

Ageing with HIV: Psychological and Functional Wellbeing and its biopsychosocial determinants at the Kenyan coast



By

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DECLARATION

I, **Patrick Nzivo Mwangala**, declare that this PhD thesis is my own, unaided work, except where specific references cited to the work of others. It is being submitted for the Degree of Doctor of Philosophy degree at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other university.



(Signature of candidate)

Date: 6th day of November 2024

DEDICATION

This research is dedicated to my loving family, particularly to my mother, Naomi Mnyazi, who taught me the value of education even though she never had the chance to go to school; my elder brother, John Mrima, for constantly fanning into flame the spirit of excellence in me; my wife Nancy for her prayers, support and understanding during my academic and research career; and my daughter Nylah whose arrival has made me stronger, better, and more fulfilled. To my Heavenly Father, all glory and honour is unto you. I testify of your providence, strength, wisdom, inspiration, faithfulness, and all-sufficient grace!

Thesis Abstract

Background:

Kenya, and sub-Saharan Africa (SSA) in general, are experiencing rapid demographic transitions, including the ageing of the HIV population. Intuitively, this has created a subgroup of vulnerable older adults living with HIV (OALWH) requiring an urgent response in research, policy, and programming to mitigate their complex and transitioning needs. Existing evidence on HIV and ageing, largely from European cohort studies, demonstrates that OALWH are vulnerable to ill health, especially psychological morbidities (e.g. mental and cognitive impairments), geriatric syndromes (e.g. frailty) and multimorbidity. For the last decade, the SSA region has witnessed noteworthy progress in ageing and health, e.g. the establishment of health and ageing cohorts in South Africa. Yet, current evidence on mental, cognitive, and geriatric syndromes among OALWH is inadequate from the region partly because of heterogeneous findings, few well-designed studies, and significant methodological limitations, e.g. small sample sizes, lack of comparison groups and few adapted/validated measurement tools. In Kenya, HIV and ageing is an emergent subject, and little is known about the burden and determinants of these impairments.

To address some of these research gaps, this PhD thesis sets out to:

- (a) Understand the health challenges faced by OALWH and the coping strategies they use to confront these challenges on the Kenyan coast,
- (b) Document the burden and associated factors of common mental disorders (CMDs) and frailty among OALWH compared to their HIV-uninfected peers on the Kenyan coast,
- (c) Examine the acceptability, reliability, and validity of a local (Swahili) measure of cognitive function, the Oxford Cognitive Screen Plus (OCSPlus), among older adults and provide a preliminary understanding of their cognitive performance (by HIV status) and associated factors.

Methodology:

We used a mixed methods research design to answer our research questions, employing both qualitative and quantitative approaches. The qualitative phase of the study recruited 34 OALWH receiving routine HIV care and treatment, together with their healthcare providers (n=11) and primary caregivers (n=11). Qualitative data were drawn from semi-structured in-depth interviews that were audio-recorded, transcribed verbatim, and analyzed using the framework approach. Data management was done in Nvivo software. The quantitative phase, a cross-sectional survey, involved 440 older adults aged ≥ 50 years (58% OALWH). Locally adapted and/or validated tools were used to assess CMDs, frailty and cognitive function. All quantitative analyses were conducted using STATA software. Proportions were used to estimate the prevalence of CMDs and frailty among OALWH and their HIV-uninfected peers. Logistic regression was used to examine the factors associated with CMDs and frailty. Different psychometric tests were used to assess the reliability and validity of the OCSPlus tool. Test-retest reliability was evaluated using intra-class correlations. We computed Pearson correlation coefficients to assess convergent validity between OCSPlus and conventional cognitive tests. Multiple linear regressions were used to examine correlates of cognitive function.

Results:

Our findings from the qualitative phase showed that OALWH face multiple mental health challenges (e.g. symptoms of depression, anxiety, cognitive complaints) and physical health challenges (e.g. hypertension, diabetes, ulcers, somatic symptoms, and functional impairments), which were often complicated by a host of psychosocial challenges including food insecurity, ageism, HIV-related stigma, loneliness, and financial difficulties. Many of the perceived risk factors for these challenges were observed to overlap across the three health domains. Five major themes emerged from analyzing participants' narratives on coping strategies, including self-care, positive religiosity, social connectedness, generativity and identity and mastery. Our findings also revealed maladaptive coping strategies, including self-isolation, over-reliance on over-the-counter medication, delayed healthcare seeking and skipping meals and medications. In the cross-sectional dataset, we found no significant differences in the

prevalence of mild depressive symptoms (24% vs 18%) and anxiety symptoms (12% vs 7%) among OALWH compared to their uninfected peers, respectively. However, the prevalence of frailty was significantly higher among OALWH (24%) than their uninfected peers (13%). After adjusting for biopsychosocial factors, HIV seropositivity was not independently associated with CMDs or frailty. In multivariable analyses, the factors associated with increased odds of CMDs and frailty included HIV-related stigma, ageism, loneliness, functional impairment, sleeping difficulties, increasing household HIV burden, chronic fatigue, increasing medication burden, advanced age (>70 years), higher waist/hip ratio, visiting traditional healers, history of combination antiretroviral therapy (cART) regimen change/interruption, and prolonged illness following HIV diagnosis. In contrast, factors associated with reduced odds of CMDs and frailty included easier access to an HIV clinic, residing in larger households, higher household income, having a social network of friends, and being physically active. Most of these factors were corroborated in the qualitative phase of the study. In our last objective, the OCSPlus measure was found to be acceptable, reliable, and valid. Concerning cognitive performance, OALWH presented with significantly lower mean scores on language and executive function compared to their uninfected peers; however, they (OALWH) performed significantly better on memory. Several factors ranging from behavioural and lifestyle, sociodemographic, medical or treatment factors and psychosocial factors were significantly associated with cognitive performance (using OCSPlus).

Discussion:

Due to effective antiretroviral therapy (ART), people living with HIV are ageing, and this is witnessed across the world wherever ART is readily available. While this represents the success of HIV care and treatment, those ageing with HIV confront numerous health challenges, some of which are unique to this population, as observed in this study. Older adults living with HIV on the Kenyan coast are vulnerable to mental, cognitive, and functional health challenges, which appear to be complicated by several psychosocial challenges. Despite the observed health challenges, OALWH are able to integrate several positive strategies to promote or address their mental health and well-being. The findings of this study are timely in addressing some of the existing gaps in

understanding the mental, cognitive, and functional health of OALWH in the country and set the stage for further research and the development of relevant interventions and healthcare strategies to improve the care of these adults.

OALWH need to be recognized as an unique subpopulation requiring targeted health and social services, given the unique health challenges observed in this study.

Relatedly, there is a need to build the capacity of healthcare providers, for instance, in the screening and management of CMDs and frailty, at least for the OALWH at risk of poor health outcomes, e.g., those facing multiple psychosocial challenges and deteriorating HIV treatment indicators. The majority of healthcare providers interviewed in the qualitative phase lamented their lack of skills and capacity to screen and manage CMDs and cognitive impairments. Additional support may include helping OALWH and their caregivers to mobilize social support and referrals, where possible, to relevant institutions and increase access to basic needs and services. The Kenya HIV prevention and treatment guidelines also need to be updated to highlight the unique needs of OALWH, e.g. multimorbidity. Different models of care have been recommended for the care of OALWH, including comprehensive geriatric assessment and integration of chronic care services into routine HIV care services. Formative work can be conducted to assess the possibility of introducing these models into care. Future work needs to ascertain the cause-and-effect association of the reported correlates and carry out formative work on the feasibility of multicomponent psychological and physical interventions to address identified health problems, e.g. psychosocial challenges, CMDs and frailty.

Preface

This thesis is submitted to the University of the Witwatersrand, Faculty of Health Sciences, for the fulfilment of the requirements for the degree of Doctor of Philosophy by publication in the major area-subject of Public Mental Health. The doctoral research has been undertaken at the School of Public Health. My supervisors were Professor Amina Abubakar, Dr. Ryan Wagner, and Professor Charles Newton.

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Presentations arising from this research study

- 1) **Mwangala PN**, Mabrouk A, Wagner RG, Newton CR, Abubakar A. A Systematic Review of Health and Wellbeing in older adults living with HIV in Sub-Saharan Africa (*abstract oral presentation at the 11th KEMRI Annual Scientific & Health (KASH) Conference – 8th to 10th June 2021 – held virtually*).
- 2) **Mwangala PN**, Wagner RG, Newton CR, Abubakar A. Navigating life with HIV as an older person at the Kenyan coast: perceived health challenges seen through the biopsychosocial challenges. (e-poster presented at the 2021 International Workshop on HIV & Aging held virtually from 23rd to 24th Sept 2021).
- 3) **Mwangala, PN**. Mental health and wellbeing of vulnerable older people in a Kenyan rural setting (delegate for the McGill University's workshop on Community-based Mental Health interventions: Critical perspectives and innovative approaches held virtually from 6th to 9th April 2021).

Publications arising from this research study

My contribution in the PhD research work includes being the first author in the following publications. In the larger PhD project, I designed and took the lead in the acquisition of research ethics and permits, trained research assistants, monitored data collection and community-engagement and performed data management, conducted data analysis, wrote the first drafts of manuscripts and implemented the contributions of the co-authors and external reviewers up to final publication. During the process, I asked for and implemented input and feedback from supervisors.

- 1) **Mwangala PN**, Mabrouk A, Wagner RG, Newton CR, Abubakar A. Mental health and well-being of older adults living with HIV in sub-Saharan Africa: a systematic review. *BMJ Open*. 2021 Sep 1;11(9):e052810.
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- 2) **Mwangala PN**, Wagner RG, Newton CR, Abubakar A. Navigating life with HIV as an older adult on the Kenyan coast: perceived health challenges seen through the biopsychosocial model. *International Journal of Public Health*. 2023;68:1605916.
doi: <https://doi.org/10.3389/ijph.2023.1605916>
- 3) **Mwangala PN**, Wagner RG, Newton CR, Abubakar A. Strategies for improving mental health and wellbeing used by adults ageing with HIV: a qualitative exploration. *Wellcome Open Research*. 2022;7(221):1.
doi: <https://doi.org/10.12688/wellcomeopenres.18212.2>
- 4) **Mwangala PN**, Nasambu C, Wagner RG, Newton CR, Abubakar A. Prevalence and factors associated with mild depressive and anxiety symptoms in older adults living with HIV from the Kenyan coast. *Journal of the International AIDS Society*. 2022 Sep;25:e25977. doi: <https://doi.org/10.1002/jia2.25977>

- 5) **Mwangala PN**, Nasambu C, Wagner RG, Newton CR, Abubakar A. Prevalence and Factors Associated With Frailty Among Older Adults Living With HIV Compared to Their Uninfected Peers From the Kenyan Coast. International Journal of Public Health. 2024;69:1606284. doi: <https://doi.org/10.3389/ijph.2024.1606284>

- 6) **Mwangala PN**, Nasambu C, Wagner RG, Duta M, Demeyere N, Scerif G, Newton CR, & Abubakar A. Neurocognitive functioning among adults ageing with and without HIV at the Kenyan Coast: Measurement issues and correlates. 2024 (*Undergoing interactive review among coauthors*).

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List of Abbreviations

AMPATH – Academic Model Providing Access to Healthcare

AIDS – acquired immunodeficiency syndrome

ART – antiretroviral therapy

CBO – Community-based organization

CD4 count – Clusters of differentiation 4

cART – combination antiretroviral therapy

CMDs – common mental disorders

COVID-19 – coronavirus disease

GAD-7 – 7-item Generalized Anxiety Disorder scale

GPS – Global Positioning System

HICs – High-Income Countries

HAND – HIV-associated neurocognitive impairment

HIV – human immunodeficiency virus

ICOPE – Integrated Care for Older People

IHDS – International HIV Dementia Scale

UNAIDS – Joint United Nations Programme on HIV/AIDS

KEMRI – Kenya Medical Research Institute

KWTRP – KEMRI-Wellcome Trust Research Programme

KCH – Kilifi County Referral Hospital

KHDSS – Kilifi Health and Demographic Surveillance System

LMICs – Low-and-Middle-Income Countries

OR – Odds Ratio

OALWH – older adults living with HIV

OCS-EF – Oxford Cognitive Screen: Executive Function

OCSPlus – Oxford Cognitive Screen Plus

PHQ-9 – 9-item Patient Health Questionnaire

PLWH – people living with HIV

RSPM – Ravens Standard Progressive Matrices

REDCap – Research Data Capture platform

SSA – sub-Saharan Africa

UN – United Nations

US – United States of America

WHO – World Health Organization

WHODAS – World Health Organization Disability Assessment Schedule

Chapter 1

General Introduction

1.1. Chapter outline

This thesis is built around five separate but related papers. The first two papers aim to understand the health challenges experienced by older adults living with HIV (OALWH) on the Kenyan coast and the coping strategies they use to confront these challenges. The third and fourth papers document the prevalence and correlates of common mental disorders (CMDs) and frailty among OALWH compared to their HIV-uninfected peers in the same setting. The last paper reports on the validation of a local (Swahili) measure of neurocognitive function and subsequently examines the neurocognitive function of these adults.

The current chapter (structured into 11 subsections) largely collates the most recent literature on mental, cognitive, and functional (frailty) health problems in the context of HIV. Other supporting sub-topics are also highlighted to contextualize the main study themes. The chapter begins by defining an older adult in the general population and HIV literature in section 1.2. Subsequently, a brief profile of older adults globally and in Kenya is discussed in section 1.3. This section is followed by an overview of the current HIV burden (section 1.4), older adults and HIV (section 1.5), challenges of living with HIV as an older adult (section 1.6), overview of the comorbidity of HIV and mental, cognitive, and geriatric disorders (section 1.7), the burden and associated factors of mental, cognitive, and geriatric disorders comorbid with HIV (section 1.8), and the adverse outcomes of HIV comorbid with mental and geriatric disorders (section 1.9). In the second last section (1.10), the existing research gaps and justification for the current PhD study are highlighted. The last section of this chapter (1.11) describes, in detail, the present PhD study, identifying the study objectives, design, setting, and data sources. The chapter then closes with an outline of the structure for the remainder of the thesis.

1.2. Definition of an older adult in the general population and HIV literature

There is currently no consensus on the chronological age at which an individual becomes old, partly because the ageing process is asynchronous and heterogeneous. Various age thresholds have been used to define old age in the general population: e.g., ≥ 60 years by the United Nations and the African Union Policy Framework and Plan of Action on Ageing (1), and ≥ 65 years in the United States – US and Europe (2). Notably,

the World Health Organization (WHO) has recommended a lower cut-off, ≥ 50 years, to define older people in sub-Saharan Africa (SSA) to accommodate some of the definitional complexities, e.g. reduced life expectancy, cultural/social roles, and functional/biological abilities (3, 4). Consistent with the United Nations and African Union definitions, Kenya has adopted the definition of older people as those aged ≥ 60 years.

Different age thresholds have also been used to define medically advanced old age among people living with human immunodeficiency virus (HIV), ranging from 45 to 65 years, with 50 years being the most frequently utilised cut-off (5-8). This distinction is based on evidence of poorer immunological response to antiretroviral therapy – ART (5, 9), early immunosenescence and its premature deleterious effect on physiological functions and clinical consequences (10), early-onset geriatric syndromes such as frailty (11) and elevated mortality (5, 12) in these adults. In this thesis, an older person will be defined as anyone aged ≥ 50 years unless otherwise specified.

In Kenya, the number of adults aged ≥ 50 years is projected to nearly quadruple by 2050, making it one of the most rapidly ageing nations in SSA, thus underscoring the need for meaningful investments in healthy ageing in the country. The significant increase in the number of older adults in Kenya, like many countries in SSA, has been attributed to increasing life expectancy, improving healthcare and declining fertility rate in the region (13).

1.3. The profile of older people globally and in Kenya

Every nation in the world is experiencing a rise in both the size and the proportion of older people in its population – some are at its early stages, e.g. Kenya, while others are more advanced and have larger proportions of the elderly, e.g. Japan (14). Globally, the number of people aged ≥ 50 years was about 1.1 billion in 2000 and is predicted to increase nearly three-fold to 3.2 billion by 2050 (15). This demographic "megatrend" is projected to become more pronounced in Low-and-Middle-Income Countries (LMICs), especially in SSA, with lasting impacts on health, e.g. shifting disease burden and rising expenditure on health and long-term care (14). Therefore, understanding the physical, mental, and social wellbeing of older people has become a global health priority, largely motivated by the observed and projected trends of population ageing. For instance, for

the first time ever, people aged ≥ 60 years have outnumbered children < 5 years in several countries in the world (16). Additionally, the proportion of older people is expected to continue to rise even in regions such as SSA, where the HIV epidemic caused significant reduction in life expectancy in the 1990s and early 21st century (13). Kenya, like many countries in SSA, is experiencing demographic and epidemiologic transitions where the share of the country's population aged ≥ 50 years is growing rapidly (17). The increasing incidence of chronic ageing-related conditions (18) is coinciding with a high prevalence of HIV among older adults (19). The country is expected to see an increase in the population aged ≥ 50 years from 2.1 million (6.8%) in 2000 to 15.1 million (17.7%) in 2050, with those aged ≥ 65 years rising five-fold from 1 million to 5.1 million over the same period (15). That is, nearly 1 in 5 of the total projected Kenyan population in 2050 will be aged ≥ 50 years, up from 1 in 15 in 2000. Older people are the fastest-growing population segment in Kenya (20).

Within SSA, the concern of population ageing is not just based on its close association with adverse health impacts such as multimorbidity, but on the recognition that the majority of the existing policies on healthy ageing, if existent, are rarely implemented, and many older people are neglected, and prone to abuse (21). Moreover, ageing takes place against a backdrop of chronic poverty, income insecurity, adult unemployment, high rates of HIV-related morbidity and mortality, inadequate health services (both preventive and curative services), insufficient/unsustainable welfare and social protection programs, lack of both formal and informal care providers (e.g. nursing homes) in addition to changing cultural and familial norms regarding the duties and obligations by and towards older people (22, 23). According to the most recent report on the state of Kenyan population, dubbed "population anxiety in Kenya", more than half of the older people are documented to live in absolute poverty and constitute the poorest group in the country (20). In this report, the majority of old Kenyans reside within multigenerational households in rural settings, slightly more than half (55%) are women, approximately 60% are married, over a third are widowed, 21% live alone, and 11% live with minors. The older people's perceptions of old age revolve around food insecurity, worries about support and care, health issues, financial insecurity and feeling displaced

in a modern, globalized world, e.g., left alone and not consulted for advice by younger people (20).

To date, Kenya also lacks a long-term public health insurance scheme for older people, and access to private health insurance is very limited. The number of geriatric specialists is also very low, further compounding the problem. The care of older people with chronic health problems and disabilities is mainly done by family members.

However, changing family values, rising cost of living and migration into towns and cities or abroad has meant that many Kenyans are living away from parents, hence, unable to adequately fulfil their traditional role of caring for them – leading to the rise of older person's homes. Most of these homes are run by religious institutions or private institutions. A 2016 audit of residential institutions of older persons in selected counties in Kenya revealed that there are very few such institutions in the country, none of which was run by the government (24). Furthermore, the audit revealed that the existing homes lack reliable and predictable means of funding. Generally, although family caregivers play an important role in providing physical, emotional, and social support to the elderly, they face several challenges including poverty, and lack of knowledge and skills to provide effective care. Moreover, although most of the older adults live in large multigenerational households, a significant and growing number live alone in isolated homesteads. Not long ago (2009), the country enacted a draft policy for older people and ageing and subsequently revised it in 2014 and 2019, seeking to recognize, empower, and facilitate older people to participate in society, for them to enjoy their freedoms and live in dignity. However, its implementation, monitoring, and evaluation is lacking (25).

The above discourse poses difficult questions for many governments, researchers, and practitioners, particularly in LMICs like Kenya, which are still struggling to provide basic amenities for the general public and cope with the continuing burden of infectious diseases and extreme poverty. For instance, how do older adults conceptualize their health and wellbeing in different SSA settings? What are the biomedical, psychosocial, and environmental determinants of health and wellbeing for the several millions of older people in SSA? How can healthcare systems be aligned to meet the complex

healthcare needs of older people? How can research evidence inform the design of healthcare systems and other public support programs for the ageing population in SSA? Whose responsibility is it to care for older adults, families, or government – considering the changing trends of filial piety and intergenerational exchanges in many African countries? This PhD seeks to begin to contribute to answering some of these pertinent questions, more so in the context of OALWH, one of the fastest growing HIV sub-populations worldwide thanks to the widespread use of antiretroviral therapy (ART) and increasing HIV infections among older people.

The following section summarizes and provides a critical analysis of the most recent literature regarding the epidemiological characteristics of OALWH, health challenges of ageing with HIV, and HIV disease comorbidity with mental, cognitive, and geriatric disorders in this population. Several research gaps are identified, leading to the design of the current PhD study.

