he maintains "there can only be a democratic public health" and "well-articulated political demands shape the politics of public health. Democracies can *demand* public health" (de Waal, 2020).

Rather than clamoring for services, we must be demanding human rights and shaping local, regional, and global claims for these rights in the context of democratic governance, testing the boundaries of more repressive states against these claims. HIV/AIDS activists, even in places like Russia, have been able to secure significant concessions in access to HIV treatment with this very approach (Nartova et al., 2020). And in other settings extraordinary progress has been made in terms of ART coverage through the concerted efforts of activists on the ground. For instance, the Treatment Action Campaign in South Africa was able to move a recalcitrant ruling party from AIDS denialism to the establishment of the largest ART program in the world in less than a decade (Sabi & Rieker, 2017).

These same AIDS activists have branched out to cover new diseases, like tuberculosis and hepatitis C, seeing their own health and that of their comrades as endangered not by HIV alone. In fact, members of the Treatment Action Campaign took this work further in establishing spinoff groups such as Equal Education and the

Social Justice Coalition, which advocated for better schools, sanitation, and public safety around a set of constitutional rights, making demands on an often corrupt and unresponsive state.

More recently, many of the AIDS activists working in the early part of this century on access to ART, along with new campaigners, have pivoted to access to COVID-19 vaccines under the broad banner of a movement for a "people's vaccine," confronting their own governments, pharmaceutical companies, and multilateral agencies like GAVI and COVAX for creating a "vaccine apartheid" across the globe. This political challenge being made by activists is far more sweeping given the scope of the COVID-19 pandemic and provides yet another template for action on social protections, care for older adults, and those aging with HIV. In fact, this work on vaccine access and the larger critiques being made about the political, economic, and social causes of our current predicament, along with the calls for a New Social Contract and a new politics of care, are all coalescing around a set of claims on governments, international institutions, and private entities. It is these entities that can address the structural failures to invest in the health and well-being of the vast majority of people on the planet, including on the African continent.

It is clear that any short-term solutions to alleviate suffering for older people in sub-Saharan Africa, including those with HIV, will reach only a few, will be dependent on the whims of international donors, and will be insufficient to address the stark inadequacies in care and support for the older adults. As Augustine of Hippo said 1500 years ago, "Charity is no substitute for justice withheld." While it is vital to address immediate needs by expanding programs to explicitly include older people living with HIV, bringing justice to older people living with HIV on the African continent—and older people everywhere—requires a new approach. This imperative calls for an approach rooted in the historic work of AIDS activists across the globe—people who made great strides in the AIDS response in the early years and who are now called to a higher duty.

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Chapter 11
Concluding Thoughts

Catherine MacPhail, Janet Seeley, Kristen E. Porter, Jennifer E. Kaufman, and Mark Brennan-Ing

Contents

Across all chapters in this book, the authors have highlighted that ageing with HIV is a recent phenomenon in African countries, made possible by advances in the development of antiretroviral treatments (ART) and advocacy for reduced drug costs. Many of us remember earlier times in the HIV epidemic when ageing after an HIV diagnosis was not in our collective imagination or experience; we should not lose sight of that memory. We can celebrate that ageing with HIV is now possible and should continue to be possible with fair access to treatment, across the world (Beck et al., 2019).

We need to direct attention and resources towards sustaining and nurturing people living into older age with HIV (Siedner, 2019). Past research has focused on older people's caring roles within families where middle generations were decimated by HIV (Powell & Hunt, 2013). Several chapters in this volume build on that

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body of work to examine the significant caring role that continues for older people living with HIV. However, the focus shifts to the well-being of those carers. Bernard and de Rekeneire (Chap. 6) note in this volume that we need to consider a range of domains, including the social and psychological, in order to ensure that older people living with HIV continue to lead productive and contented lives, even when managing comorbidities. The two chapters on social support by MacPhail et al. (Chap. 7) and Brennan-Ing et al. (Chap. 8) suggest that it is the daily reality of personal requirements and familial responsibilities that will most impact how older people are able to manage ageing with HIV. Across both South Africa and Uganda, the countries these two chapters focus on, the failure of essential family support structures would have dire consequences for the capacity of people living with HIV to be sustained into and through their old age.

Yet we cannot advocate for, manage, or celebrate ageing with HIV where we do not have data that recognise this population as being significant in the twenty-first-century global HIV experience. Historically, as noted by Gómez-Olivé in his chapter (Chap. 1), HIV data have focused on those of (so-called) "reproductive age" (18–49 years). Assumptions about declining sexual activity prevent acknowledgement of an older population at risk of both becoming infected with HIV and sharing HIV infection with others. While there have been moves in several African nations to include those over 49 years of age in sentinel and other HIV data collection initiatives, more needs to be done to promote an uncapping of the age span for which we consider HIV to be meaningful. This has been suggested by UNAIDS, but with limited uptake, even in its own publications (see, e.g. UNAIDS, 2021). Specifically, the focus of the promotion of the 90-90-90 strategy to under-50s should be reconsidered in light of the globally ageing HIV population. Older people living with HIV cannot be supported adequately as they age if they are treated as an exception in the HIV-related data or simply not counted (Negin & Seeley, 2021).

