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

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Contents

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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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