1.4. Overview of the current HIV burden

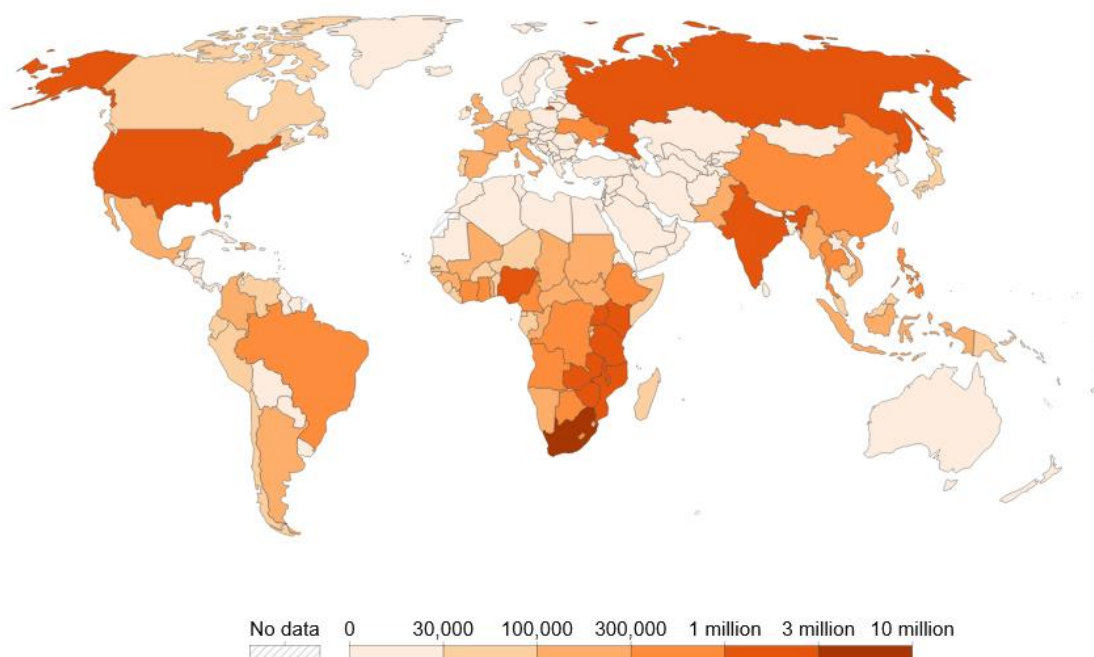
Four decades have elapsed since the first reported cases of acquired immunodeficiency syndrome (AIDS) in 1981 (26). Over the years, the world has made tremendous progress in ending the HIV/AIDS pandemic, thanks to sustained political leadership, international collaborations, extensive funding from bilateral and multilateral sources, and the rollout of innovative service delivery approaches. Since 2010, new HIV infections have reduced by 38%, while AIDS-associated deaths have declined by 69% (27). Despite the remarkable efforts witnessed, the global HIV/AIDS pandemic is far from over. According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), 39 million people were living with HIV/AIDS across the world in 2022: 37.5 million adults ≥ 15 years and 1.5 million children, 0-14 years (27). In the same year, 1.3 million people became newly infected with HIV and approximately 0.6 million people died from AIDS-associated complications. Additionally, a recent UNAIDS report showed that the global 90-90-90 HIV treatment targets (i.e., 90% of people living with HIV – PLWH know their status, of whom 90% receive ART, and of whom 90% attain viral suppression by 2020), were not achieved (28). Relatedly, the 95%-95%-95% HIV treatment targets (i.e., 95% of PLWH know their status, of whom 95% receive ART, and of whom 95% attain viral

suppression by 2025) were negatively impacted by the coronavirus disease (COVID-19) (29). Based on statistical models, it has also been estimated that ART interruption occasioned by the pandemic could elevate HIV mortality by 10% in endemic settings within five years (30).

As the epidemic enters its 5th decade, SSA continues to bear a disproportionate burden of the overall HIV burden, accounting for about two-thirds of the global burden of infection (see **Figure 1.1** for prevalence estimates). As of 2022, 25.6 million of the 39 million PLWH – 66% - lived in SSA. Moreover, about 51% of the new HIV infections and 60% of the AIDS-related deaths registered in 2022 came from SSA (27).

Number of people living with HIV, 2021

The estimated number of current cases of HIV/AIDS.



Data source: IHME, Global Burden of Disease (2024)

OurWorldInData.org/hiv-aids | CC BY

Figure 1.1: HIV prevalence across the world in 2021: Source: Institute for Health Metrics and Evaluation (IHME), Global Burden of Disease (2024).

(<https://ourworldindata.org/hiv-aids>)

1.5. Older adults and HIV

Amidst the unprecedented ageing of the world's population, is the rapid ageing of the HIV population worldwide. Presently, PLWH aged ≥ 50 years, widely recognized as older adults in HIV literature, are among the fastest-growing segments of PLWH across the world. Two factors mainly drive the rapid rise in the number of OALWH globally. First, improved survival following the introduction of effective combination antiretroviral therapy (cART). Second and of concern is the increasing incidence of HIV among older adults partly because of their engagement in high-risk sexual behaviour (e.g. multiple sexual partners, non-condom use), limited knowledge of HIV risk and prevention, and low rates of HIV testing (31-34). In some ways, older people are at a higher risk of HIV infection compared to younger people. For instance, in older women, menopause causes a natural thinning of the vaginal walls, leading to an elevated risk of internal injury during coitus and subsequent exposure to HIV (35). Also, especially in SSA, contraception is viewed more as a method to prevent pregnancy than to prevent sexually transmitted infections. Post-menopausal women no longer require contraception, which may result in a reduction in condom-use. Certain customs such as wife inheritance (that elevates vulnerability to non-consensual sex) and ritual cleansing (where widows are expected to have sex with family or community members following the husband's death) also increase older women's risk of exposure to HIV (36, 37). There is also some evidence showing that ageing is associated with lower adoption of voluntary medical male circumcision (38) – which has been shown to be about 60% effective at preventing HIV infection in men (39).

The UNAIDS first recognized PLWH aged ≥ 50 years as a special HIV population in its 2014 Gap Report, alongside 12 other populations regarded to be more at risk of HIV infection and poorer HIV treatment outcomes (40). The report cited four key reasons why OALWH were being neglected in the HIV care continuum, including low perception of HIV risk, complicated management of HIV and other health issues, low access to services and stigma and discrimination. Unfortunately, UNAIDS has not put in place any plans to specifically address the needs of OALWH apart from the special supplement to the UNAIDS report (40). The only mention of older adults in the UNAIDS's 95-95-95 strategy is the acknowledgement of accelerated ageing and the multiple comorbidities

OALWH may experience (41). Nonetheless, no direct plans or services are proposed to comprehensively mitigate issues specific to this population.

In 2014, there were approximately 4.2 million OALWH across the world (40). This number increased to 5.7 million in 2016, representing 16% of the entire HIV population (42). This proportion was modelled to reach 21% in 2020, with Eastern and Southern Africa containing the highest number of OALWH worldwide (42). **Figure 1.2** highlights the changing numbers of OALWH from 2000 to 2020. In High-Income Countries (HICs), more than 30% of the PLWH are now aged ≥ 50 years (42), and this proportion is projected to reach 70% by 2035 in certain areas, including the United States of America (43) and some parts of Europe (10, 43). Among PLWH in SSA, 15% are aged ≥ 50 years, and this proportion is expected to double by 2040 (44). In East Africa, Kenya has an estimated HIV prevalence of 9% (for those aged 50-54 years), 8% (among those 55-59 years), and 6% (for those aged 60-64 years), compared to the national HIV prevalence of 5% (19).

HIV and ageing is generally an emergent research area in many countries in SSA compared to HICs, where its course and implication are better described. Most population-based HIV prevalence surveys in SSA have not included older adults, limiting the accuracy of prevalence estimates in this age group.

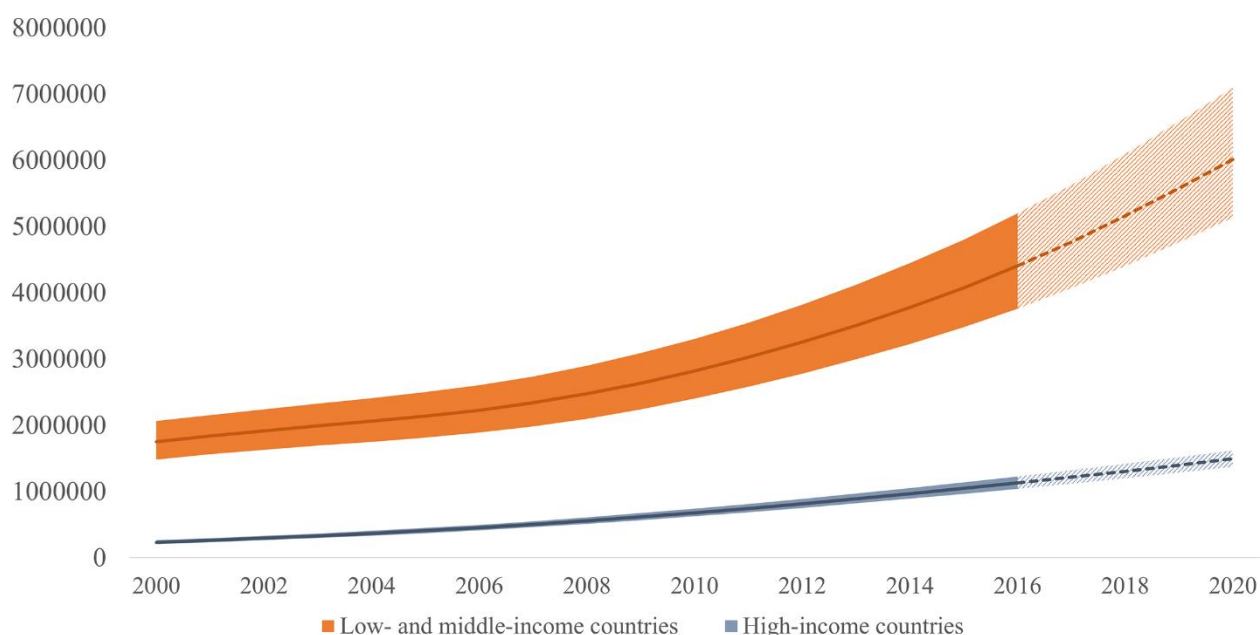


Figure 1.2. Number of older adults living with HIV who are aged ≥ 50 years in HICs and LMICs, 2000 – 2020. Source: Autenrieth, Christine S., et al

"Global and regional trends of people living with HIV aged 50 and over: Estimates and projections for 2000–2020." PloS one 13.11 (2018): e0207005.

(<https://doi.org/10.1371/journal.pone.0207005.g003>)

1.6. The challenges of living with HIV as an older adult

People living with HIV, in general, face a myriad of challenges that may compromise their long-term health. These challenges include the burden of managing a life-long diagnosis (with strict adherence to ART medications, regular medical check-ups, and treatment of opportunistic infections), special dietary considerations in addition to the health uncertainties surrounding the condition (e.g., due to social stigmas, and unstable viral loads). Others include psychosocial challenges. Reports exploring the lived experiences of PLWH in different parts of the world have documented several psychosocial challenges: including difficulties in accepting HIV-positive status, HIV disclosure fears, ART adherence obstacles, social isolation, and HIV-related stigma and discrimination (45-48). In many SSA countries like Kenya, inadequate resources further complicate the living situation of PLWH. Not surprisingly, socioeconomic challenges

such as financial difficulties, prolonged cycles of poverty, food insecurity, and caregiving burden have been identified as some of the additional concerns experienced by PLWH in the region (46, 49-51).

For OALWH, there are several other considerations, even though many of the issues highlighted above also apply to older individuals. Older adults living with HIV face unique challenges compared to their younger counterparts. Many healthcare professionals and the general public believe that older adults have a lower risk of HIV infection. A fairly recent study from SSA analyzed data from demographic and health surveys of 10 SSA countries, documenting the covariates of high-risk sexual behaviour among men aged ≥ 50 years (52). Findings indicated that 74% of men were sexually active, and a significant proportion of the men regularly engaged in unsafe sexual behaviours, including multiple sexual partners and unprotected sex. The covariates of high-risk sexual behaviour included older age, urban residence, and having primary or secondary education. The presumption that older adults are not sexually active or drug users creates obstacles to early HIV testing and access to preventive health information for these adults. Consequently, a significant proportion of OALWH (nearly 50%) get diagnosed late in the course of their disease, i.e., CD4 cell counts below 350 cells per microliter or the presence of an AIDS-defining event (53). This is concerning because delayed presentation for HIV treatment reduces OALWH ability to benefit from early ART initiation and also prolongs the period in which they may expose others to infection. Additionally, research evidence (mainly from European cohorts of HIV and ageing) shows that older people are more likely than younger people to have multiple health conditions which complicate their care and treatment, e.g., neurocognitive impairment, elevated levels of polypharmacy (8, 10, 54). OALWH also have elevated levels of multimorbidity compared with individuals of similar age without HIV (10). Alongside late HIV diagnosis and multimorbidity, OALWH also experience an intersection of HIV-related and age-related stigma (ageism), a crucial challenge for attaining long-term health and healthy longevity (55).

Generally speaking, there are two distinct groups of OALWH: those who were diagnosed before the age of 50 years and have been living with HIV and taking ART for

a longer time (sometimes referred to as long-term survivors), and those who were diagnosed in their old age. Evidence from HICs shows that many of the long-term survivors (from the pre-ART era) continue to be impacted by the legacy of the early years of the epidemic, including multiple HIV-related bereavements, “survivor guilt”, post-traumatic stress disorder, living for many years with an uncertain diagnosis, financial insecurity, lack of caregivers and historical and ongoing stigma and discrimination (56-58). These adults have also had to contend with the long-term toxicity of ART regimens (59). Some of the common comorbidities associated with long-term ART use and chronic HIV infection include renal and metabolic disease, fractures, osteoporosis, central nervous system disorders, cardiovascular and liver diseases (59). As it stands, most healthcare systems, especially LMICs, are ill-equipped to address the unique needs of the rising population of OALWH.

In SSA, where the vast majority of OALWH live, there have been a few studies exploring the health challenges these older adults face (60-70). From these studies, the challenges that OALWH face are similar to those highlighted above (delayed diagnosis and care seeking, difficulty disclosing or non-disclosure, double burden of stigma, suboptimal ART adherence, financial burden, and food insecurity). Additional challenges include multiple healthcare appointments (as services are not integrated), poor patient-provider communication, attitudes and behaviours, inadequate quality facilities, inadequate training or limited knowledge for healthcare providers, shortage of staff (leading to long queues), unemployment, and end-of-life concerns. Within the SSA region, the mental, cognitive, and functional health experience of OALWH has barely been investigated using qualitative studies, highlighting a vital research gap to better understand the experiences and needs of OALWH in the region.

1.7. HIV, mental, cognitive, and geriatric disorders: an overview of the comorbidity

The advent of ART more than 20 years ago has successfully changed the management of HIV/AIDS from a life-threatening disease to a manageable chronic condition akin to diabetes and hypertension (71-73). Effective use of cART has led to significant gains in

the fight against the HIV epidemic, including reduced HIV-related morbidity and mortality (74, 75) and extended longevity (76). As of the end of 2022, 29.8 of the 39 million PLWH were on cART, representing 76% of ART coverage globally (27). Similar trends are being experienced in SSA, with a steady rise in ART coverage. More than three-quarters (81%) of PLWH in the region were on HIV treatment by the end of 2022 (27). In Kenya, this proportion was significantly higher (94%) during the same period (27). Given these achievements, the focus is now shifting towards understanding HIV-associated comorbidities and their long-term impacts on health and wellbeing (10).

Neuropsychiatric disorders and geriatric syndromes are some of the most important comorbidities in PLWH, including OALWH (77-81). Of the neuropsychiatric disorders comorbid with HIV, common mental disorders - CMDs (e.g. depression and anxiety disorder), and neurocognitive impairments are most prevalent (79, 80, 82). It is challenging to estimate the precise burden of CMD comorbid with HIV in different contexts due to variations in measurement tools or diagnostic criteria, lack of a suitable comparison group and differences in contextual factors (83). In a fairly recent global systematic review and meta-analysis (84), the pooled prevalence of depression was found to be 31% among adults living with HIV but with a very high heterogeneity index (98%). In terms of geographical location, the prevalence of depression among adults living with HIV was highest in South America (44%) and lowest in Europe (22%). In another global metanalysis by Rahmati, J., *et al.* (2021), the pooled prevalence of anxiety among PLWH was found to be 25%, but with a significant level of heterogeneity of 98%. By geographical region, the prevalence of anxiety was lowest in Africa at 19% and highest in South America at 38%. Within SSA, studies examining CMDs in PLWH are not as extensive as those from HICs in North America and Europe. However, this narrative is slowly changing as more contextually appropriate measures of CMDs are being adapted or developed for use in these settings, thus laying the foundation for more research (85-89). Reviews documenting the prevalence of CMDs among adults living with HIV in SSA have registered prevalence estimates of over 30%, particularly for depressive symptoms (87, 90). For anxiety, prevalence is as high as 19% among adults living with HIV (91) and 46% among young PLWH in SSA (92). Anxiety disorders have received much less scientific and clinical attention compared to depressive disorders.

From a public health standpoint, the lack of research in this area is alarming because anxiety disorders are likely to be very prevalent and have a significant detrimental effect on functioning.

HIV-associated neurocognitive impairment (HAND) is also a common comorbidity among PLWH (79, 80). Evidence shows that PLWH have higher levels of cognitive impairment compared to their uninfected peers (93). Similar to CMDs, the accurate burden of HAND in PLWH is highly variable, depending on the measurement tools, diagnostic criteria, study design, geographical area, and respondents' ART status (80, 94-97). In a global review of the literature on HAND in PLWH (80), a pooled prevalence of 50% was reported. In this review, HAND prevalence estimates were comparable in HICs and LMICs. Within SSA, however, the prevalence of HAND was found to be highly variable in a recent systematic review (95), ranging from 14% to 88%, and a pooled prevalence of 46%.

One of the most striking consequences of the ageing process in HIV infection is the development of geriatric syndromes (such as sarcopenia, frailty, and falls), multifactorial conditions resulting from deficits in several domains, including psychological, clinical and environmental vulnerabilities (81, 98). Studies primarily carried out in HICs have revealed a high prevalence of geriatric syndromes in OALWH, as well as an early incidence of these conditions (99). Frailty, one of the most common geriatric syndromes, is frequently characterized by a decline in physiological capacity in multiple organ systems, resulting in intensified vulnerability to stressors (100). In a recent systematic review, the overall pooled prevalence of frailty and prefrailty was 11% and 47%, respectively, but with a high degree of heterogeneity (93%) (101). The next section provides an overview of the burden and underlying factors of these outcomes but with a focus on OALWH.

1.8. HIV, mental, cognitive, and geriatric disorders among OALWH: burden and associated factors

Common mental disorders (e.g., depression and anxiety), HAND, and geriatric syndromes (frailty) are also evident among OALWH. Many of these conditions co-exist and account for a significant burden of years lived with disability among older adults

(102, 103). The known risk factors for these conditions, e.g., loneliness, HIV-related stigma, ageism, caregiving burden, multimorbidity and poor health-seeking behaviours, are significantly elevated among OALWH (104, 105). The prognosis of these conditions appears worse among OALWH (106). Despite this, these conditions are often overlooked, undetected, under-researched, and not treated in line with appropriate guidelines (103). Anxiety disorders and geriatric syndromes have received much less attention compared to depression and HAND; thus, their aetiology, manifestation and management are poorly understood.

The extant literature on the burden and determinants of these conditions among OALWH is mainly based on studies carried out in HICs. Only one global systematic review (107) has attempted to summarize the prevalence of depression among OALWH. In this review, the authors reported a pooled prevalence of depression of 28% but with a high heterogeneity index of 95%. In the same review, the prevalence estimates of depression ranged from 15% in the Netherlands to 42% in South Africa. To the best of my knowledge, no review has summarized the global burden of anxiety among OALWH. However, among the few available empirical studies, prevalence estimates range from 36% (108) to 65% (109). Relatedly, no review has systematically summarized the factors associated with both depression and anxiety among OALWH globally. Among the existing empirical studies, social capital (108, 110), physical exercise (111), resilience (112), being employed (113), and higher income (113) have been documented as important correlates of reduced CMDs while smaller social networks (111, 114), HIV-related stigma (114-116), loneliness (115), poor perceived health status (111), food insecurity (117), older age (≥ 70 years) (113), rural residency (113), and other comorbidities (118) have been shown to be important predictors of elevated CMDs among OALWH.

To the best of my knowledge, no global meta-analysis has exclusively reviewed the burden of HAND among OALWH. Wang et. al summarized the global prevalence of HAND among adults aged ≥ 18 years in 2020, but also provided age-disaggregated prevalence estimates, including that of ≥ 50 years which was reported to be 42.5% (119). Evidence from existing empirical studies, largely from European cohorts, report HAND

prevalence estimates as high as 50% (8, 120, 121). Notably, the pooled prevalence of HAND is shown to vary widely across settings and populations partly because of the assessment and diagnostic criteria used. The HAND criteria, also referred to as Frascati criteria, is the most common criteria of assessment around the world. Although it has been successful in providing a consistent pattern of classification in global research efforts, it has been associated with overestimating the burden of cognitive impairment, given the drastic changes of HIV disease in the era of potent ART (122). New approaches have been thus recommended (94).

Among existing studies, factors associated with an elevated risk of HAND include a history of low nadir CD4 (120, 123), older age (124), lower educational level (123-125), comorbidities such as diabetes, frailty, stress, depression (123, 126), lack of social support (126, 127), and stigma (127). A global meta-analysis of 21 studies examining the association between HIV infection and cognitive impairment reported that OALWH were more likely to be cognitively impaired than their uninfected counterparts (Odds Ratio – (OR) = 2.4), especially for studies from HICs, e.g. the US and Europe but not in upper-middle-income countries such as Southeast Asian countries and South Africa (93). Moreover, OALWH presented with lower scores than uninfected adults in five out of seven major cognitive domains, including processing speed, verbal, motor/psychomotor, executive function, and recall. Recently, Spooner *et al.* examined the longitudinal prevalence of HAND among 253 OALWH over three years in what is arguably the first longitudinal follow-up of a cART-treated cohort of OALWH in SSA (124). Forty-seven percent of the cohort met HAND criteria at baseline.