There is still work to be done on challenging social norms that assume declining sexual interest and sexual activity in older age. While we are comfortable in acknowledging that people are living longer, and therefore ageing with HIV, recognition of older people as sexual beings who remain at risk of HIV infection is less advanced (Negin et al., 2016). A lack of recognition is coupled with the stigma, particularly for older women, of being found to have an infection associated with sexual activity. This means that as well as supportive treatment with counselling and living environments for older people already living with HIV, we need to ensure the expansion of preventative interventions, information, and services to older people more generally. Brennan-Ing et al. (Chap. 4) note in their chapter on sexual health that our blindness to HIV-related risks among older people has been a roadblock to older people being tested for HIV, being provided with counselling, and accessing treatment, leading to diagnosis being delayed until a person has more advanced and more complex HIV disease.

While the concerns about HIV prevention are justifiably focused on young women in sub-Saharan Africa—the group with the highest incidence in a number of different settings (UNAIDS, 2021)—we cannot ignore their grandmothers and grandfathers. As Porter et al. (Chap. 5) recommend, long-term strategies and interventions to address the increasing needs of older cohorts, including grandparent caregivers, as they age with HIV are vital; this includes advocating not only for treatment and care for comorbidities but also for mental well-being and socioeconomic support. With this focus, we also need to acknowledge that the experience of HIV among older people is gendered. Older women are often burdened with care responsibilities and may be growing old isolated from friends and peers, yet they are still, sometimes, seen as a burden by relatives. Ironically, in places such as South Africa where old age pensions exist, ageing relatives are valued for their productive role in bringing income to the home. During the COVID-19 pandemic in South Africa, when jobs have been lost or wages reduced, having a pensioner at home has provided a lifeline for some families (Cantillon et al., 2021).

In sub-Saharan Africa, there are wide variations in the availability of health-care services, the historical response to HIV, and the experiences of different individuals and groups during the different phases of the epidemic in different places (as Seeley and Mugisha, Chap. 3 observe in their chapter). This legacy can affect older people's responses to the provision of care, often in very positive ways, since they know the devastation the infection can bring, but it can also affect their views of treatment and the trust they place in drugs continuing to work against such a strong disease.

Much has been written about the success of the rollout of focused HIV care provision and the move to differentiated care, which recognises that people in different circumstances need to access that care in different ways (Grimsrud et al., 2016). Despite these moves, we still lack multidisciplinary and multiple-disease-focused health-care settings suitable for older people living with or at risk of HIV infection who also need care for other chronic conditions. In their chapter in this volume, Kiplagat et al. (Chap. 9) suggest that work is needed to ensure that this population is not ignored and that appropriate changes to health-care systems, including task shifting, might assist in avoiding fragmented care. Matlho et al. (Chap. 2), writing about Botswana, take this further, suggesting that the neglect of the management of HIV infection in older people may have implications for the increasing burden of comorbidities that require care. They highlight the importance of managing tuberculosis (particularly among men) and hypertension to enable a healthier ageing process for people living with HIV.

We acknowledge that this volume is particularly focused on a small number of sub-Saharan African countries, particularly in eastern and southern Africa, and the experience of ageing with HIV is broader than that represented in this book, not least because some of the countries included here have very specific historical and social contexts. The apartheid history of South Africa and the historical stability and small population size of Botswana are not reflected in other countries of the region. Additionally, our work here has focused specifically on heterosexual experiences of ageing with HIV, and we have not examined the experience of sexual minority or gender diverse older people. Yet the material in this book does draw attention to particular dimensions of the experience of ageing with HIV which may resonate with the experience in countries that have small populations living with HIV, such as in North Africa, where services tailored to the needs of older people may be scarce.

Finally, as the content of the chapters in this volume shows, the experience of ageing with HIV in sub-Saharan Africa is varied and for many very hard. These older people are survivors; they have lived to see ART transform HIV into a chronic condition, to support them and others in growing old. Memories remain—for some these are quite recent memories—of lives cut short by HIV, by difficult and painful deaths of people they nursed and cared for, which can make it hard to trust the treatment to keep working. It seems particularly harsh that many of these people who are now over 50 were dogged by the threat of AIDS in their younger years and recently have faced the threat of COVID-19 in their older age. Finkelstein et al. (Chap. 10) in this volume underscore that the challenges faced by those ageing with HIV in Africa are couched in the larger context of a lack of policies and programmes to support economic security and social care among older people in general, despite the formulation of yet-to-be-realised policy frameworks to address this issue. Being able to provide a social safety net for older and younger Africans alike will require fundamental reforms to governance and service provision. Meaningful change in the relationship between African countries and high-income nations is also needed to empower Africans to have greater control of their own destinies.

While documenting the challenges and hardships older people living with HIV in Africa have faced, we celebrate their lives in this volume—and we acknowledge the resilience so many older people continue to show. We hope this collection can contribute to knowledge that builds a better future for everyone living with HIV.

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