Two meta-analyses have summarized the global burden of frailty among OALWH. The first one (128) reported a varied prevalence of frailty ranging from 5% to 29%, depending on the population studied. The second review (101) reported a pooled prevalence of frailty of 11% as defined by the Fried frailty phenotype. Factors associated with elevated frailty, as reported in one of the two reviews (128), included older age, lower educational attainment, unemployment, low income, comorbid conditions (psychiatric disease, cognitive impairment, chronic kidney disease, diabetes mellitus and low body mass index), low current and possibly nadir CD4+ cell count.

We have systematically reviewed the published literature on the burden and determinants of depression, anxiety, cognitive function, and frailty among OALWH aged ≥ 50 years residing in SSA (129). The review included 44 studies (26 on depression, 13 on cognitive function, 3 on frailty and 2 on anxiety) conducted across 15 SSA countries, mainly from Ethiopia, South Africa, and Uganda (about two-thirds of the studies). Since the publication of our systematic review in 2021, three new studies (2 on depression and 1 on frailty) have been published (130-132). Our review found wide-ranging prevalence estimates for depression (6% to 59%), anxiety (3% to 21%), cognitive impairment (4% to 61%) and frailty (3% to 15%) among OALWH. Only a handful of the included studies were carried out exclusively among older adults ≥ 50 years. Our review noted several methodological concerns, including a high risk of bias (about 40% of the included studies), small sample sizes, unrepresentative samples, and failure to report tool reliability and validity. Some of the outcomes, e.g., cognitive impairment, were documented in multiple ways, e.g., HAND, dementia, and cognitive dysfunction, thus making it difficult to quantify and compare across studies. Moreover, a good number of the included studies had overlapping age groups for their comparison groups, e.g., 18 to 50, 18-54, 18-55), thus making it difficult to compare their outcomes with those of older adults ≥ 50 years. The correlates of CMDs, frailty and cognitive impairment were rarely investigated in the articles included in our review. The frequently reported correlates were largely sociodemographic factors. Female sex was more consistently associated with poorer outcomes. Relatedly, low socioeconomic indicators e.g. low income, unemployment, and food insecurity were more consistently associated with poor mental and cognitive health outcomes.

1.9. Adverse outcomes of HIV comorbid with mental disorders or geriatric syndromes

An extensive corpus of HIV literature has shown that the co-occurrence of HIV with mental morbidities (both CMDs and cognitive impairments) and geriatric syndromes is associated with deleterious health outcomes across the HIV care continuum thus affecting HIV management and its overall prognosis in all populations of PLWH, including older adults (133, 134). Some of the detrimental outcomes of these comorbidities on the health and wellbeing of PLWH include increased proclivity for risky

sexual behaviours such as multiple sexual partners and non-condom use (135, 136), reduced health-seeking behaviours, poor quality of life (133), reduced economic productivity and increased risk for suicidality (133). Frailty, one of the commonest geriatric syndromes, has been associated with disability (137), dementia (138), premature mortality (139), and emergency hospital admissions among older adults (140).

Research has also demonstrated that mental morbidities among PLWH are associated with HIV-specific negative outcomes such as faster disease progression and subsequent mortality (141), virologic and immunologic failures (134), suboptimal adherence to ART (142, 143), and the onset of drug-resistant HIV strains (144, 145).

1.10. Existing research gaps and study justification

Sub-Saharan Africa has the youngest population in the world, yet it is ageing rapidly. The population of older adults aged ≥ 50 years in the region is projected to triple by 2050 from the current estimates of 117 million (15). With a myriad of competing needs, issues of older adults are given limited attention, let alone prioritized. Although many countries in SSA have formulated policies on healthy ageing, not much has been achieved with the implementation of the existing policies, especially on mental, cognitive and functional health, which appears to have been completely neglected (21). Amidst this demographic shift is also the rapid ageing of the HIV population in the region, which has produced a subgroup of vulnerable older adults (42). While the course and effects of ageing in the context of HIV are well documented in HICs, HIV and ageing in most SSA countries, including Kenya, is an emergent area of research. Consequently, little is known about the health and wellbeing of OALWH in the region, and any programs and policies regarding their wellbeing have been made on the basis of limited evidence. Data from HICs may not be readily generalized to inform policies and programs in SSA given the differences in the profile of OALWH, e.g., with respect to age, sex, identity, race and ethnicity, sexual orientation, and socioeconomic status. For instance, in the US alone, over three-quarters of the OALWH are males and most of them (about two-thirds) were infected through male-to-male sexual contacts, and a significant proportion of the OALWH are long-term survivors (started living with HIV before effective ART became

available); this compared to the population of OALWH in SSA where most OALWH are heterosexuals, slightly more women than men, and most are in their early 50s and 60s (105). These differences and others, including burden and contextual factors, healthcare systems, and formal and informal support systems, call for local data to inform meaningful progress and policy in the prevention, identification, and management of the complex needs of OALWH.

Much of what is known about HIV and ageing in SSA is predicated on quantitative studies. This data is essential and much needed; nonetheless, it does not capture the lived experience of ageing with HIV. The utility of qualitative enquiries to highlight the lived experiences of OALWH will provide a rich, holistic account of how these individuals perceive their lives and adjust to their age-associated complications and psychosocial modifications as they age with HIV. This is especially critical within SSA, where most of the healthcare systems are unprepared to meet the needs of OALWH and older adults in general. Studies exploring the challenges that OALWH face are currently few in many sub-Saharan African countries, including Kenya. More of these studies are needed to provide a more comprehensive understanding of how the OALWH create meaning around HIV in their lives and how they cope with daily health challenges. This is even more important in SSA as new cohorts of HIV and ageing are emerging for the first time and, given the variability in some of the current findings (129).

Research on the prevalence and factors associated with CMDs among OALWH are limited, and most of the existing studies are concentrated in Uganda, South Africa and Ethiopia (129). Virtually all the existing research on CMDs among OALWH in the region has focused on depression rather than anxiety (129). Besides, the correlates of CMDs in OALWH are not well established. Few studies have examined the correlates of CMDs, and most of those examined are sociodemographic, the majority of which are inconsistent across studies (129). Because of these reasons, further research is urgently needed in the region to enhance our understanding of the burden and determinants of CMDs among OALWH. Strikingly, among the existing studies on depression/depressive symptoms, there appears to be a growing body of studies showing lower prevalence estimates for CMDs among OALWH than their uninfected

peers (129). This finding offers an interesting contrast to the commonly reported findings from HICs which point to a higher burden of depression among OALWH compared to their uninfected counterparts. The mechanisms responsible for these observations are not well established and require further research in the region, as the findings are based on a limited number of studies.

Studies documenting the prevalence and correlates of HIV-associated cognitive impairment among OALWH are similarly limited in the SSA region partly because of limited HAND screening and diagnostic tools (129). Although HAND screening is recommended in routine HIV care to allow for early interventions, it is rarely done in SSA partly because of the lack of contextually relevant screening tools. Most of the existing tools have inadequate psychometric properties, and very few have been adapted and validated for use among OALWH (146). It is imperative that more HAND tools are validated for the growing population of OALWH to generate accurate prevalence estimates, enable domain-specific understanding of HAND and allow early opportunities for intervention. One such tool that has shown promise is the Oxford Cognitive Screen Plus (OCSPlus) tool, a brief, tablet-based, domain-specific cognitive assessment tool designed for low-literacy settings (147). OCSPlus was an advancement of an initial tool – Oxford cognitive screen (OCS), to detect subtle cognitive changes in older adults. OCSPlus is a free and easy to use tool developed by the Translational Neuropsychology Research Group at the University of Oxford. Unlike many conventional tests, which rely on reading and numeracy skills, the OCSPlus relies more on visual abilities, with literacy and numeracy are not required to complete the test, thus more relevant for the population of older adults in SSA, where a significant number have low literacy levels (148, 149). In SSA, OCSPlus has only been validated among adults from the HAALSI cohort in South Africa (147). The initial validation in South Africa among adults aged 40-79 years indicated that the tool had excellent construct and external validity. Outside SSA, OCSPlus has been validated among neurologically healthy older adults from a pooled English and German normative sample, the results also showing the validity and reliability of the tool (149). The tool has been standardized, normed and validated in healthy ageing in HICs. More

validation data is needed for the OCSPlus tool in the region e.g. reliability, and acceptability among different populations of older adults e.g. OALWH.

Studies on frailty among OALWH are generally few across the globe. In SSA, these studies are particularly limited. Only three studies, from Tanzania, South Africa and Ethiopia, have reported prevalence estimates among OALWH (129, 132). Thus, the burden and factors associated with frailty among OALWH in SSA are grossly understudied and inconclusive, highlighting the urgent need for more studies to understand this construct in the region properly.

This PhD thesis provides initial data to help us understand the mental, cognitive, and functional health needs of OALWH in the SSA setting, specifically on the Kenyan coast. To begin with, this work explores the perceptions of OALWH, primary caregivers and healthcare providers to understand the health challenges of ageing with HIV and the coping strategies used by OALWH to confront these challenges. Subsequently, this work documents the prevalence and factors associated with CMDs and frailty. Further to this, I also provide preliminary evidence on the reliability and validity of the OCSPlus measure and document the cognitive performance and associated factors among OALWH in the study setting. No study in Kenya has examined the burden and determinants of CMDs, frailty and cognitive function among OALWH. Several HIV studies (among PLWH) have documented poorer psychosocial, mental, and physical health than their HIV-uninfected peers in the study setting. Unfortunately, it is unclear whether the patterns observed in the younger PLWH are similar or different among OALWH in the same study setting. Anecdotal reports from many HIV clinics in the study setting suggest an increasing number of OALWH and concurrent unmet healthcare needs for this population. So as to have a comprehensive understanding of the aforementioned outcomes among OALWH in this setting, I adopt a broader approach utilizing diverse research methodologies. The following section contains a description of the current PhD study. The various PhD sub-studies are described in detail in the subsequent chapters of this thesis.

1.11. Current study

The research gaps identified in the previous sections are addressed in the studies presented in this thesis. The remainder of this chapter describe the study objectives, design, setting, data sources and the overall thesis outline. Further methodological details will be provided for each PhD study in the subsequent chapters.

1.11.1 Study objectives

The studies reported in this thesis were carried out in two phases: Phase I and Phase II, each with distinct objectives. The overarching objective of the first phase was to understand the health situation of OALWH (challenges and coping strategies) on the Kenyan coast. The phase I dataset generated two manuscripts (Chapters 2 and 3 of the thesis respectively). For phase II, the overall objective was to document the burden and associated factors of CMDs and frailty and also highlight the neurocognitive profile of OALWH on the Kenyan coast. The phase II dataset generated three manuscripts (Chapters 4, 5 and 6 respectively).

The specific objectives included:

Phase I specific objectives:

- a) To explore the biopsychosocial health challenges faced by OALWH (≥ 50 years) from the Kenyan coast.
- b) To explore the coping strategies and support systems used by OALWH (≥ 50 years) to improve their mental health and wellbeing from the Kenyan coast.

Phase II specific objectives

- c) To determine the prevalence and factors associated with depressive and anxiety symptoms among OALWH (≥ 50 years) from the Kenyan coast compared to their HIV-uninfected counterparts.
- d) To determine the prevalence and factors associated with frailty among OALWH (≥ 50 years) from the Kenyan coast compared to their HIV-uninfected counterparts.

- e) To examine the acceptability, reliability, and validity of a local (Swahili) measure of neurocognitive function, the Oxford Cognitive Screen Plus (OCSPlus), among OALWH (≥ 50 years) and their HIV-uninfected peers and provide an initial understanding of the cognitive performance of these adults (by HIV status) and the biopsychosocial factors associated with their cognitive performance.

1.11.2 Study design

I utilized a mixed methods research design to achieve the stated research objectives, employing both qualitative and quantitative research methodologies. The primary purpose of utilizing mixed methods was to provide a better and deeper understanding, by providing a fuller picture that enhances description and understanding of the health and wellbeing of older adults in the study setting. The qualitative component was essential in contextualizing the issues of HIV and ageing in the study setting (as no other study has been reported from the Kenyan coast previously), seeking to build a greater understanding of the individual, family, healthcare providers, and broader socio-cultural and economic factors that may influence the quantitative outcomes (CMDs, frailty and neurocognitive performance).

1.11.3 Study setting

The studies reported in this thesis were carried out at the coastal region of Kenya, in Kilifi and Mombasa counties, through the Centre for Geographic Medicine Research – Coast. Kenya is an Eastern African country bordering the Indian Ocean (to the Southeast) with an area of about 580,000 square kilometres. Kenya's immediate neighbours are Uganda (to the West), Ethiopia (to the North), Somalia (to the East), South Sudan (to the Northwest) and Tanzania (to the Southwest). The country is divided into 47 devolved units of government (counties) with a total population of 47,564,296, of which 23,548,056 (49.5%) are males (17). The country has the fifth-largest number of people living with HIV worldwide, with 1.3 million PLWH in 2018 (150). Estimates from national population-based surveys and sentinel surveillance show that the national HIV prevalence peaked at about 11% in the mid-1990s and reduced to around 6% in 2006 (151, 152). Prevalence estimates have remained relatively stable at that level for many

years, with a reduction witnessed from 2010 to 2017 (153). In 2018, the countrywide prevalence was estimated at 4.9%, twice as high in women (6.6%) compared to men (3.1%) (150). The epidemic is geographically diverse in the country, with prevalence estimates ranging from 21% in Western Kenya (Siaya County) to a low of 0.1% in the North-East region (Wajir County) (153). Prevalence estimates for older adults ≥ 50 years are limited in the country. Major sources of statistics typically only present data for men and women aged 15 and 49 years and selected groups of older adults, e.g., those aged 50-54, 55-59, and 60-64 years. Recent reports indicate that HIV prevalence is 9.2% (for those aged 50-54 years), 7.5% (for those aged 55-59 years) and 5.9% (for those aged 60-64 years) (150). Anecdotal reports also indicate an influx of older adults seeking HIV care services in HIV-specialized clinics. HIV care in the country is usually free, but care for other medical conditions is harder to access; as such, families and other social contacts are important sources of support for the overall health and psychological needs of OALWH.

Kilifi County, one of the six counties in the coastal region of Kenya, has a land area of about 12,540 square kilometres and borders the Indian Ocean (to the east), Taita Taveta County (to the west), Kwale County (to the Southwest), Mombasa county (to the south) and Tana River county (to the north). Kilifi County is predominantly a rural setting (about 60%) with a population of about 1.5 million people (17), and among the poorest counties in Kenya (154) with low literacy levels, high rates of school dropout and teenage pregnancy (155, 156). Subsistence farming and local home businesses are the primary sources of livelihood. The HIV prevalence for adults ≥ 15 years in Kilifi is estimated at 4.5%, with women more disproportionately more affected (157). The HIV prevalence estimate for older people ≥ 50 years is unknown in this setting as it is not routinely documented during surveys. However, anecdotal reports from several HIV clinics in the study setting suggest an increasing number of older PLWH with unmet healthcare needs.

Mombasa County, with a land area of about 220 square kilometres, borders Kilifi County (to the north), Indian Ocean (to the east) and Kwale County (to the Southwest). It is primarily an urban setting with an estimated population of 1.2 million (17). The common

sources of income in Mombasa include tourism, wholesale, and retail trade. The Mombasa adult HIV prevalence is estimated at 7.5% (157). **Figure 1.3** presents the map of Mombasa and Kilifi counties and surrounding catchment areas where the recruitment of participants for this PhD was conducted.

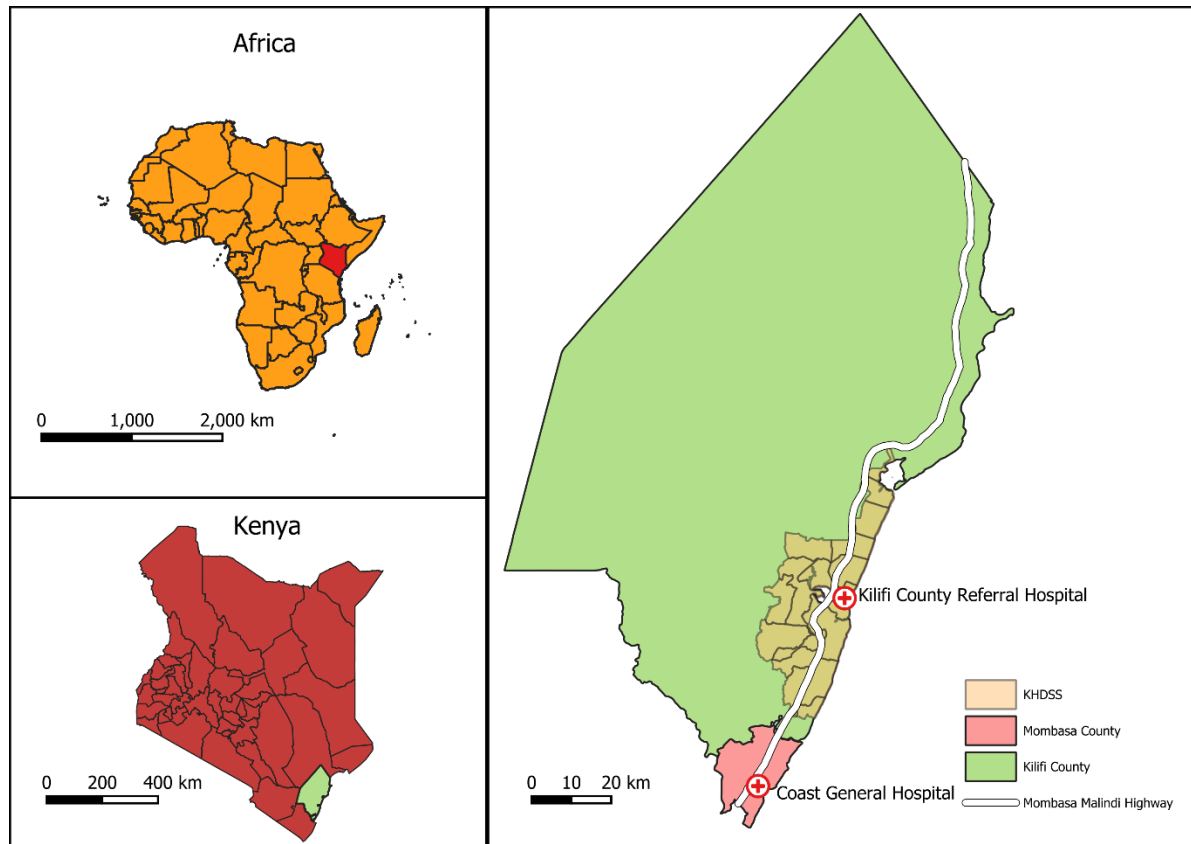


Figure 1.3. A map of Mombasa and Kilifi counties and study recruitment sites

1.11.4 Sources of data

The aforementioned specific objectives were implemented utilizing data from sampling of different study participants (as highlighted in **Table 1.1**).

Phase I, specific objectives 1 & 2

To explore the biopsychosocial health challenges that OALWH aged ≥ 50 years experience and the coping strategies for enhancing their mental health and wellbeing, in-depth interviews were conducted with 34 OALWH, 11 healthcare providers and 11 primary caregivers in an empirical qualitative study carried out at the CGMR-C in Kilifi

county. Semi-structured interview guides were used during the interviews, and all interviews were audio-recorded. Chapters 2 and 3 detail the results of Phase 1, which were published as two separate qualitative peer-reviewed articles. Further methodological details of the studies are provided in the respective chapters.

Phase II, specific objectives 3, 4 and 5

To investigate the CMDs, frailty (burden and associated factors) and neurocognitive profile of OALWH on the Kenyan coast, I designed a cross-sectional study, collected, and analyzed data from 440 older adults aged ≥ 50 years (257 adults living with HIV).

Table 1.1 summarizes the research methodologies utilized in the study. In this specific study, a set of sociodemographic, psychosocial and outcome measures (depression, anxiety, frailty, and cognitive function) alongside clinical and health or lifestyle history forms were collected from the respondents and data recorded in the Research Data Capture (REDCap) platform on Android tablets (158). Chapters 4, 5 and 6 detail the results of Phase II, which are presented as separate quantitative articles. Further methodological details of the studies are provided in the respective chapters.

1.11.5 Outline of the subsequent portions of the thesis

Chapter Two is a qualitative inquiry exploring the perceptions of adults living with HIV (≥ 50 years), healthcare providers and primary caregivers on the health challenges of ageing with HIV. The biopsychosocial model of health is applied for this exploration.

Chapter Three presents the results of a qualitative study exploring the strategies for improving mental health and wellbeing used by adults with HIV aged ≥ 50 years from the Kenyan coast. *Chapter Four* is an empirical descriptive cross-sectional study measuring the prevalence and associated factors of depressive and anxiety symptoms in OALWH compared to their HIV-uninfected peers on the Kenyan coast. *Chapter Five* presents the findings of an empirical cross-sectional study, measuring the prevalence and factors associated with frailty among OALWH compared to their HIV-uninfected peers. *Chapter Six* of the thesis presents the findings of an empirical descriptive cross-sectional study seeking to examine the acceptability, reliability, and validity of a local (Swahili) version of the OCSPlus measure among older adults aged ≥ 50 years. Also, it describes the cognitive performance of these adults (by HIV status) and the biopsychosocial factors

associated with their cognitive performance. Finally, *Chapter Seven* provides a general discussion of the thesis, integrating the findings from the various research studies reported in this thesis. Additionally, the chapter discusses the methodological limitations of the different studies and highlights the implications of the study in terms of future research, policy, and clinical practice.

Table 1.1. A highlight of the sources of data, applied measures and primary outcomes in the different thesis chapters

Chapter	Objective of the study	Type of study	Sample description	Measurement tools	Primary outcomes
Two (159)	To explore the biopsychosocial health challenges faced by OALWH (≥50 years) from the Kenyan coast	Qualitative inquiry	- 34 adults ageing with HIV (≥50 years), 11 healthcare providers and 11 primary caregivers - Purposive sampling to maximize participants characteristics	Pre-tested semi-structured interview schedule	- Physical health challenges - Mental health challenges - Psychosocial health challenges
Three (160)	To explore the coping strategies and support systems used by OALWH to improve their mental health and wellbeing from the Kenyan coast	Qualitative inquiry	- Participants were recruited from the specialized HIV clinic of the Kilifi County Referral Hospital (KCH)		Coping strategies and support systems for enhancing the mental health and wellbeing of OALWH
Four (161)	To determine the prevalence and factors associated with CMDs among OALWH (≥50 years) from the Kenyan coast compared to their HIV-uninfected counterparts	Quantitative cross-sectional study	- 440 older adults aged at least 50 years (257 living with HIV and 183 without HIV) - OALWH were systematically recruited from two public HIV specialized clinics, one	- Sociodemographic, clinical, health/lifestyle forms - Psychosocial measures (stigma, ageism, loneliness) - PHQ-9 and GAD-7	Common mental problems: ○ Anxiety symptoms ○ Depressive symptoms ○ Comorbid anxiety and depressive symptoms

Five (162)	To determine the prevalence and factors associated with frailty among OALWH (≥50 years) from the Kenyan coast compared to their HIV-uninfected counterparts	Quantitative cross-sectional study	in Kilifi (KCH) and one in Mombasa (Coast General Teaching and Referral Hospital) - HIV-uninfected older adults were randomly identified using the Kilifi Health and Demographic Surveillance System (KHDSS) database and followed up at their homes for recruitment using Global Positioning System (GPS) coordinates.	- Sociodemographic, clinical, health/lifestyle forms - Psychosocial measures (stigma, ageism, loneliness) - Reported Edmonton Frail Scale	Frailty
Six	To examine the acceptability, reliability, and validity of a local (Swahili) measure of neurocognitive function, the Oxford Cognitive Screen Plus (OCSPlus), among OALWH and their HIV-uninfected peers and provide an initial understanding of the cognitive performance of these adults (by HIV status) and the biopsychosocial factors associated with their cognitive performance	Quantitative cross-sectional study		- Sociodemographic, clinical, health/lifestyle forms - Psychosocial measures (stigma, ageism, loneliness) - OCSPlus - Ravens standard progressive matrices - International HIV dementia scale	- Acceptability of Swahili OCSPlus - Internal consistency of Swahili OCSPlus - Test-retest of Swahili OCSPlus - Convergent validity of Swahili OCSPlus - Cognitive performance profile

Chapter 2

Navigating life with HIV as an older adult on the Kenyan coast: perceived health challenges seen through the biopsychosocial model

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2.0 Background to Chapter 2

This thesis has so far summarised the existing evidence on HIV and ageing, pointing out the epidemiological characteristics of OALWH and the unique health challenges they face in SSA, thus laying a foundation for the empirical research conducted for this PhD. This chapter provides site specific insights of the health and wellbeing of OALWH at the Kenyan coast. The overall qualitative study was divided into two clear objectives and sub-analyses and published separately. The current chapter addresses the first objective which was to explore the health challenges faced by OALWH at Kilifi, a low literacy setting at the coast of Kenya. The second objective, which was to explore the coping strategies used by the OALWH to improve their mental health and wellbeing, is presented in the next thesis chapter, Chapter 3.

2.1 Abstract

Background: Kenya, like many sub-Saharan African countries (SSA), is experiencing a rise in the number of HIV-infected adults aged ≥ 50 years (recognized as older adults living with HIV). Unfortunately, there is a paucity of data on the challenges faced by this emergent population of OALWH. This study explores the perceptions of OALWH and their primary caregivers and healthcare providers on the health challenges of ageing with HIV at Kilifi, a low literacy setting on the coast of Kenya.

Methods: We utilized the biopsychosocial model to explore views from 34 OALWH and 22 stakeholders on the physical, mental, and psychosocial health challenges of ageing with HIV in Kilifi in 2019. Data were drawn from semi-structured in-depth interviews, which were audio-recorded and transcribed. A framework approach was used to synthesize the data.

Results: Symptoms of common mental disorders, comorbidities, somatic symptoms, financial difficulties, stigma, and discrimination were viewed as common. There was also an overlap of perceived risk factors across the physical, mental, and psychosocial health domains, including family conflicts and poverty.

Conclusion: OALWH at the Kenyan coast are perceived to be at risk of multiple physical, mental, and psychosocial challenges. Future research should quantify the burden of these challenges and examine the resources available to these adults.

Keywords: Older adults, HIV, Kenya, biopsychosocial challenges

2.2 Introduction

The last decade has witnessed a dramatic shift in the demographic profile of people living with human immunodeficiency virus (HIV) globally. Presently, many HIV clinics are caring for a growing number of adults aged ≥ 50 years (categorized as older adults) due to increased survival in people living with HIV (PLWH) and a steady rise in HIV diagnoses in this age cohort (42). More than 30% of the PLWH in High-Income Countries (HICs) are now aged ≥ 50 years (42) compared to 15% in sub-Saharan Africa (SSA) (44). These statistics herald a new era in the HIV epidemic response, where the needs and demands of the OALWH can no longer be ignored, especially in Eastern and Southern Africa, home to more than half the number of OALWH globally (42).

Research findings, mainly from HICs, indicate that OALWH present with an average of three comorbid conditions in addition to HIV, including medical diseases (e.g., diabetes, hypertension), mental health problems (e.g., depression, anxiety, substance use, cognitive problems) and social challenges (e.g., stigma, loneliness, and lack of social support) (129, 163-165). The observed mental health challenges reduce the quality of life of these adults and have important health implications, e.g., poor HIV treatment (166). The physical health problems faced by OALWH may also be complicated by environmental and psychosocial challenges such as poverty, food insecurity and lack of support (166).

Despite the evidence of complex health challenges related to ageing and HIV, little research has qualitatively examined how OALWH understand their health and care needs. To date, most studies of ageing and HIV in SSA are cross-sectional studies focusing on biomedical processes and outcomes and rarely provide local insight into the health and wellbeing of these adults (167). Qualitative studies are needed to better

understand the experiences and needs of this diverse population, especially among low-literacy populations. This is especially important as many cohorts of OALWH are emerging for the first time across the SSA region, and the apparent variability in findings among previous studies, e.g. in the prevalence and determinants of chronic comorbidities (167). Apart from complementing quantitative studies in accurately documenting the burden and determinants of the health challenges in these adults, qualitative studies will shed light on the contextual factors to guide the development or adaptation and subsequent implementation of culturally appropriate interventions in this population. Overall, the few qualitative studies among OALWH in SSA are mainly concentrated in Uganda (60-63, 168) and South Africa (64-66, 169, 170). Others are from Kenya, Eswatini and Malawi (68, 171-173). In Uganda, ageing with HIV is seen as a daily challenge financially and socially (60-63, 168). The key barriers to successful ageing with HIV in this setting include stigma, food insecurity, and unmet healthcare needs, particularly for associated comorbidities such as common mental disorders. In South Africa, the crucial barriers to living with HIV in old age include food insecurity, unemployment, stigma, and access to transportation and healthcare (64-66, 169, 170). Our study is timely and addresses some of the key gaps in the existing literature. For instance, the existing studies have only explored the perspectives OALWH themselves, leaving out important stakeholders including caregivers and healthcare providers. Additionally, most of the available studies are concentrated in regions having the highest prevalence of HIV like in Kenya. Some of the studies are quite old, more than 10 years back – hence the need for updated studies given the rapidly changing environment of HIV disease e.g. demographics of OALWH.

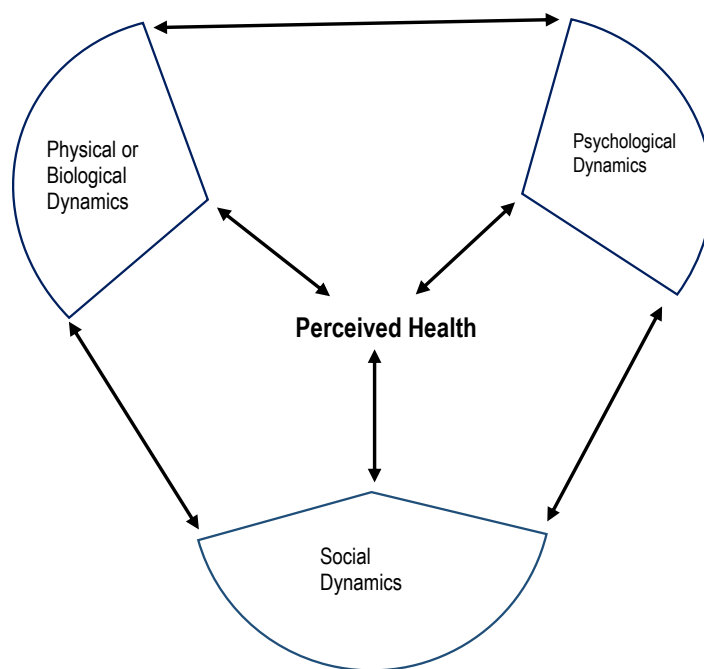
Emerging data suggest that OALWH in Kenya face complex challenges when seeking care, including visits to multiple providers to manage HIV and comorbidities, ageist discrimination, and inadequate social support (171, 172). However, these data come from the Western region of Kenya. As such, the health and wellbeing experiences of OALWH from other parts of the country is not known. To bridge this research gap, we conducted in-depth interviews to explore the health challenges faced by OALWH at Kilifi, a low literacy setting at the coast of Kenya.

2.3 Methods

Theoretical Framework

We utilized Engel's biopsychosocial model of health (174), which provides a logical account of the chronic, complex, and dynamic nature of HIV. This model recognizes healthy ageing as the ability to thrive in an evolving environment influenced by physical/biological, mental/psychological, and social factors (Figure 2.1). The model provides a holistic approach to understanding the health needs of older adults and is supported by calls for research that positively impact the physical, mental, and social aspects of ageing with HIV (175-177). According to this model, the cause, manifestation and outcome of wellness and disease are determined by a dynamic interaction between physical, psychological, and social factors (174). Each model component includes systems that reciprocally influence other dynamics in the model and also affect health.

Figure 2.1: Components of the Biopsychosocial Model of Health (Kilifi County, Kenya. 2019).



2.3.1 Study context and participants

This study was conducted in 2019 at the Kenya Medical Research Institute (KEMRI) located within Kilifi County on the coast of Kenya. By the end of 2019, there were roughly 1.5 million residents in Kilifi County, the majority of whom were rural dwellers (~60%), and 11% were aged ≥ 50 years (178). Kilifi has an HIV prevalence of 38 per 1000 people (179) in the general population and is currently unknown in those aged ≥ 50 years. People living with HIV usually receive care in specialized HIV clinics within primary care facilities.

This study involved the following three groups of participants:

- a) 34 OALWH aged ≥ 50 years receiving HIV care and treatment at the HIV Comprehensive Care Clinic of the Kilifi County Hospital (KCH).
- b) 11 Healthcare providers attending to OALWH.
- c) 11 Primary caregivers of OALWH.

2.3.2 Recruitment and eligibility

Study participants were selected purposively to represent diversity in the participants' characteristics, including age, sex, and the cadre of service (for healthcare providers). Initial contact was made via a community health volunteer stationed at the KCH. Recruitment was conducted by a trained research assistant in liaison with the community health volunteer during their routine clinic visits. OALWH had to be ≥ 50 years old and on HIV treatment to be eligible. Primary caregivers were identified through the OALWH, usually during their scheduled clinic visits. These caregivers had to be directly involved in providing care and support, e.g., medical care to an OALWH. HIV providers were approached at their place of work and invited to participate. We specifically targeted providers who provided direct care to OALWH. Participants who agreed to participate were invited to a face-to-face interview at a convenient place, usually at KEMRI Kilifi.

2.3.3 Data collection and tools

The lead author (PNM) conducted in-depth interviews lasting, on average 45-60 minutes with each participant. All the interviews were guided by a pre-tested semi-structured interview schedule developed with guidance from prior work on HIV and ageing. All interviews were conducted in Swahili, English or Giryama. We also sought permission from the participants to take notes and audio record the interviews.

Among OALWH, topic guide themes included: patient illness experiences following diagnoses. These issues were explored using general open-ended questions, followed by additional probing to highlight further the issue raised e.g. specific services rendered to OALWH in the HIV clinics and the extent to how their health concerns were addressed in the clinics. For healthcare providers, participants were invited to share their experiences providing care to OALWH. Among caregivers, we explored different issues, including their experiences taking care of OALWH and the challenges these adults faced in their environment. We also collected respondents' demographic information such as age, sex, educational status, and employment status. For OALWH, we also collected HIV-related information. All participants were given Ksh 350 (about US\$3) as compensation for time spent in the research, with transport expenses also reimbursed.

2.3.4 Data analysis

All the audio-recorded interviews were transcribed verbatim by a team of four trained research assistants. Subsequent data management was done using NVivo software (version 11). We applied the framework approach to analyze our qualitative data (180). Initially, two authors (PNM and AA) developed a preliminary coding framework inductively through in-depth reading of transcripts and deductively by considering themes from the interview schedules. These codes were discussed, and consensus reached on how they should be brought together into themes with guidance from the biopsychosocial model. The initial coding framework was progressively expanded to capture emergent themes as coding continued. When the coding was complete in NVivo, the lead author grouped all themes related to a specific concept to form categories and exported this to a word-text processor to produce charts. The generated

charts were used to summarize data, look for similarities or differences and explore patterns among the three groups of participants in the analyzed data.

2.3.5 Ethical considerations

Written informed consent was obtained from all participants in the study. The study also obtained ethical clearance from the Kenya Medical Research Institute Scientific and Ethics Review Unit (KEMRI/SERU/CGMR-C/152/3804) and the Kilifi County Department of Health Services (HP/KCHS/VOL.X/171).

2.4 Results

2.4.1 Sample characteristics

We interviewed a total of 56 participants (34 OALWH, 11 healthcare providers and 11 primary caregivers) in this study. Among OALWH, 53% were women; most (82%) had up to a primary level of education, and their age ranged from 50 – 72 years. All the OALWH were on HIV treatment. Healthcare providers included six registered nurses, two clinical officers, two project managers of community-based organizations and one HIV counsellor. All the primary caregivers were family members, most of whom (73%) were female. Further sociodemographic information and HIV-related characteristics of the OALWH are summarized in Table 2.1.

Table 2.1: Sociodemographic and clinical characteristics of older adults living with HIV (Kilifi County, Kenya. 2019).

Characteristic	n (%) or median (IQR)
Median age	57 (54 – 63)
Female	18 (53%)
Educational level	
None	7 (20%)
Primary Level	21 (62%)
Secondary level	5 (15%)
Tertiary level	1 (3%)
Type of employment	
Unemployed/not working	12 (35%)

Small scale trader	15 (44%)
Casual worker	4 (12%)
Professional/skilled work	3 (9%)
Marital status	
Never married	1 (3%)
Married	19 (56%)
Separated/Divorced	7 (21%)
Widowed	7 (21%)
Living arrangements	
Alone	5 (15%)
Single generation household	4 (12%)
Multigenerational household	25 (73%)
Median household size	5 (2 – 9)
Residence (rural)	30 (88%)
Median duration since HIV diagnosis (years)	12 (10 – 15)
On ART treatment	34 (100%)
HIV status disclosure	
Non-disclosure	1 (3%)
Partial disclosure (to close family only)	18 (53%)
Full disclosure (beyond close family)	15 (44%)

Notes: ART – Antiretroviral treatment; IQR – Interquartile Range

2.4.2 Perceived biopsychosocial challenges confronted by OALWH

The different forms of biopsychosocial challenges faced by OALWH are summarized in Table 2.2. Overall, most of the OALWH shared their 10-plus years of experience living with HIV, from the time of diagnosis to their current state. The majority of the OALWH described moving from a state of shock, fear, anger, denial, hopelessness, or suicidal ideation upon diagnosis to a state of acceptance and ownership. This transition was not without challenges, as many of the OALWH noted going through traumatic experiences from family members, friends, workmates, and healthcare providers. Thereafter, they narrated moving from a state of ownership to a state of constant survival characterized

by an array of health problems which we have conceptualized as physical (biological), mental (psychological) and social in the following sections according to the biopsychosocial model.

Table 2.2: Perceived forms of physical, mental, and psychosocial health challenges facing older adults living with HIV as discussed by study participants (Kilifi County, Kenya. 2019).

Forms of health challenge	Number of in-depth interviews (among OALWH) where the health challenge was discussed (N = 34)	Number of in-depth interviews (among caregivers) where the health challenge was discussed (N = 11)	Number of in-depth interviews (among healthcare providers) where the health challenge was discussed (N = 11)
Physical complaints			
Comorbidities: chiefly ulcers/hyperacidity, hypertension, and diabetes	29	9	11
Wide-ranging physical symptoms, e.g. pain/body aches, fatigue, insomnia	33	10	9
Functional impairments, e.g. difficulties walking, writing, holding things	18	3	3
Mental complaints			
Symptoms suggestive of common mental health problems, e.g. thinking too much, worry, stress, low mood, hopelessness/giving up easily	29	9	9
Cognitive complaints chiefly memory difficulties. Others including slow mental processing/learning, attention/concentration problems	22	7	4
Current drug and substance use, mainly 'mnazi' and 'ugoro', which are the local palm wine and smokeless tobacco, respectively	5	0	9

Suicide and suicidal ideations	3	0	4
Psychotic-like symptoms, e.g. disorganized behaviour, aggression, lack of restraint and unwanted thoughts.	1	3	3
Psychosocial complaints			
Financial difficulties, e.g. lacking school fees for dependents, walking long distances for HIV care	31	8	9
HIV-related stigma and discrimination especially internalized and enacted stigma	29	8	11
Ageism/ageist stereotype, e.g. neglect, verbal insults, vandalism	19	5	7
Isolation and lack of support	19	5	8
Loneliness	17	1	8
Food insecurity, e.g. skipping meals or going days without food	16	5	9
Note: The complaints noted by caregivers and providers mostly relate to the patients under their care and to some extent also their general observations to the larger population of OALWH.			

2.4.3 Perceived physical health challenges

Physical complaints were commonly described by several participants. Key among these concerns was the onset of multiple comorbidities in these adults, which was frequently associated with pain, loss of control of one's body, emotional distress, and increased treatment burden. Hypertension, diabetes, ulcers/hyperacidity, hearing, and visual impairments were the most frequently reported comorbidities across the participants. Other conditions discussed (though to a lesser extent) included obesity, arthritis, stroke, teeth problems, cervical cancer, TB, and pneumonia. Apart from these comorbidities, somatic symptoms were also discussed in several interviews across the groups. Body pain, headaches, insomnia, fatigue or low energy, and limb numbness were also frequently reported. Some participants believed that the onset of the physical challenges was because of HIV-related factors (e.g., HIV infection itself, long-term ART), multimorbidity, old age, food insecurity, emotional distress, substance use, and the nature of someone's work. Participant quotes are given in Table 2.3.

Table 2.3: Participants' physical health challenges quotes (Kilifi County, Kenya. 2019).

Perceived health problem	Examples
Multiple comorbidities	I am weak and constantly fatigued because I have ulcers, high blood pressure, and diabetes. My eyes are also painful and feel strained, and I sometimes experience toothache. As we are talking right now, my ears are not hearing well. So, all these diseases make me weak and significantly affect my well-being (Female OALWH - 10 years with HIV)
	Ulcers is their main problem. Many of them complain of ulcers, and this is mainly because of stress. Anything small affects them. Sometimes you find one thinking too much and another telling you, 'My children do not take care of me; they have forgotten about me' or 'I have one child.' Someone tells you about their child who died long ago but is still affected. Stress is a big problem because they pile up issues, not because of HIV but other issues. Another issue is food. The elderly must look for food for themselves and their irresponsible children, who may be drunkards. Often, you find that they deal with their stress and that of their children (Nursing officer)
	Last year, my hands were painful, and I could not bend. I carried out an X-ray and was told it was arthritis. I was told there was no treatment, and the only relief was by massaging myself and using painkillers. So, I bought clove oil, and it is what I have been using. There are improvements, but the problem is not resolved yet. I am also unable to work, and to make it worse, and I have difficulties sleeping whenever I am stressed. I was recently diagnosed with high blood pressure but am not taking medications yet. I also have ulcers, but I do not usually keep it in mind (Female OALWH - 11 years with HIV)
Somatic symptoms	My knees are painful. Sometimes even squatting is a big challenge. I also cannot rise too quickly from a seated position; I have to support myself. I must also use painkillers for some relief before I can work. This has affected me because I cannot work without them. Whenever the analgesic effect wears out, it becomes very difficult to use my legs. I also experience headaches sometimes, and my relief is usually the painkiller. These painkillers have become my life now (Female OALWH - 2 years with HIV)
	My pace has become very slow nowadays. I feel heavy, and there is nothing I am lifting or carrying. I often feel tired, and, at such times, I prefer walking around for some time. I must do this to ward off intrusive thoughts. Since being diagnosed, I have also grown weak and lost my libido. In fact, whenever I start having sex, I

	have this sensation of my waist being cut with a razor (Male OALWH - 10 years with HIV)
	My husband cannot do heavy manual jobs. He used to work at the sea at night, which is usually cold and requires energy. It reached a point I had to stop him from going there anymore because he was weak and felt he was risking his life. Before this, he often used to complain of being sick. I was not at peace. I found it pointless for him to earn money that way and end up using it to medicate him. So, I told him to stay at home and do anything else. We are living by the mercies of God (caregiver)

2.4.4 Perceived mental health challenges

We have discussed these issues under the following headings: symptoms suggestive of common mental health problems, cognitive symptoms, substance use problems, and others (suicidal ideation and psychotic symptoms). Participant quotes are given in Table 2.4.

2.4.4.1 Symptoms suggestive of common mental health problems

Emotional and behavioral symptoms, suggestive of anxiety and depression, were described to be prevalent across the participant groups. Key among these symptoms included thinking too much, persistent stress, low mood, anger/irritability, worrying a lot, hopelessness, restlessness, panic attacks, and nightmares. Other prominent symptoms included insomnia, self-isolation, low self-esteem, headaches, and low libido. Overall, these symptoms were described to be on-and-off among the OALWH and were frequently associated with the exacerbation of physical conditions, chronic use of drugs, financial instability, and overall poor quality of life. For many participants, the onset and persistence of physical body changes (e.g., peripheral neuropathy, obesity, body weakness) were considered a significant risk for mental complaints.

2.4.4.2 Cognitive/neurological challenges

The commonly reported complaint in this category was memory difficulty, e.g., difficulties recalling important dates or finding items. Surprisingly, most OALWH reported that they rarely forgot to take their medications. Many healthcare providers corroborated this, although they also noted that there are some OALWH at risk of poor adherence caused by cognitive impairments. Other cognitive symptoms included

attention/concentration, processing/learning, movement, and multi-tasking difficulties. Peripheral neuropathy was also reported to be a common neurological problem in these adults and was associated with significant distress. Among OALWH, the cognitive symptoms were viewed as an additional disease, and many did not understand its causes. The few who sought medical attention ended up being disappointed, sometimes being advised that it will resolve on its own or there is medicine, but it is costly.

2.4.4.3 Drugs and substance use problems

Current drug and substance use was mainly discussed by healthcare providers. In contrast, most OALWH reported having a history of drug and substance use, especially alcohol and tobacco but stopped following HIV diagnosis. However, some confessed to being social drinkers. '*Mnazi*' and '*ugoro*' (smokeless tobacco or snuff) were the commonly used substances. Many providers emphasized that *mnazi* drinking is a big problem, noting that some OALWH came for their routine clinic appointments while drunk and sometimes forgot to take their ART drugs. Some providers also associated the *mnazi* drinking problem with unsuppressed viral loads, treatment default, and sexual risk-taking behaviors, e.g., multiple partners. The key underlying factors for the increased use of *mnazi* included family conflicts which often led to stress, unstable sexual partners, negative coping skills, culture, and easy access to these substances. *Ugoro*, the other commonly abused substance, was especially common among women. Beer, cigarettes, khat and marijuana were also discussed, although to a lesser extent.

2.4.4.4 Suicidal ideation and psychotic-like symptoms

Three OALWH reported having intermittent suicidal ideations. This was corroborated by the healthcare providers. The commonly associated factors included persistent stress (caused mainly by financial difficulties and family conflicts), evil spirits, and HIV-related (e.g., getting tired of taking ART and not getting healed). Though limited, there were also few reports of psychotic-like symptoms (e.g., disorganized behaviour, aggression, lack of restraint and unwanted thoughts) across the three groups of participants. These cases were frequently observed around the time of HIV diagnosis.

Table 2.4: Participants' mental health quotes (Kilifi County, Kenya. 2019).

Perceived health problem	Examples
Symptoms of stress, depression, anxiety, trauma	Living with HIV is difficult, my brother because you must take medications daily without missing and must live knowing that you are sick and could die any moment. This reality makes me depressed. I also do not know who will take care of my family if I die because my relatives are useless to me! I am jobless, and this makes me very sad and depressed because I have a family that needs to be cared for! I do not have money, getting food is a big problem, and to tell you the truth, I cannot even afford to pay school fees for my children. I must borrow to survive. As we are speaking, I have a court case because am unable to repay a loan I took (Male OALWH - 20 years with HIV)
	My eyes cannot see well and are very itchy. Today in the morning, I had to compress them with hot water. The itchiness is often accompanied by coughing. I was prescribed some medications, but they were not helpful. You see this paper am holding; I cannot read anything on it unless I view it in very bright light during the day. At night, I can hardly make out the person calling my phone! This has affected me a lot. I am worried and do not know when this problem will end. Sometimes I want to work, e.g. write something, but I cannot. At night I must also depend on someone else to guide me. Other times I cannot work at all because of my eyesight problems. Whenever I am depressed, I just run to God (Female OALWH - 2 years with HIV).
	My mum is generally stressed and very irritable. Sometimes she can get so stressed that she falls sick, forcing us to take her to the hospital (Male Caregiver).
	Sometimes, she gets very preoccupied with thoughts until she cries...not often, but it happens. Sometimes she also has trouble sleeping, and when I inquire why she tells me, 'I am always thinking, and I do not know exactly what I am thinking about, and I do not have peace.' I think she would love to be free with everyone and go anywhere she wants without people talking behind her back. She is sensitive, you know. When she hears people laughing, she usually asks me, 'Why are they laughing? Are they laughing at me?' Sometimes, she does not come out of her room for two or three days and must force her to eat something (Female Caregiver).
	There is this client; her skin has spots, her jaw has dropped, and looks weak when she walks. She is often in deep thought; for instance, we could be in a seminar where many people participate, but you find her lost in her thoughts. We had to talk to her at some point, and we realized she had been abandoned by her husband, who had married another wife. We had to do a referral for this client because of these issues (Project manager of a community-based organization)

	You know these people are dealing with so many things which affect them. Stress, anxiety, and depression, and that is why screening is being done, and any positive case is linked with the psychiatric clinic (Nursing officer)
Cognitive symptoms	I can plan to do one or two things but later abandon them and do something different without any reason. For instance, I could be having a meeting, perhaps with some elders, but end up not doing and instead do other things. There is also this issue of forgetting, which is like a disease to me. I usually have a problem finding my things. Like yesterday, I could not find my money. I am worried about this problem, which is like a disease nowadays. I start doing one thing, then abandon it, and do the same to another. Sometimes my food gets burnt in the kitchen because I forget I was cooking and start doing other things. One time I decided to see a clinician about this disease because it was too much. I do not know whether it is because of these medications we are taking or something else. The clinician told me it would end with time. One thing I know, though, is that I was not like this before. This problem started when I began taking these medications. I am very surprised! I am not alone in this; many of my peers also complain of the same thing. Or could it be old age (Female OALWH - 13 years with HIV)
	I can place my things in one place and forget about them. This can be money or even fruits. If I do not tell my husband that I have bought, e.g. fruits and have placed them in the cupboard, those bananas will go bad. He (my husband) will remember, but I will not. My body also becomes numb sometimes. My hand becomes heavy and immobile, especially in the morning. This extends to the shoulders and usually makes it impossible to carry things. The hands sometimes tremble and experience prickly feeling (of pins) in addition to numbness and general weakness. One of the legs is also involved in this (Female OALWH - 10 years with HIV)
	To speak the truth, my husband does not concentrate nowadays. Actually, the real issue is his forgetfulness. It is a real concern for me. I have tried to make him understand that he has this challenge, but he never accepts it. I have suggested we look for medications, but he does not want to. He has also become very irritable lately. I think very few people will be able to tolerate him (Female Caregiver)
	You might explain something to one of them (OALWH) and moments later find that they contradict that same information. We have such cases, but not very many. Some take their ARVs and septrin/ co-trimoxazole the same way when it is not supposed to be. In fact, some interchange these drugs when they come for their refill appointments. Because of this, we usually emphasize how the drugs should be taken and give them shorter appointments, e.g. weekly, for those who stay nearby. We also ask them to come with their treatment support persons, but some say they do not have them (Nursing officer)

Substance use and suicide	My only addiction is to smokeless tobacco, but I stopped taking alcohol long ago. I have never smoked cigarettes before. I must use it (smokeless tobacco) every morning; otherwise, my heart will not be at peace; I will start feeling sad and not concentrate on any task. I only feel okay once I use it (Female OALWH - 2 months with HIV)
	Adults of my age in this community are ill-mannered. They like taking alcohol and smoking cigarettes. They also have extra-marital affairs. Every morning, they must have a packet of cigarettes and ensure they do not miss a bottle of the local palm wine because they cannot afford beer. They have to take a bottle or two for them to sleep well (Male OALWH – 14 years with HIV)
	I often feel like taking my own life. These thoughts come to me quite often, especially when I am stressed. Usually, a certain voice tells me that I am better off dead than alive, and another voice tells me not to do it. There is a fight between God and the devil. Sometimes I wake up in the middle of the night around midnight and start thinking about many things, which is how I lose my sleep entirely. I am just thinking, ‘I do not have money, my wife is unemployed, and my children are still in school. Where will I get food?’ So, in the morning, I share this with my wife. At the church, we are also told that suicide is not the solution; it is adding the problems, so it is better to struggle but survive (Male OALWH - 14 years with HIV)
	Not just suicidal ideations. Sometimes we also have cases of actual suicides. Last month, an older adult committed suicide. He was recently diagnosed with HIV, and two of his three wives also turned positive. We do not know what happened, but we received news that the old man had committed suicide two days later. So, it is a challenge (Clinical officer)

2.4.5 Perceived psychosocial challenges

We present these issues under the following categories: a) financial challenges, b) stigma and discrimination, and c) loneliness and isolation. Participant quotes are given in Table 2.5.

2.4.5.1 Financial challenges

This was discussed in virtually all the interviews we conducted. Many participants felt that financial difficulty was the most crucial issue affecting OALWH in the study setting because of its massive impact on food security, caregiving responsibilities, emotional well-being, and management of HIV and other comorbidities. Many OALWH reported skipping meals or going hungry for some days, lacking school fees for their dependents, and walking long distances to access HIV care for lack of money. This was corroborated

by the healthcare providers and caregivers, who further stated that many of those who slept hungry tended to skip their medications, complaining of dizziness, headaches, and stomach discomfort. To some extent, this was associated with poor treatment outcomes, including unsuppressed viral load and poor retention in care.

2.4.5.2 Stigma and discrimination

This theme incorporates HIV-related stigma and ageism (discrimination based on age). Despite relatively high levels of disclosure, many OALWH experienced HIV-related stigma. Discriminatory behaviour (enacted stigma from malicious gossip to outright discrimination, e.g., neglect, isolation, verbal insults) was reported to be common, especially in the most rural areas of the study setting. The perpetrators were mainly family members. Stigma was also reported to be common in mnazi drinking dens called 'mangwe', burial ceremonies, and HIV clinics. Internalized stigma emerged as an important theme, especially among the OALWH and was frequently associated with self-isolation, anxiety or high consciousness of self, fear of seeking assistance, attending very far HIV clinics, stress, and irritability.

Many participants also highlighted discrimination based on age, which was perceived in multiple settings, including the home (mainly through isolation, neglect, and lack of respect from children), HIV clinic (e.g., scolded openly and verbal insults), and the community level. It also emerged that some community members around the study setting (especially in the most rural areas) regarded older people suspiciously. Many participants narrated hearing or witnessing several older people being beaten, beheaded, or burned alive in their houses for suspected witchcraft, and the perpetrators were mainly close family members.

2.4.5.3 Loneliness and isolation

This emerged as an important theme in the conversations with OALWH and healthcare providers. Despite living in multigenerational households, many of the OALWH expressed loneliness and isolation. Some had lost their partners, some their closest relatives and others saw their circle of friends getting smaller. Still, others felt neglected by those around them.

Table 2.5: Participants' psychosocial challenges quotes (Kilifi County, Kenya. 2019).

Perceived health problem	Examples
Financial challenges	I am jobless, my brother. I have also lost my hands-on skills and experience with time. I am weak and do not have money. Getting food is a problem, and to speak the truth, even raising school fees for my children is a huge problem. Nevertheless, I have a very good friend, a lawyer, who is of great help to me. Sometimes, I eat at his place, lunch and dinner, but he does not know I live with HIV. Sometimes I am depressed and anxious because I do not know how to provide for my family. My relatives are of no help to me. Like yesterday, we did not have dinner, and I had to borrow the fare to come to this place. As we speak, I am in debt and face a court case because I cannot repay a loan. Often, I sleep hungry and must borrow to survive (Male OALWH - 20 years with HIV). To speak the truth, I do not receive any support from my relatives, and this is not because there are no people to help. My husband and father died. I often sleep hungry. Sometimes, I only have a cup of porridge for three consecutive days...and this is usually borrowed from a neighbour so that I can take my medications. Other times, I survive on a cup of tea or hot water. Fare is also a big challenge. However, whenever I lack fare, I usually walk to the clinic from Bamba to Kilifi (around 50 km). I usually start my journey two days ahead of my clinic appointment and have two rest points in between, first at <i>Magogoni</i> and then at Kilifi at my uncle's place. From my uncle's place, I then walk to the clinic very early in the morning before 6 am (Female OALWH - 5 years with HIV). Financial challenge is a big problem for these adults because they are neglected by their children sometimes. The day I am on duty at the clinic, I usually give many of them fare. You will hear many saying, 'sister, please help me with fare, I walked to the clinic, and I have to walk back.' If you have a good look at them, they appear exhausted, so you end up helping them. Even food is a challenge. In our discussions, the majority say that they have one meal per day and mind you, some fail to take their medications whenever they miss a meal due to dizziness claims (Nursing officer). The other day, we visited an elderly client in the community, a woman caring for two grandchildren living with HIV. The grandmother is unemployed, and the children's mother is not around. The grandchildren are in school. They need support with their schooling in addition to food. She is largely unable to provide all these and often must borrow. Sometimes, you find that even the skills you give them, e.g. rearing chicken or fish and making baskets, are not helpful

	because they are old and unable to work. In such cases, we assist them with food, counselling sessions, linkages, and referrals to foster treatment adherence and the well-being of the children (Project manager of a community-based organization)
	I usually borrow money from neighbours or friends to buy food whenever my mother does not have. I do not mind the debt because my target is to ensure that my mother has food to take her medications. However, it is a bit stressful because sometimes she sleeps hungry. And this is complicated by my father, who often quarrels my mother over small issues, increasing her stress. Every time my mum asks for money, he says he does not have it, and if we ask him how we will survive, he replies, 'Can't your son look for the money?' It is frustrating because how can I take up this responsibility while in school? In fact, the one educating me is usually my grandfather (Caregiver)
Stigma and discrimination	The elderly living with HIV undergo many challenges in the community. For instance, you find one is sick, and no one is taking care of him at home. In fact, people will avoid interacting with this person, especially where he sleeps, out of fear of contracting the virus. Some of them have called me seeking help. Sadly, when I go to their homes, I find some have not even bathed for a whole week! In such a case, I usually clean up the person and assist him in eating. It is sad because the family places the food there; the person is sick and can hardly eat alone! Some are told to stay with their HIV because they know where they took it from! As we are speaking, there is a woman I would like to talk to because she stays in Malindi but takes her ART medications from Nakuru because she does not want relatives to know that she is living with HIV. So, HIV education has come for sure, but it is far from being complete (Female Peer counsellor)
	She is often in a low mood. She gets offended whenever she hears people talking and laughing on the other side. I think she would really like to be free and move about without people badmouthing her. (Caregiver)
	For men, there is a challenge, a huge challenge. Getting them is a very big challenge. We have tried to work with male champions to convince their fellow men to join us. Stigma is a big issue. In our meetings, you mainly find the ladies coming, and when you ask them about their husband's whereabouts, they often tell you, 'He has gone to work and has sent me to listen to the messages on his behalf.' So, they have that fear; they do not want to be seen. The case is not different in the primary facilities because many of them are not coming. He either sends the wife or comes but is very careful not to be seen, e.g. comes in through the back. Because of this fear, you find that some of the men do not want to be tested. We have several cases where the wife is living with HIV; the husband got tested and turned positive but is still in denial. You will find the wife saying, 'We went and got tested with him but has insisted that the machines

	were not functioning and as such, he is not infected.’ Others also note that their husbands have constantly refused to start ART and use condoms, and whenever these issues are brought up, they end up quarrelling (Project manager of a community-based organization)
	That is a big problem (stigma). Ours is a small facility, so we schedule one day in a week to see the clients living with HIV. Surprisingly, even the community knows Tuesday is the day for those taking ARV drugs. So, most of them come very early in the morning. Therefore, I must come in very early to serve those who have stigma. Alternatively, that person will hang around the clinic from morning till evening when everyone has left so that people will not understand what she is doing there, or you will find that they will skip their appointed clinic dates (Nursing officer)
	Some of them are mistreated when they come for their appointments until I get angry! Let’s say you are late for your appointment; you will be shouted at, insulted, and reprimanded like a child. In fact, some end up crying and I have to calm them down. It is sad because the culprits are usually the nurses who often shout at them, saying, ‘Take your drugs, or you will die of AIDS alone, and you won’t see us!’ It is shocking because some of them are treated very badly to the point that I am also angered. Some come to my desk, shedding tears, so I have to calm them down. At some point, it was too much that some of them transferred to other clinics (Adherence counsellor)
	The elderly are being burned alive and cut with pangas. As a matter of fact, some of my neighbours recently cut their elderly aunt severally with a panga because of witchcraft accusations. Later, their father also passed through the same ordeal by one of his children...the head was completely slashed off with a very sharp panga! And the reason is always witchcraft; I have not heard of any other thing. Such cases are numerous where I am living. I have witnessed four elders being cut with pangas, and the sad part is that these people will never expose each other to the police...even if I know it is you who did it, I will never say it. Even when the police come, the locals will never expose the culprit (Female OALWH - 12 years with HIV)
Loneliness and isolation	I desire to have an exclusive male companion my age to spend the rest of my life with. Having one who is already married is problematic because sometimes I am very lonely and would want to call him, but I end up avoiding it out of fear, ‘What if he is with the wife? And you know it is not good to break someone’s marriage.’ Because of such challenges, I would like to have my own man who does not belong to anyone, one I can relate to freely and love fully. You know, with someone else’s husband, the love is incomplete, and it feels like I must hide constantly, and it reaches a point I feel afraid. Sometimes he does not answer my calls and sends a text message saying he is at home. So, you see, with such problems, I just want to get my own man who will live with me,

	someone I can talk with, especially when things are difficult because it is stressful at times (Female OALWH - 11 years with HIV)
	Sometimes, I wish I could have friends with whom I can confide and share my challenges, but I am afraid of being discriminated. You cannot trust anyone. I have many friends, but they are all fake (Male OALWH - 20 years with HIV)
	There are times he isolates herself from other people. You might see her seated alone and in deep thought. Sometimes she wakes up and begins to shed tears. She usually feels that her life has come to an end, perhaps (Caregiver)
	Whom will I share my problems with? I do not have anyone. Anyone I open myself to will want to know how and why my husband is facing those challenges. What is the cause? This will mean I start discussing and revealing the issues of my husband, which is not good (caregiver)

2.5 Discussion

2.5.1 Summary of key findings

We conducted this study to gain a preliminary understanding of the health challenges facing OALWH on the coast of Kenya. Our study provides insight into the complex challenges of ageing with HIV and opens up opportunities for further epidemiologic research and subsequent development of tailored interventions for OALWH. Overall, our findings reveal that OALWH in this setting are particularly vulnerable to mental health problems, especially symptoms suggestive of common mental conditions. They are also at risk of physical health challenges, including comorbidities and somatic complaints. Mental and physical health impairments are complicated by psychosocial challenges, including poverty, lack of support, stigma, and discrimination. Noteworthy, there was an overlap of perceived risk factors across the three health domains (e.g., family conflicts, poverty, food insecurity), suggesting that OALWH who experience these shared cumulative risk factors are more likely to face multiple health challenges. It also implies that the action taken to mitigate any or some of the shared enabling factors is likely to have a preventive spillover effect across multiple health domains. Most of the views of OALWH on health challenges were corroborated by views from the providers and caregivers. However, a few disparities emerged in some of the perceived health

challenges. Current drug and substance use, for instance, was reported mainly by healthcare providers, while cognitive complaints were discussed by OALWH.

2.5.2 Physical health challenges

Our discussions clearly showed that physical challenges are important concerns for older adults living with HIV on the coast of Kenya, given their negative impacts on other health domains and overall health. As the number of OALWH increases in many HIV clinics, HIV care will increasingly need to draw on a wide range of medical disciplines besides evidence-based screening and monitoring protocols (10). Unfortunately, most healthcare providers presently lack guidance and training to identify and manage declines in physical and mental capacities in this population. The siloed provision of HIV care and other comorbidities could also imply that providers are unaware of the patients' other conditions. Our findings are similar to those reported in a recent qualitative exploration of challenges seeking HIV care services for OALWH (171). Integration of services for HIV and non-communicable diseases in primary care may enable settings like Kenya to expand healthcare coverage for PLWH.

The current findings also revealed a prominent intersection between ageing and HIV. For most participants, ageing rather than HIV was the primary concern. This is not surprising considering that among PLWH with controlled viraemia, HIV infection often stops being the overriding comorbidity but is simply a key element in the overall milieu of multiple conditions (181, 182). In a few instances, however, participants discussed that their experiences were associated with HIV, long-term medication use, or side effects, although their providers attributed these conditions to normal ageing. They advised the OALWH to 'wait', and they will improve with time. Disagreements about the cause of a symptom or health condition may contribute to doubts about the effectiveness of treatment or conceal an emerging disease and contribute to delayed diagnoses such as medication side effects and polypharmacy.

2.5.3 Mental health challenges

Our finding of substantial symptoms suggestive of common mental health conditions among OALWH is consistent with previous reports of poor mental health among PLWH in the study setting, albeit among younger populations (183, 184). However, our study does not establish whether the burden among OALWH is higher or lower than that observed among young PLWH. Quantitative studies are needed to confirm this comparison. Nonetheless, OALWH may be facing a higher burden of common mental problems than their younger counterparts for different reasons. Firstly, many of the longest surviving OALWH may be significantly impacted by the legacy of the early years of the epidemic, including multiple bereavements and 'survivor guilt' (185). Secondly, the higher burden may also be attributed to the numerous challenges that OALWH face, e.g., poverty, food insecurity, caregiving responsibility, double stigma, and the onset of physical body changes, as evidenced in our study.

Since the beginning of the HIV epidemic, the manifestations of cognitive and neurological problems have been ubiquitous and frequently associated with poor treatment outcomes and impairment of activities of daily living (166). In our study, the most frequently reported cognitive problem – memory difficulty – was commonly associated with stress and shame. Strikingly, healthcare providers seldom suspected cognitive impairments among OALWH and screenings were never done. This observation is similar to what has been reported in South Africa (182, 186). Despite the reported memory challenges in this study, OALWH rarely forgot to take their medications (from their own self-reports and that of their providers). This finding is not unique in the HIV literature (187). It is possible that OALWH are more organized and experienced and possibly more motivated after experiencing the initial devastating outcomes of the HIV pandemic. However, it is still essential to monitor the cognitive function of these adults to prevent treatment non-adherence, considering the multiple challenges they face, which are likely to impact their cognitive function and worsen as they grow older.

Our findings also noted a section of OALWH at risk of substance use dependence, especially home-brewed alcohol, called mnazi. This is not surprising given that the

consumption of mnazi is common among the inhabitants of Kilifi because it is cheap and often less regulated (188). The need to address this problem is even more crucial since it was associated with rising cases of sexual risk-taking behaviour and poor treatment outcomes in this cohort.

2.5.4 Psychosocial challenges

Psychosocial factors are well-known predictors of treatment adherence, disease progression and quality of life for PLWH (115). Findings from our exploratory study suggest that financial difficulties, loneliness, stigma, and discrimination are prevalent among OALWH in the study setting and are associated with mental complaints and physical health problems. Similar findings have been reported in Western Kenya among OALWH (171). These findings are not surprising, given the country's prevailing situation of older adults. According to Help Age Kenya, the majority of older people in Kenya, especially those in rural areas, live in absolute poverty (189). A recent report, the National Gender and Equality Commission Report, dubbed 'Whipping Wisdom', also established that older adults in Kenya faced various forms of violence, including social stigma, neglect, abandonment, and hindrance from using and disposal of property (190).

2.5.5 Implications

Our study highlights opportunities for interventions and further research. It is important to reiterate that the health challenges faced by OALWH at the coast of Kenya are often interconnected and require a cohesive and collaborative response to achieve maximum benefits. Such interventions should target modifiable factors such as emotional support and integrate needed social and community support, e.g., case management services, food and nutrition support, financial assistance with caregiving responsibilities, and transportation. Context-specific interventions to help OALWH develop and nurture their own coping strategies are also critical in this population. Patient-centred care and patient self-management principles (e.g. self-reliance and empowerment) are critical elements in chronic care and are advocated as universal strategies in international frameworks of chronic care (191). Integrated care models – which focus on the holistic view of the person by considering both medical and psychosocial needs, e.g.,

comprehensive geriatric assessment, are likely to improve the patient situation and the treatment outcomes. While OALWH are the primary target of most of the existing interventions in this cohort (192-194), research is required on how to build the capacity of healthcare providers, family members who act as informal caregivers and friends to provide support and care to those ageing with HIV. Future research should also examine the resources and resilience among these individuals to fully understand the vital role of resilience in empowering OALWH to enact processes that buffer health from the identified stressors. Future research is also needed to quantify the existing burden of physical and mental challenges in this population in Kilifi and confirm the risk and protective factors of these challenges. Furthermore, there is an urgent need for research to pilot and test the applicability and effectiveness of interventions underlying the determinants of physical and mental impairments in this setting.

2.5.6 Strengths and limitations

To our knowledge, this is the first study to richly explore the health challenges of OALWH on the coast of Kenya and among the few studies in Kenya. Unlike previous studies, a key strength of this work is that participants comprised a diverse group of stakeholders. This ensured that the views were diverse and contrasted across participant groups. Using a biopsychosocial model helped us obtain a richer insight into the complexity of the identified health challenges. However, our findings emanate from a predominantly rural setting, and circumstances may differ from those in urban areas. Only OALWH who were on long-term HIV treatment were interviewed in this study; thus, their circumstances may also differ from those who are not in care or the newly diagnosed. As is the norm for qualitative studies in general, data collection, analysis, and interpretation are subject to individual influences and researcher biases; nonetheless, we countered this effect by maintaining reflexivity and constant discussion with the research team to provide rigour and credibility to the study.

2.6 Conclusions

Our findings provide initial insight into the biopsychosocial challenges confronted by OALWH in a low-literacy Kenyan setting. The participants' views indicate that mental complaints (especially symptoms suggestive of common mental health conditions and

memory difficulties), physical problems (particularly comorbidities and somatic symptoms) and psychosocial challenges (especially poverty, stigma, and discrimination) are of concern among OALWH. Many of the perceived risk factors for these challenges often overlap across the biopsychosocial domains. Our study also highlights several opportunities for interventions and future research to tackle these issues in the study setting. Future research should quantify the burden of these challenges, examine the resources available to these adults, pilot, and test feasible interventions in this setting, and in doing so, aim to improve the lives of older adults living with HIV. Follow up studies could also explore in detail how the HIV healthcare system can be restructured to suit the needs of OALWH in light of present challenges. The current study could not establish how the reported health challenges have transitioned over time for the OALWH. Future studies, with appropriate designs e.g. longitudinal studies, will be able to explore this.

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2.8 Declaration of conflict of interests

The authors declare no potential conflict of interest with respect to the research, authorship, and/or publication of this article.

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2.10 Data availability

No additional data is available. The data that support the findings of this study have been included in this article.

Chapter 3

Strategies for improving mental health and wellbeing used
by adults ageing with HIV from the Kenyan coast: a
qualitative exploration

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3.0 Preamble

In the previous chapter, I explored the biopsychosocial health challenges faced by OALWH at the coast of Kenya. Findings revealed that OALWH in this setting are at risk of multiple mental and physical health problems, which are complicated by several psychosocial challenges. The present chapter is a reproduction of the published article and builds on the previous chapter by exploring the coping strategies that the OALWH utilize to confront the multiple health challenges they face, against the backdrop of a largely unprepared healthcare system.

3.1 Abstract

Background: Physical and mental health problems are common among older adults living with HIV (OALWH). Adaptive coping strategies play a vital role in improving these adults' mental health and well-being despite the deleterious effects of HIV and ageing. However, in sub-Saharan Africa, limited evidence exists on the commonly utilized coping strategies in this population. We explore the coping strategies used by Kenyan OALWH to improve their mental health and wellbeing.

Methods: Semi-structured in-depth interviews were conducted between October and December 2019 with 56 participants: 34 OALWH (53% female), 11 healthcare providers (63% female) and 11 primary caregivers (73% female) in Kilifi County. All interviews were audio-recorded and transcribed verbatim. We used the framework approach to synthesize the qualitative data.

Results: Five major themes emerged from the analysis of participants' narratives, including self-care practices, religion and spirituality, relational living (social connectedness), generativity, identity, and mastery. Our study further revealed maladaptive coping strategies, including reliance on over-the-counter medications, self-isolation, waiting to see if symptoms would subside despite doing nothing, and HIV treatment interruptions during prolonged periods of prayer and fasting.

Conclusions: Our findings provide an initial understanding of the coping strategies used by OALWH to confront HIV and ageing challenges in a low-literacy, low socio-

economic Kenyan setting. Our results suggest that interventions designed to enhance personal capacity, social support, positive religiosity and spirituality, and intergenerational connections may be beneficial in improving the mental health and well-being of OALWH.

Keywords

HIV; ageing; Kenya; coping; mental health and well-being

3.2 Introduction

Population ageing is now a reality worldwide, and sub-Saharan Africa (SSA) has the most rapidly ageing population (195). Thus, ageing and health are important priorities (196, 197). Investing in healthy ageing and long-term healthcare systems is more important than ever as the world grapples with this demographic shift. One subpopulation of older adults that deserves special attention is that of adults ageing with HIV aged ≥ 50 years. With improved access to combination antiretroviral therapy (cART) and a rising trend of HIV infection among the elderly, the number of older adults living with HIV (OALWH) in the world is expected to rise rapidly (33). This puts more pressure on HIV health services to develop and implement appropriate programs that address these adults' unique needs. The research on HIV and ageing in SSA is limited (129). However, most of the global evidence suggests that apart from physical health challenges, OALWH face unique mental health burdens and challenges to their social well-being that may differ from their uninfected peers and younger counterparts, e.g. elevated comorbidity and early-onset geriatric conditions (10, 164, 176, 198-200). Despite the observed challenges, intervention research designed to address the unique needs of OALWH is insufficient (201), and it is unclear how these adults cope and age with HIV, especially in SSA, where health systems are largely unprepared to meet their complex healthcare needs.

Based on one perspective in the existing literature on HIV and ageing (164, 176), it would appear that the outlook for OALWH is bleak despite the gains conferred by cART.

Nonetheless, there is another approach to understanding the life experiences of OALWH – an approach focusing on strength and not on deficit (202-204). The deficit or challenges approach, which focuses on monitoring the presence of chronic comorbidities in OALWH, has important limitations. It is disease-centred and measures a person's health deficits at a stage in life where little can be done to prevent the decline in function. Moreover, the approach overlooks the fact that the process of ageing with HIV is multidimensional where, in addition to the impact of the virus on biological systems, other factors shape the ageing process, often well before an individual gets to middle age. The strengths approach encourages policymakers and health professionals to look beyond disease states and approach ageing with HIV as a process to maximize a person's well-being by strengthening positive factors, e.g., adaptive coping skills.

As an intermediate mechanism of psychological stress and health outcomes, coping strategies are vital in maintaining physical and mental health (205, 206). The research on coping originates and is largely influenced by the work of Lazarus and Folkman (207). They define coping as the cognitive and behavioural efforts undertaken by an individual to alter or manage a problem caused by a specific stressful situation.

According to Lazarus et al., stress emanates from an imbalance between demands and resources or when pressure surpasses one's perceived ability to cope (207).

While several studies have examined how people living with HIV (PLWH) cope with a chronic illness, few have addressed this issue among OALWH, especially in SSA (206, 208). Drawing on semi-structured interviews with 76 OALWH in the United Kingdom, Rosenfeld et al. identified a few coping strategies, including volunteering, accentuating the positive, minimizing the role of HIV medications, and accessing support from mental health workers and HIV organizations (209). In America, the frequently reported coping strategies for healthy ageing among OALWH include self-care, spirituality, social support (from family, friends, professionals, and pets), and generativity (e.g., mentoring and volunteerism) (210-214). In SSA, little research has focused on how older adults cope with HIV and illness-related stressors. In one of the few studies on coping in this population in the region, OALWH in South Africa adopted HIV status acceptance, ART adherence, abstinence from sexual relations, and accessing social support as key

coping strategies in dealing with HIV diagnosis, stigma, disclosure and the healthcare system (64).

As the HIV and ageing agenda gain momentum in SSA, there is a crucial need for a greater understanding of how the OALWH cope and live with HIV. In this paper, we explore the perceptions of 34 OALWH, 11 primary caregivers and 11 healthcare providers on the coping strategies and support available to OALWH in a low-resource Kenyan setting.

3.3 Methods

3.3.1 Ethics

Written informed consent was obtained from all respondents before participation. Ethical clearance was granted by the local institutional review board, the Kenya Medical Research Institute Scientific and Ethics Review Unit (KEMRI/SERU/CGMR-C/152/3804), on March 6, 2019. Permission to conduct the study in Kilifi County was granted by the research office, Department of Health (HP/KCHS/VOL.X/171), on April 3, 2019.

3.3.2 Study design, setting and sample

This study is part of the phase I qualitative study conducted in 2019 at the Kenya Medical Research Institute-Wellcome Trust Research Programme (KWTRP) in Kilifi County on the Kenyan coast. The study focused on understanding the health challenges and coping strategies of older adults living with HIV among 56 participants (34 OALWH, 11 caregivers and 11 healthcare providers). Arising from the primary dataset are two manuscripts; the first one (159) reports the health challenges facing the OALWH. Briefly, the participants' narratives indicated that mental and psychosocial complaints, e.g., common mental health problems, poverty, stigma, and discrimination) were common among the OALWH in addition to physical health challenges, e.g., comorbidities and somatic symptoms). The current manuscript is the second paper, where we explore the same participants' perceptions to understand the coping strategies and support available to the OALWH in this low-resource setting.

Kilifi is mainly rural, and the majority of the inhabitants belong to the Mijikenda tribe, whose primary source of livelihood is small scale trading and subsistence farming. More than half of Kilifi residents live below the poverty line, and a significant proportion (about 40%) do not have formal education (215). The HIV prevalence is higher among females (54 per 1000 people) than males (23 per 1000 people) (179).

Our sample included: a) older adults living with HIV aged ≥ 50 years receiving HIV care and treatment at the Kilifi County Referral Hospital (KCH) HIV clinic, b) primary caregivers of older adults living with HIV and c) healthcare providers attending to the older adults living with HIV including nurses, clinical officers, counsellors, and project coordinators of community-based organizations.

3.3.3 Sampling strategy and recruitment

We recruited our sample using a purposive sampling technique to maximize diversity in respondents' characteristics, e.g. age and sex. Participants were recruited by trained study staff in liaison with a community health volunteer stationed at the KCH specialized HIV clinic. After introducing the study at the clinic, OALWH were approached (during their routine clinic visits), and those expressing interest were given more information regarding the project, e.g., study objectives and how to participate. We had no specific target sample size. We recruited and assessed participants until when we reached data saturation. The older adults living with HIV had to be at least 50 years old and on cART for them to take part. Caregivers were identified through the OALWH during their routine clinic visits. To participate, they had to be directly involved in the care of an OALWH. We approached healthcare providers at their places of work and invited them to participate. We targeted providers who were directly involved in the care of OALWH. Participants who agreed to take part were interviewed once, immediately after enrolment, if available, or at an appointment made for a future date. Apart from a few health providers who were interviewed at their place of work, the majority (over 80%) were interviewed at the KEMRI Wellcome Trust Research Programme. Only the interviewing researcher and participant were present during the interview. The researcher and participants had no prior contact/relationship in this study.

3.3.4 Data collection and instruments

We used key-informant interviews to collect data from all the participant groups. The lead author (PNM) conducted all the interviews, which lasted approximately 45 – 60 minutes each. At the time of conducting this study, PNM was a PhD Fellow at the KEMRI-Wellcome Trust Research Programme, Kilifi, Kenya, with extensive training in mixed methods. A pre-tested, semi-structured interview was used to guide the interviews. The interview guide was created new for this study. Over three-quarters of the interviews were conducted in Swahili – the Kenyan national language. The rest of the interviews were conducted in either Giriama (the local language) or English. All interviews were digitally recorded with permission from the participants.

Interview questions focused on what challenges participants were experiencing (for OALWH) or presented with (for the other key informants) regarding ageing with HIV, what helped the OALWH through difficult periods, and how they coped daily and long-term basis. General information about coping/living strategies and social support was elicited among the participants, leading to specific explorations of coping with long-term HIV, ageing, and health changes, e.g., mental difficulties. The interviewing researcher took down some notes during and after the interview, which helped plan subsequent interviews.

3.3.5 Data analysis

The audio-recorded interviews were transcribed verbatim by four research assistants. Translation of data took place during the analysis stage. Participants' original language (Swahili) was used to develop codes, categories and themes, which were then translated into English. QSR Nvivo software version 11.0 was used for data management and analysis. The analysis of our qualitative data followed the Framework approach (180) based largely on descriptive phenomenology. A preliminary coding framework was developed inductively (through in-depth reading of transcripts) and deductively (considering themes in the interview guide) by two authors (PNM and AA). This was done independently by the two authors. The arising codes were then discussed, and a consensus was reached on how they should be brought together into themes. The initial coding framework was subsequently expanded to capture any

emerging theme as coding progressed. After coding, themes related to specific concepts were grouped to form categories and later exported to a word document to produce charts. The charts were then used to summarize the data, looking for similarities or differences.

3.4 Results

3.4.1 Summary of participant characteristics

We included 56 participants in this study (34 OALWH, 11 healthcare providers and 11 primary caregivers) after reaching data saturation. All approached participants agreed to participate. Among OALWH, slightly more than half were women (53%); most (82%) had up to a primary level of education, most (73%) lived in multigenerational households, and had a median age of 57 years (54 – 63 years). All the OALWH were on HIV treatment and had lived with HIV for a median duration of 12 years (10 – 15 years). Healthcare providers comprised six registered nurses, two clinical officers, two project managers of community-based organizations and one HIV counsellor. On the other hand, all the primary caregivers were family members, the majority (73%) of whom were female. Table 3.1 gives more sociodemographic and clinical details of OALWH.

Table 3.1. Sociodemographic and clinical characteristics of older adults living with HIV

Characteristic	n (%) or median (IQR)
Median age	57 (54 – 63)
Female	18 (53%)
Educational level	
None	7 (20%)
Primary Level	21 (62%)
Secondary level	5 (15%)
Tertiary level	1 (3%)
Type of employment	
Unemployed/not working	12 (35%)
Small scale trader	15 (44%)

Casual worker	4 (12%)
Professional/skilled work	3 (9%)
Marital status	
Never married	1 (3%)
Married	19 (56%)
Separated/Divorced	7 (21%)
Widowed	7 (21%)
Living arrangements	
Alone	5 (15%)
Single generation household	4 (12%)
Multigenerational household	25 (73%)
Median household size	5 (2 – 9)
Residence (rural)	30 (88%)
Median duration since HIV diagnosis (years)	12 (10 – 15)
On ART treatment	34 (100%)
HIV status disclosure	
Non-disclosure	1 (3%)
Partial disclosure (to close family only)	18 (53%)
Full disclosure (beyond close family)	15 (44%)

Notes: ART – Antiretroviral treatment; IQR – Interquartile Range

3.4.2 Perceived coping strategies for mental and well-being challenges

Participants utilized multiple strategies to maintain or improve their mental health and well-being in the face of various biopsychosocial challenges. Analysis of the respondents' narrative accounts revealed five major themes: self-care, religion and spirituality, generativity, social connectedness, identity, and mastery.

3.4.2.1 Self-care

Within the respondents' narratives, this was either a change in behaviour or a pattern that developed over time to cope and live with HIV. The frequently discussed self-care strategies included abandoning/abstaining from risky behaviours (e.g., multiple sex

partners, unprotected sex, tobacco smoking, and hazardous alcohol use), strict treatment adherence (e.g., cART and routine HIV clinic appointments), acceptance and disclosure of one's HIV status, shifting focus (from negative to positive things), and practising self-control (e.g., managing thoughts or attitudes). To a lesser extent, some OALWH reported monitoring their diet (as a form of weight loss strategy), seeking information (e.g., from seminars and HIV clinics), and using traditional forms of treatment to stay healthy. Similarly, some OALWH engaged in physical exercise, including walking, jogging, running, swimming, skipping rope, traditional dances, and makeshift weightlifting. However, many of these activities were unstructured and irregular, while some of the OALWH (especially women) felt embarrassed doing some exercises, e.g., swimming and weightlifting. Still, a few of the OALWH acknowledged that their nature of work (e.g., walking long distances to work; heavy manual work - such as pulling carts, casual labourer at construction sites; farming, grazing livestock, and house chores) was as good as physical exercise. Common sources of information for these strategies were trial and error and sometimes healthcare providers, family, and friends. Some self-care strategies were regarded as helpful, e.g., in reducing distress and improving physical health outcomes.

Other self-care strategies included relying on over-the-counter medications (especially for symptoms like pain and sleeping difficulties) and skipping HIV medications when one lacks food. *Waiting* to see if the symptoms would lessen despite doing nothing was also practised by a few OALWH. Some of the participants' quotes on this theme are provided in Table 3.2.

Table 3.2. Participants' quotes on perceived coping strategies for mental and well-being challenges

Main coping strategy	Participant's quote
Selfcare	“Letting go of certain behaviours has helped me a lot. I wasted much money on drinking sprees, multiple sexual partners who, of course, needed upkeep, and other pleasures. However, I abandoned all these things following my diagnosis, and I can see some improvements in my health and life”. (Male OALWH)
	“I maintain a very active life! I usually wake up early in the morning, make my bed, mop my house, prepare breakfast, take a shower, and leave for work. I have a niece staying with me, but I do most of the work myself. I wash my clothes after every two days. I also do farming. I tend my greenhouse and chicken. I wash the dishes in the morning. I am very happy”. (Female OALWH)
	“I usually wake up very tired and having muscular pains! I have to take <i>action (a common analgesic)</i> to work and be productive. It is frustrating because I have to buy medications every day. My well-being is dependent on these medications”. (Female OALWH)
	“Some of the clients stop taking their ART medications. Some usually say, “I found a herbal doctor who said my disease will go away if I use their herbal medication.” So they will stop the ART medication until they realize that the herbal medicine is not helping and then come back to the clinic, usually in worse off conditions”. (Clinical officer)
Religion and spirituality	“When I find myself crowded with thoughts, as I shared with you initially, I usually run to God because he is the one who knows why I am undergoing those issues. And when I pray, I usually feel comforted, relieved and at peace even if I still do not have anything ...but I feel much better when I put God first”. (Female OALWH)
	“Sometimes I am worried, stressed, anxious and experience nightmares, but I encourage myself in God. I usually kneel and pray to God. I wake up my wife, we pray together and go back to sleep, and we usually feel much better in the morning.” (Male OALWH)

	“Sometimes back, one of my kidneys had problems...it was quite painful. Later, as I was studying the bible, I was instructed (<i>by God</i>) to go for prayers for 18 days. I left home and camped in a nearby bush for 18 days, and that was the end of that problem. I have never had that issue again; I never went to a hospital. You know God does not need help to do his work...he is perfect!” (Male OALWH)
	“In our community, most of them go to traditional doctors or <i>waombezi</i> (seers or prophets) in addition to their routine clinics. And some of them stop taking their ART medications. For instance, one may be instructed to leave their ART medications and pray for three months or sometimes drink some traditional drugs for a certain duration. So, it becomes complicated; they usually come back in worse conditions.” (Clinical officer)
Generativity	“I usually volunteer at the clinic as a peer counsellor. I have had a few clients come to me looking for marriage partners. I usually go ahead and connect them. As a matter of fact, I have succeeded in joining five people who are now happily married”. (Female OALWH)
	“On several occasions, the clinicians have called upon me to talk to my peers on different issues, e.g., stigma and non-suppressed HIV”. (Female OALWH)
	“My role as a counsellor or an elder happens on different platforms...at the clinic, I may advise people on various issues, including adherence to ART. I also like discussing and sharing things with community members, my children...e.g., on different issues such as developments, health, and well-being. I love it very much”. (Male OALWH)
	“I have one person who is their...like their head...So in case I find a client with stigma ...I call him, And he talks with the client...I find him very helpful”. (Nursing officer)
	“She (<i>OALWH</i>) helps me a lot. For instance; she educates women in church on various issues relating to HIV...she also teaches children and girls... let us say she has the qualities of a leader”. (Caregiver)
Social connectedness/ support systems	“It affects me a lot (<i>living with HIV</i>)...for instance, we slept without supper yesterday. I had to borrow the fare to come here today. However, it is not every day that we sleep hungry because I have a good friend who owns a hotel nearby...he usually gives us food. Sometimes I take the children to eat there and pay later. He encourages me not to be worried”. (Male OALWH)

	I usually encourage, advise and motivate him so that he can bounce back to his normal well-being. I always try to understand him...be empathetic so he can recover completely. I also help him with food, and even other people support him with food...however, most of the time, we counsel him". (Caregiver)
	"I did not see the importance (of going to support groups)...why spend hours listening to people...it was even depressing...every time people are saying the same things. People were complaining a lot...there were no benefits...you know, sometimes you want to see tangible benefits, e.g. we get registered, look for financial support, but there was nothing like that. I like a positive outlook". (Female OALWH)
	"Financial problem is a big issue among these adults...there is one I had to give some little income [<i>about \$10</i>] to start selling fish...because I had to ask her what she could do...then she told me she used to sell fish. So, I gave her 1000 Ksh [<i>about \$10</i>] to start her small business. Since that day, I have never had a problem with her routine clinic appointments. I thank God. Even her overall health has improved". (Nursing officer)
	"We have five areas of empowerment, including spiritual, economic, emotional, social and physical aspects. We support them in all these areas...our primary goal is to help them stand on their own". (Project Manager CBO)
Identity and mastery	"To be honest, my brother...I do not despair easily...I have trained myself that way...I know I was born one day, and there is an appointed time for me to die! I have made up my mind to do everything I can to live today, and when my time to die comes, I will say goodbye! As long as I am alive, I will take my medications. I am the last person to surrender! I am like a soldier". (Male OALWH)
	"I did not plan on getting this disease...so I have chosen to take each day at a time...I have not aged because of HIV...as a matter of fact, I am least concerned about the HIV infection...I have forgotten about it! I believe that as long as I take my medications well, I will continue living like anyone else...if I follow the clinician's advice. That is my philosophy, and I am not worried at all!" (Female OALWH)
	"The cohort I have is very informed about their medications and health. They even carry their medications everywhere. They tell you that 'this medication is my life'". (Nursing officer)
	"I have not received help or support from people, and I do not bother to ask! I like taking care of myself...I do not want to make this disease a source of income by depending on others...I do my own business...not

	big, but I can live off my sweat... I have learnt to go out of my way and be active, and hardworking. I have realized this is important for my health and well-being as well. I also eat well and do some exercises...mostly walking". (Female OALWH)
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3.4.2.2 Religion and spirituality

Most respondents described religion or spiritual practices as an important strategy through which OALWH drew their strength, besides giving them hope to live. Prayers, belief in God, attending religious meetings, singing, or listening to worship music, reading the scriptures, or listening to uplifting messages of hope, fellowship with other believers, membership to church groups and other expressions of spirituality were regarded as instrumental in providing OALWH with emotional, social, and sometimes financial support. For instance, several OALWH reported using prayer when faced with persistent emotional challenges, e.g., thinking too much, sleeping problems, and having nightmares. Others sought emotional support (counselling) and material support (with basic needs) from pastors.

However, a few healthcare providers felt that some religious activities or beliefs among OALWH had negative implications on health, e.g., poor retention in care and virologic non-suppression. For instance, some of the OALWH (especially women) sought the services of religious people popularly known as “*waombezi*”, believed to be seers or prophets with special healing powers. Subsequently, they stopped taking their ART drugs, believing they have been cured of HIV infection after receiving prayers from these seers, only for them to come back later to the HIV clinic with severe HIV disease. Others occasionally go into prolonged periods of prayer and fasting, where they change their ART medication schedule or stop taking them altogether. Still, others mixed biomedical and traditional forms of treatment, which sometimes led to poor health outcomes in the OALWH.

3.4.2.3 Generativity

Generativity is the willingness to engage in acts that promote the well-being of other people besides self and family, especially younger generations, to ensure their survival. Our analysis of participants’ narratives revealed three main categories of generativity. In the first category, many OALWH took leadership roles in the family and community, e.g., as family heads, village elders, religious leaders, and HIV support group coordinators. Through sharing stories of the years of the HIV epidemic, serving on different committees, and being involved with HIV advocacy, these respondents utilized their

status, time, and experience to lead others and, in the process, derived personal satisfaction and fulfilment. The second form of generativity discussed was volunteerism, where some of the OALWH offered their skills and services to benefit other individuals. Participants volunteered in different ways, including serving as community health volunteers. They provided various services such as health education to families of people living with HIV and caregiving to some people living with HIV. For many of these respondents, volunteering provided a focus, purpose, and opportunities to make a social contribution and reciprocate the support they had experienced. Given their extended duration of living with HIV, some participants acknowledged the need to serve as mentors to nurture and guide those recently diagnosed with HIV and young people living with HIV. This came out as the third form of generativity.

3.4.2.4 Social connectedness/support systems

Respondents' narratives also uncovered various formal and informal support systems regarded as positive contributors to mental health and well-being. Support was received from diverse sources, including family members, friends, healthcare providers within the HIV clinics, HIV community organizations, and informal support groups. Family was an important source of comfort and support in managing the challenges of ageing with HIV for some of the OALWH. Specific support included occasional financial support (for fare and basic needs), companionship, medication and routine clinic appointment reminders, and emotional support. However, some of the OALWH felt more comfortable seeking help from other sources (e.g. friends and healthcare providers) than the family, partly because of dysfunctional families, fear of disclosing their HIV status, or simply because they lacked the means.

Several participants also portrayed existing mental health services (within HIV clinics) as especially important settings for formal and informal therapeutic conversations with people who would listen and support them, as well as providing specialist knowledge vital in the management of HIV and ageing challenges. Some of the mental health support services offered by HIV clinics included occasional psychoeducation on HIV, occasional screening of depressive symptoms, psychopharmacology (e.g., provision of antidepressants), peer counselling, referral services (with community organizations or

other higher-level hospitals) and HIV support groups (e.g., for discordant couples). However, many of services tended to vary from one HIV clinic to another, according to some participants (those who had experience receiving care or attending to clients from other HIV clinics). Specialist services, e.g., psychologists, psychiatrists, and geriatricians, were unavailable.

Community-based organizations dedicated to the health and well-being of OALWH did not come up in our discussions with the participants. The few existing organizations supported different groups of people living with HIV, including OALWH. Some of the support services they offered included occasional assistance with basic needs (e.g., food and tuition fees for orphans), supporting community health volunteers (e.g., fare), employing healthcare providers (e.g., counsellors), community HIV testing, empowering people living with HIV (spiritually, economically – e.g., through skills training including making soaps, tailoring, weaving, psychosocial counselling, referral services), and legal services (mainly for women).

Although the HIV support groups were perceived as instrumental in giving a sense of belonging, membership, and camaraderie, which buffered or moderated many of the stresses of ageing with HIV, some of the OALWH avoided these groups or scaled back their involvement. To some of these adults, attending the groups undermined their goal of lessening HIV's role in their current and imagined future, which they regarded vital for their mental health and well-being. Thus, they avoided the groups to limit a persistent focus on that issue. Other OALWH cited monotony, time-wasting, gossip, lack of support, poor leadership, and no apparent benefits with such groups hence their collapse.

3.4.2.5 Identity and mastery

Identity refers to how individuals perceive themselves in relation to HIV, while mastery is the ability to accomplish what needs to be done to live a good life. Identity can also be understood as HIV centrality, how much of oneself is defined by the HIV diagnosis. Many of the OALWH described themselves as much more than their diagnosis. The concepts of self-reliance, self-supporting, depending on oneself as a resource and managing one's care incorporated behaviours and self-perceptions of mastery and

control in ageing with HIV. According to several OALWH, identity and mastery developed over time. In the process, respondents utilized their background and personal strengths to identify tools to achieve mastery over the challenges of ageing with HIV. Several participants noted that they no longer had problems with their HIV status as they used to be in the early years of HIV diagnosis. As a matter of fact, they could disclose to anyone, including public gatherings. Others later came to the point of viewing their HIV status as a blessing in disguise or a wake-up call, making them gain control of their lives, e.g., through investments, personal development, abandoning risky behaviours such as multiple sexual partners and substance use. Some considered themselves better off than their uninfected peers who still engage in such behaviours. Attaining mastery also gave OALWH opportunities to engage in mentorship and psychoeducation, especially for newly diagnosed HIV individuals.

3.5 Discussion

3.5.1 Summary of key findings

Given the demographic imperative of a rapidly ageing society and the growing number of older adults ageing with multiple chronic conditions such as HIV, there has been rising attention in recent years on understanding ways to promote resilience among older adults and on designing interventions that can strengthen their ability to cope, improve quality of life, prevent, or delay functional decline, and decrease healthcare costs. This study provides a preliminary understanding of coping among OALWH residing in a low-resource setting in Kenya. Overall, our findings portray a picture of OALWH who integrate various living strategies into their lifestyle to address their mental health and well-being challenges. Five main strategies emerged: self-care practices, religion and spirituality activities, relational living (social connectedness), generativity, identity, and mastery. Many of these strategies were developed by the OALWH themselves, sometimes collaborating with other peers, providers, and caregivers, thus representing respondents' deep engagement with their mental health and well-being and a culture of survival. This highlights the importance of working with OALWH to understand their values and aspirations and reinforces calls to include their subjective

experiences in care and management. Our study also revealed maladaptive coping strategies among these adults highlighting the crucial need to identify such patterns and look for ways to address them, given their impact on health.

3.5.2 Self-care

Although a well-established approach for several chronic conditions (216, 217), self-care programmes for OALWH are still emerging, especially in SSA. Self-care is regarded as a critical element in chronic care; thus, a major focus of many interventions and patients who engage in self-care have been shown to have significantly improved clinical outcomes, a better quality of life, fewer hospitalizations, and longer survival (216, 218). Participants in the current study discussed several self-care strategies to promote their mental health and well-being. Reported self-care practices ranged from those with beneficial health impacts to those potentially deleterious to their overall health. Most of the selfcare strategies discussed in the present study, e.g., positive lifestyle behaviours, were perceived to be beneficial and effective in promoting the mental health and wellbeing of OALWH. For instance, stopping harmful use of substances was associated with better family relationships, and financial capacity such as investments that improved household wellbeing. Physical exercise was also associated with improved moods and reduced symptoms of worry and anxiety. However, existing research provides only modest evidence on the effectiveness of selfcare strategies in this population (219). Intervention research will be able to establish which selfcare strategies yield positive effects in this setting. Many of the OALWH relied upon their internal strengths for continued adherence to HIV treatment and avoidance/abandoning of previously harmful lifestyle elements, including drug use. With time, several OALWH reported reduced family conflicts, improved self-efficacy, and better financial decisions (investments and planning for one's old age). Although male and female OALWH acknowledged the importance of others, many observed that they were responsible for their self-preservation. Our findings of OALWH embracing their responsibility for self-preservation are consistent with those reported by Emlet et al. in the United States of America among 25 OALWH (210) and Solomon et al. in Canada among 14 older men living with HIV (213).

3.5.3 Religion and spirituality

Consistent with previous work, this study found that religion and spirituality played an essential role in coping among OALWH (214). In literature, involvement in religious and spiritual practices has been noted to correspond to better health-related outcomes (214). Such association may provide one with social support, norms for healthy behaviours, and a sense of hope and well-being, ultimately promoting mental health (220). These strategies may also act as buffers to life stress by allowing them to interpret their life experiences in the context of their beliefs, which provide purpose and meaning in life and promote transcendence over circumstances. Nevertheless, certain religious practices may hinder positive biopsychosocial outcomes. In the current study, some of the healthcare providers noted that some of the OALWH abandoned their ART medications after receiving prayers from their pastors or taking part in an extended duration of prayer and fasting. There is a need to re-examine the role that “traditional healers” and other “influencers” play in the identification and care of OALWH and how to work together to ensure that OALWH maintain their treatment routines.

3.5.4 Social connectedness

While several studies of PLWH have identified the value of receiving social support (221, 222), few have examined this subject among OALWH. Understanding the influence of perceived social support on the mental health and well-being of OALWH is crucial because it is likely to play a major role in managing their multiple negative life stressors. Greater social connectedness may address the negative mental and physical impacts of ageing with HIV through enhanced cognitive efficiency, better social competency, productivity, personal control, and life satisfaction. Our results attest that OALWH are aware of the significance of others in their lives. Family members, sexual partners, friends, religious groups, and the HIV clinics were regarded as important sources of support by many OALWH. Similarly, Rosenfeld et al. attest to the importance of social support in improving the mental health and well-being of OALWH residing in the United Kingdom (209). Our findings also echo previous observations by Emlet et al. in the US (210). Interestingly, avoidance of HIV support groups was noted as a strategy to support mental health and well-being by a few OALWH by shifting the constant focus

to HIV. This finding is consistent with previous findings in other places (209, 213). This underscores the need for HIV support groups to understand clients' needs and fine-tune their support services accordingly. Although having others to rely upon for help and support, many OALWH maintained an aspect of independence to avoid overreliance on others who, according to them, had responsibilities and problems of their own.

3.5.5 Generativity

Another important element of coping for OALWH revealed in this study was generativity. This concept has its origin in the psychoanalyst Erik Erikson emphasizing a concern for establishing, caring, nurturing, guiding, and maintaining the next generations (223). Taking up leadership roles, volunteerism and mentorship were identified as important elements of generativity among OALWH. They were often associated with personal satisfaction and happiness and reduced the focus on their health challenges. Our findings reinforce the importance of social connectedness among OALWH but, more importantly, add a new element to previous research. Instead of viewing OALWH as the passive recipients of social support and care, it places the individuals in a contributory role of giving back to the community through these acts of generativity. Our findings align with those of Emlet et al. among 30 OALWH in Canada (211). Programmes that enhance intergenerational connections, community involvement and generative acts within the HIV community could potentially promote the mental health and well-being of OALWH.

3.5.6 Identity and mastery

Mastery has previously been examined in the HIV literature, and results show that acquiring mastery is essential in improving mental health and reducing symptoms of common mental disorders (224, 225). Our participants discussed how they achieved identity and mastery in their lives, and this was important in ageing with HIV. Many of them described their HIV diagnosis as a turning point in their lives and expressed relief (from the persistent unknown suffering before HIV diagnosis). After the initial shock was over, many of them drew on their backgrounds and strengths to identify tools to achieve mastery over the challenges of ageing with HIV. This ushered in a period of lifestyle adjustments, e.g., diet, risky behaviours, taking personal control of one's life, and

thinking of one's future (e.g., investments). For some of these clients, the awareness of the complexities of ageing with HIV increases their urgency for mastery of self-care. Our findings mirror those of earlier research conducted among OALWH in High-income Countries (HICs) (226).

Apart from the positive highlights on living strategies, our study also reveals important concerns in the coping of OALWH in this setting which may threaten their mental health and well-being. Though not many, some of the OALWH reported over-reliance on over-the-counter medications. Overreliance on OTC drugs could be due to medications being the only option offered to these clients by their healthcare providers, health illiteracy on the part of caregivers, or financial difficulties in seeking other therapies. Still, some of the OALWH isolated themselves from sources of support, afraid of what people will say about them. Others tended to wait for symptoms to run their course or do 'nothing'. Many of such symptoms were part of the symptom profile for common mental disorders suggesting undiagnosed or inadequately treated common mental disorders. The OALWH may not know how to relieve such symptoms or maybe lack the motivation to find a solution. This emphasizes the need for healthcare providers to screen for such symptoms adequately and have knowledge of the overlapping presentation of these disorders experienced by OALWH. The providers noted that they rarely screened for common mental disorders in these clients mainly because of competing interests (e.g., the treatment emphasis is predominantly on physical health outcomes such as HIV viral load suppression) and inadequate treatment modalities for common mental disorders (CMDs). Others mixed biomedical care with traditional therapies, many of which were deemed ineffective, leading to health deterioration among those affected. Still, other OALWH skipped their medications whenever they missed food. These observations highlight some of the well-known patient-related challenges (e.g. health illiteracy, culture, financial difficulties) as well as health system challenges (e.g. inadequately trained providers to screen for CMDs and inadequate resources such as essential medicines) (227, 228) which have been pointed out as some of the barriers in the delivery of chronic care and promotion of coping strategies in this population.

3.5.7 Implications

Our paper has highlighted the importance of self-care, its different forms, and potential opportunities to embrace some of these modalities further. From our present findings and the available evidence on some of these strategies, ignoring them could lead to poorer health outcomes and poorer care in this population (206). To attain more favourable mental health and well-being, OALWH require training and support to effectively cope with HIV and ageing challenges, communicate their potential needs to access services and participate in shared decision making with their providers. Given that the challenges of OALWH can be diverse-including medical, physical, and social - and that individual preferences will often dictate uptake of and access to different models (e.g., new technologies, group work, individual therapy), theoretically, sound models of intervention should be considered to meet the preferences of various population groups. Further research to consolidate how patients can support themselves, building on positive coping strategies and minimizing negative ones (e.g. working with religious groups to deliver shared messages on HIV) is critical. Future studies could also design and assess the feasibility of a multicomponent intervention that aims to improve the self-care, peer support, mastery and volunteerism of OALWH. Additional qualitative studies could further examine how characteristics of resilience and strengths are utilized in HIV and ageing outcomes. Quantitative studies could shed some light on which subgroups of OALWH are more likely or less likely to cope effectively. These findings could lead to identifying at-risk individuals and developing targeted interventions.

Policymakers and service providers need to recognize OALWH as a unique client population in need of targeted HIV care. Through in-service training or continuing medical education, healthcare providers can build their skills, knowledge and attitudes on HIV and ageing to respond to the dynamic needs of OALWH adequately. In the long term, however, policymakers need to build a pool of HIV experts, e.g., geriatricians, to respond to the current gaps in human resources in HIV clinics. Shared decision-making models will empower and actively engage OALWH to manage their unique healthcare and social needs effectively. Of key importance is also the integration of other health

services, e.g., mental health and chronic care, into HIV care services. There is also a crucial need to strengthen the financial and nutritional support of OALWH as many of them are affected by poverty, which sometimes affects their HIV care, e.g., by skipping medicines when missing food.

3.5.8 Strengths and limitations

Our study is among the few reports in SSA and the first in Kenya to comprehensively explore the coping strategies for OALWH with mental health and well-being challenges. Unlike previous reports, an important strength of this work is that respondents included a diverse group of stakeholders, including clinicians, community-based organizations, primary caregivers, and the OALWH themselves. This helped us develop a comprehensive understanding of the research question through triangulation.

Nonetheless, our participants were predominantly from a rural setting and in routine HIV care; thus, their circumstances may differ from those in urban areas and those who may not be in routine HIV care. We used reflexivity to minimize individual biases (e.g., researchers' personal beliefs on the research methods and previous knowledge of the subject) by maintaining research diaries and fieldnotes of observations, interactions, incidents, emotions, and conversations and holding frequent discussions with fellow researchers how this may have affected the research process.

3.6 Conclusions

Our findings provide an initial understanding of the coping strategies utilized by OALWH to confront HIV and ageing challenges in a low-literacy Kenyan setting. This study underscores the importance of coping in this vulnerable population and suggests that interventions designed to enhance personal capacity, social support, positive religiosity and spirituality, intergenerational connections, self-identify, and mastery may be beneficial in the improvement of mental health and well-being in this growing population. Our study also highlights a few potential obstacles that may impede successful coping in this population, including over-reliance on over-the-counter medication, waiting for symptoms to run their course or doing 'nothing', self-isolation, seeking support in the wrong places, and skipping meals. Traditional healers and biomedical practitioners need to deliberate on how they can collaborate to promote the health and wellbeing of

OALWH. These findings will assist providers, caregivers, and other stakeholders to best address the specific health and well-being needs of OALWH in this setting.

3.7 Data availability

3.7.1 Underlying data

The underlying data transcripts are not publicly available due to confidentiality reasons. However, individual applications can be made through the data governance committee of the KEMRI Wellcome Trust Research Programme, which will review the application and advise as appropriate. Requests can be sent to the coordinator of the Data Governance Committee using the following email dgc@kemri-wellcome.org. Successful applicants will be provided with de-identified transcripts (in the Swahili language). In the event that one requires translation services for the transcripts, this will be agreed upon with the applicants for it to be done within the programme.

3.7.2 Extended data

The study interview guide “*Additional file 1: Interview guide for in-depth interviews among adults living with HIV, healthcare providers and primary caregivers*” has been shared as extended data on Figshare (10.6084/m9.figshare.20489208).

3.8 Acknowledgements

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3.9 Declaration of conflict of interests

The authors declare no potential conflict of interest with respect to the research, authorship, and publication of this article.

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Chapter 4

Prevalence and factors associated with mild depressive and anxiety symptoms in older adults living with HIV from the Kenyan coast

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4.0 Introduction

The previous two chapters of this thesis described the prevailing health challenges facing OALWH and the coping mechanisms they utilize to confront these challenges at the Kenyan coast. Symptoms of common mental health problems were reported to be frequent in the qualitative phase of the study. The present chapter builds on this finding by determining the prevalence and associated demographic and biomedical factors of depressive and anxiety symptoms among OALWH compared to their HIV-uninfected peers in the same setting. Likewise, the current chapter is a reproduction of the published article.

4.1 Abstract

Introduction: Empirical research on the burden and determinants of common mental disorders (CMDs), especially depression and anxiety, among older adults living with HIV (OALWH) in sub-Saharan Africa is inadequate. To bridge the gap in Kenya we: a) determined the prevalence of CMDs among OALWH on routine HIV care compared to HIV-negative peers; b) investigated HIV status as an independent predictor of CMDs in the older adults; c) investigated CMD determinants.

Methods: In a cross-sectional study conducted between 2020 and 2021, the prevalence of CMDs and associated determinants were investigated at the Kenyan coast among 440 adults aged ≥ 50 years (257 OALWH). The 9-Item Patient Health Questionnaire and 7-Item Generalized Anxiety Disorder scale were administered alongside measures capturing biopsychosocial information. Logistic regression was used to examine the correlates of CMDs.

Results: No significant differences were found in the prevalence of mild depressive symptoms, 23.8% vs 18.2% ($p = 0.16$) and mild anxiety symptoms, 11.7% vs 7.2% ($p = 0.12$) among OALWH compared to HIV-negative peers, respectively. HIV status was not independently predictive of CMDs. Among OALWH, higher perceived HIV-related stigma, ageism, increasing household HIV burden, loneliness, increasing functional disability, sleeping difficulties, chronic fatigue, and advanced age (>70 years) were associated with elevated CMDs. Among HIV-negative older adults, loneliness,

increased medication burden, and sleeping difficulties were associated with elevated depressive symptoms. Easier access to HIV care was the only factor associated with lower CMDs among OALWH.

Conclusions: On the Kenyan coast, the burden of moderate and severe CMDs among older adults is low, however, both OALWH and their HIV-negative peers have a similar relatively high burden of mild depressive and anxiety symptoms. Our results also suggest that determinants of CMDs among OALWH in this setting are predominantly psychosocial factors. These results highlight the need for psychosocial interventions (at the family, community, and clinical levels) to mitigate the risks of mild CMDs as they are known to be potentially debilitating.

Keywords: Common mental disorders, HIV infection, Older adults, Prevalence, Correlates, Kenya

4.2 Introduction

Common mental disorders (CMDs), especially depression and anxiety, are among the leading causes of disability worldwide (229, 230) and cost the global economy about US\$1.2 trillion a year (231). Notably, the global burden of both disorders has not reduced since 1990, despite compelling evidence of cost-effective interventions (232). Efforts to address this substantial burden of CMDs should be directed at the most vulnerable in society, including older adults living with HIV (OALWH) residing in sub-Saharan Africa (SSA). In Kenya, the increasing population of OALWH (233) is experiencing an elevated incidence of chronic age-related conditions (234), all potentially resulting in an increase of CMDs.

The prevalence of depression among OALWH in SSA ranges from 6 to 59% (129) compared to 26% among their HIV-negative peers (235). Outside SSA, estimates of depression among OALWH range from 19 to 45% in Asia (236, 237), 39 to 90% in the US (111, 115), 16 to 35% in Latin America and the Caribbean (238), and 28% in Europe

(239). Anxiety, on the other hand, ranges from 3 to 21% among OALWH in SSA (129) and 35 to 56% in HICs (114, 239).

Understanding the determinants of CMDs among older adults is critical in designing and implementing contextually-relevant mental health interventions. A recent review indicated that frequently reported determinants of depression among OALWH were mainly sociodemographic in nature (129). Among psychosocial factors, HIV-related stigma (240), HIV status disclosure (240), and increasing disability scores have been associated with higher odds of depressive symptoms, while social support (130), resilience (240), and spirituality (130) have been shown to be protective factors. Biomedical and lifestyle factors, including alcohol use (130), current/former tobacco smoking (241), and back pain (242), have been associated with elevated levels of depression among OALWH. Among HIV-negative older adults in SSA, rural residence (243, 244), poor social network (243), living alone (245), being female (235, 243), and a lifetime of unskilled occupation (244) have been associated with elevated odds of depression. No study in SSA has examined the determinants of anxiety among OALWH.

Several reasons call for investigating depression and anxiety among older adults. Firstly, known risk factors for CMD, such as poverty are more prevalent in older ages (166, 246). Secondly, CMDs in late life are severely under-researched and underdiagnosed in primary care (129, 247). Besides, the prognosis of CMDs among old adults appears to be worse than for young people (248). Late-life CMDs may also elevate the risk for developing dementia (249). Among people living with HIV (PLWH), depression and anxiety have been associated with non-adherence to combination antiretroviral therapy (cART), risky sexual behaviours, reduced quality of life, and higher suicide rates (87, 133, 250). Given that CMDs are rarely detected but can have serious health impacts on older people, it is increasingly important to assess for mild, moderate, and severe levels to determine the scale of the problem (251).

To bridge the gap in Kenya, our study seeks to: a) determine the prevalence of depressive and anxiety symptoms among OALWH compared to their HIV-negative peers; b)

investigate HIV status as an independent predictor of depressive and anxiety symptoms in the older adults, and c) investigate the determinants of CMDs among older adults at the coast of Kenya.

4.3 Methods

4.3.1 Study design and setting

This cross-sectional study was conducted at the Kenyan coast in Kilifi and Mombasa Counties between February 2020 and October 2021. The majority of Kilifi residents are rural dwellers whose main form of livelihood is subsistence farming and small-scale trading (178). Kilifi has an adult HIV prevalence of 4.5% (252). Mombasa County borders Kilifi County to the north and is considered urban. The common sources of income in Mombasa county include tourism, wholesale, and retail trade. The Mombasa adult HIV prevalence is 7.5% (252).

4.3.2 Study participants and recruitment

4.3.2.1 Older adults living with HIV

OALWH were recruited from two public HIV specialized clinics in Kilifi and Mombasa Counties. As inclusion criteria, participants had to be aged ≥ 50 years of age, with a confirmed HIV seropositivity status, and on cART. In both facilities, we were assisted by community health volunteers or healthcare providers in reviewing existing records to identify all potential participants. We used systematic sampling to identify potential clients for the study.

4.3.2.2 Older adults without HIV

All HIV-negative older adults were recruited in Kilifi County. The Kilifi Health and Demographic Surveillance System (KHDSS) was used to identify families with eligible older adults. Potential participants aged ≥ 50 were randomly identified from the existing database and followed up at their homes using GPS coordinates. To be included in the study, individuals had to be ≥ 50 years, and residents of Kilifi county, and provide consent for participation, including willingness to be tested for HIV using a rapid HIV testing kit

(OraQuick) for a confirmation of HIV negative status. We chose HIV-negative adults aged ≥ 50 years as our comparison group to the OALWH based on previous research (3, 253).

4.3.3 Sample size calculations

Our sample size was calculated using previous studies from Uganda (254) and South Africa (253). An overall sample size of at least 370 individuals was needed to detect a difference in CMDs between OALWH and HIV-negative community controls (15 vs 30% for depressive symptoms and 19 vs 8% for anxiety symptoms) respectively, at 80% power and a 5% level of statistical significance. A sample of 450 participants was considered sufficient, allowing for missing data.

4.3.4 Measures

The research instruments were programmed on android tablets using the Research Electronic Data Capture (REDCap) platform (255) for face-to-face interviewer administration. All research assistants were trained for two weeks by the first author prior to data collection.

4.3.4.1 Sociodemographic and asset index form. Sociodemographic information was captured in REDCap. We also collected information on individual and family ownership of disposable assets for asset index computation. Participants also were asked to provide information on their access to social support, food security in the past week, the number of PLWH within the household and whether they were caring for a sick family member.

4.3.4.2 General health form. We captured the participant's anthropometric details. Other information included hours spent on sedentary activities in a day, sexual activity, household HIV burden, number of medications one used, and common somatic complaints.

Among OALWH, HIV-specific information questions were asked relating to the disclosure of HIV status, and access to HIV care. Information regarding their current cART regimen and overall duration on cART were extracted from medical records. Blood samples were also collected from OALWH for viral load testing.

4.3.4.3 Psychosocial measures:

The brief 12-item HIV stigma scale (256) was utilized to assess participants perceived HIV-related stigma. Higher scores indicate a greater level of perceived stigma. In the

current study, this scale yielded good internal consistency alpha, 0.78 (95% CI 0.73, 0.83).

The 12-item World Health Organization Disability Assessment Schedule 2 (WHODAS 2) (257) was used to assess for functional disability among participants. Higher scores indicate a greater level of disability. In this study, the tool demonstrated good internal consistency alpha, 0.77 (95% CI 0.70, 0.84).

The UCLA 8-item loneliness scale (258) was used to assess participants' perceived loneliness. Higher scores equate to a greater level of loneliness. In the present study, this scale had acceptable internal consistency alpha, 0.61 (95% CI 0.56, 0.64).

The 20-item Ageism survey (259) was used to assess participants' experiences of ageism. Higher scores indicate more frequent experiences of ageism. In the current study, the internal reliability (Cronbach's alpha) was 0.89 (95% CI 0.87, 0.92).

4.3.4.4 Measures of common mental disorders. The 7-item Generalized Anxiety Disorder scale (GAD-7) (260) and the 9-item Patient Health Questionnaire (PHQ-9) (261) were utilized to measure anxiety and depressive symptoms in the previous 2-week period, respectively. The total scores range from 0 to 21 for GAD-7 and 0 to 27 for PHQ-9. For GAD-7, total scores of 5 – 9, 10 – 14, and 15 – 21 represent mild, moderate, and severe anxiety symptoms, respectively (262). For PHQ-9, total scores of 5 – 9, 10 – 14, and 15 – 27 indicate mild, moderate, and severe depressive symptoms (88), respectively. A cut-off score of ≥ 5 for both PHQ-9 and GAD-7 was used to define a positive screen for depressive and anxiety symptoms in the current study, similar to previous studies in Ethiopia (263) and Tanzania (264). In the present study, the internal consistency alphas for PHQ-9 and GAD-7 were good, 0.75 (95% CI 0.70, 0.79), and 0.74 (95% CI 0.70, 0.79), respectively.

4.3.5 Translation of new study measures

All study questionnaires not previously adapted to the local language of Swahili underwent the recommended adaptation procedure in line with international guidelines (265).

4.3.6 Statistical analysis

All analyses were carried out in STATA version 15.0 (StataCorp LP, College Station, Texas, USA). Independent Student's t-test and Chi-square test were used to compare differences in continuous and categorical independent variables, respectively. We used proportions as percentages to estimate the prevalence of CMDs among OALWH and their HIV-negative counterparts. Chi-square test was utilized to compare group differences on binary outcome variables. To investigate HIV status as an independent predictor of CMDs, we utilized logistic regression analyses adjusting for exposure variables that accounted for differences in CMDs. To examine the correlates of CMDs, we used logistic regression models to explore univariate relationships between the binary outcome variables and the different exposure variables. Exposure variables with a p -value <0.15 in the univariate analysis were subsequently entered in the multivariable models using forward selection (data for OALWH and HIV-negative older adults were analysed separately for this set of analyses). In all models, collinearity was checked and for all tests of hypothesis, a two-tailed p -value <0.05 was regarded as statistically significant. The overall fit of the final models was examined by Hosmer and Lemeshow (HL) goodness of fit test where a p -value of > 0.05 was considered a good fit. The HL test results were cross-checked using McFadden's pseudo-R squared statistic.

4.3.7 Ethics approval and consent to participate

The study was approved by the Kenya Medical Research Institute Scientific and Ethics Review Unit (Ref: KEMRI/SERU/CGMR-C/152/3804). Permission to conduct the study was granted by the research office Kilifi (Ref: HP/KCHS/VOL.X/171) and Mombasa (Ref: COH/Msa/RSC/04). All respondents provided written informed consent for their participation.

4.4 Results

4.4.1 Sample characteristics

A total of 440 participants were included in this study, with a mean age of 60.1 (SD = 6.9) years. Participant response rate was 90%. Most participants had formal education (63.2%), were unemployed (65.5%), living in multigenerational households (81.6%), and caring for a sick family member (66.4%). OALWH were likely to be younger, unmarried, more educated, have lower monthly household income, living alone, with a smaller number of dependents and more food insecure (Table 4.1).

Table 4.1. Characteristics of the study population by HIV status, *n* = 440

Characteristic	Total sample <i>n</i> = 440	HIV status		
		<i>HIV-negative, n</i> = 183	<i>OALWH, n</i> = 257	<i>p-value</i>
Sociodemographic				
Age (years)				
50 – 59	227 (51.6)	84 (45.9)	143 (55.6)	0.02
60 – 69	171 (38.9)	74 (40.4)	97 (37.7)	
≥70	42 (9.5)	25 (13.7)	17 (6.6)	
Sex				
Female	258 (58.6)	98 (53.6)	160 (62.3)	0.07
Male	182 (41.4)	85 (46.4)	97 (37.7)	
Marital status				
Never married	12 (2.8)	4 (2.2)	8 (3.1)	<0.001†
Separated/Divorced/Widowed	181 (41.1)	45 (24.6)	136 (52.9)	
Married/cohabiting	247 (56.1)	134 (73.2)	113 (44.0)	
Education level				
None	162 (36.8)	90 (49.2)	72 (28.0)	<0.001†
Primary	182 (41.4)	65 (35.5)	117 (45.5)	
Secondary	73 (16.6)	22 (12.0)	51 (19.9)	
Tertiary	23 (5.2)	6 (3.3)	17 (6.6)	
Employment				
Unemployed	288 (65.5)	126 (68.9)	162 (63.0)	0.1
Employed	116 (26.3)	39 (21.3)	77 (30.0)	
Retired	36 (8.2)	18 (9.8)	18 (7.0)	
Monthly household income (Ksh)				
≤10,000	279 (63.4)	69 (37.7)	210 (81.7)	<0.001
Above 10,000	161 (36.6)	114 (62.3)	47 (18.3)	
Living arrangements				
Multiple generational families	359 (81.6)	169 (92.3)	190 (73.9)	<0.001†
Single generational families	41 (9.3)	6 (3.3)	35 (13.6)	
Alone	40 (9.1)	8 (4.4)	32 (12.5)	
Number of dependents, mean (SD)	3.2 (2.6)	3.6 (2.5)	2.9 (2.7)	0.01

Caring for a sick family member, OM = 2				
Yes	291 (66.4)	104 (57.1)	187 (73.1)	0.001
No	147 (33.6)	78 (42.9)	69 (26.9)	
Access to instrumental/social support				
None	199 (45.2)	93 (50.8)	106 (41.2)	0.07
Sometimes	215 (48.9)	83 (45.4)	132 (51.4)	
Most of the time	26 (5.9)	7 (3.8)	19 (7.4)	
Food insecurity (lack of food in the past week), OM = 3				
Never	293 (67.1)	134 (73.6)	159 (62.4)	0.002 [†]
Sometimes	119 (27.2)	45 (24.7)	74 (29.0)	
Most of the times/always	25 (5.7)	3 (1.7)	22 (8.6)	
Asset index score^a – mean (SD)	2.3 (1.5)	1.9 (1.2)	2.5 (1.6)	<0.001
Body mass index – mean (SD), OM = 11	24.9 (6.0)	24.7 (6.1)	25.0 (5.9)	0.7
Loneliness score^b – mean (SD), OM = 3	13.9 (3.7)	13.0 (3.4)	14.6 (3.7)	<0.001
Functional disability score^c – mean (SD), OM = 2	2.5 (4.3)	1.5 (3.0)	3.1 (4.9)	<0.001
Ageism score^d – mean (SD)	4.2 (5.9)	3.0 (4.4)	5.0 (6.6)	<0.001
Hours spent in sedentary activities in a day, mean (SD), OM = 12	4.5 (2.6)	4.3 (2.1)	4.6 (2.9)	0.3
Sexually active, OM=4				
Yes	206 (47.3)	105 (57.4)	101 (39.9)	<0.001
No	230 (52.7)	78 (42.6)	152 (60.1)	
Sleeping difficulties in the past month, OM = 4				
None	276 (63.3)	125 (68.3)	151 (59.7)	0.01 [†]
Sometimes	131 (30.1)	53 (29.0)	78 (30.8)	
Most of the times/always	29 (6.6)	5 (2.7)	24 (9.5)	
Chronic fatigue				
Yes	56 (12.7)	21 (11.5)	35 (13.6)	0.5
No	384 (87.3)	162 (88.5)	222 (86.4)	
Number of medications participants are currently using, mean (SD), OM = 8	1.6 (1.6)	0.4 (1.2)	2.4 (1.2)	<0.001

All numbers are reported as frequencies with percentages unless otherwise stated

p-values are for the difference between OALWH and their HIV-negative peers by sample characteristic

[†] based on Fisher's exact test; *SD* standard deviation; *OM* observation with missing value; *Ksh* Kenya shillings ^a – score range = 0 to 8, higher scores indicate better socioeconomic status; ^b – score range = 8 to 27, higher scores indicate greater loneliness; ^c – score range = 0 to 33, higher scores indicate increasing disability; ^d – score range = 0 to 34, higher scores indicate increasing agism.

P-values have been derived from Chi-square test (or Fisher's exact test) and independent Student's *t*-test for categorical and continuous independent variables, respectively.

4.4.2 HIV-related characteristics of OALWH

The majority of the OALWH had disclosed their HIV status (95.3%) and were on first-line cART treatment (90%). The majority of the participants were on Lamivudine (242), Tenofovir disoproxil fumarate (230), and Dolutegravir (210). The remaining were Atazanavir/ritonavir (23), Zidovudine (7), Abacavir (5), Efavirenz (4), Nevirapine (4), Lopinavir boosted with ritonavir (2) and Ritonavir (1). The mean (SD) duration of HIV treatment was 11.4 (4.3) years. Nearly all (98.1%) of the OALWH had a viral load of ≤ 1000 copies/mL (Table 4.2).

Table 4.2 HIV-related clinical and psychosocial characteristics of OALWH, $n = 257$

Characteristic	Mean (SD) or Frequency (%)
HIV status disclosure	
Yes	245 (95.3%)
No	12 (4.7%)
Household HIV burden, mean (SD); OM = 5	1.4 (1.6)
cART regimen	
First line	233 (90.7%)
Second line	23 (8.9%)
Third line	1 (0.4%)
cART regimen change/interruption since HIV diagnosis	
Yes	110 (42.8%)
No	147 (57.2%)
Duration on cART (years), mean (SD), OM = 10	11.4 (4.3)
Viral suppression, OM = 45	
Yes	208 (98.1%)
No	4 (1.9%)
Access to HIV care, OM = 4	
Easily accessible	169 (66.8%)
Not easily accessible	84 (33.2%)
Perceived HIV-stigma score, OM = 1	
Personalized stigma ^a – mean (SD)	5.0 (1.9)
Disclosure concerns ^b – mean (SD)	8.6 (2.0)
Concerns about public attitudes ^c – mean (SD)	7.6 (2.2)
Negative self-image ^d – mean (SD)	6.4 (2.1)
Overall stigma ^e – mean (SD)	27.5 (5.4)

^a – score range = 3 to 12, higher scores indicate greater stigma; ^b – score range = 3 to 12, higher scores indicate greater stigma; ^c – score range = 3 to 12, higher scores indicate greater stigma; ^d – score range = 3 to 12, higher scores indicate greater stigma; ^e – score range = 12 to 44, higher scores indicate greater stigma; OM observation with missing value; cART combination antiretroviral therapy

4.4.3 Prevalence estimates for CMDs

The prevalence of mild depressive symptoms was 23.8% among OALWH compared to 18.2% in the comparison group ($p=0.16$). The prevalence of mild anxiety symptoms was 11.7% among OALWH compared to 7.2% in the comparison group ($p=0.12$). The prevalence of comorbid mild depressive and anxiety symptoms among OALWH was 10.1% compared to 4.4% in the comparison group ($p=0.03$) [Table 4.3].

Table 4.3. Prevalence of common mental disorders in OALWH versus their HIV-negative peers

	HIV-negative, <i>n</i> = 181		OALWH, <i>n</i> = 256		<i>p</i> -value
	Number	Prevalence (95% CI)	Number	Prevalence (95% CI)	
Severity of depressive symptoms					
Mild	28	15.5 (10.5, 21.6)	49	19.1 (14.5, 24.5)	0.3 [†]
Moderate	5	2.8 (0.9, 6.3)	8	3.1 (1.4, 6.1)	
Severe	-	-	4	1.6 (0.4, 4.0)	
Positive depressive symptoms screen (cut-off ≥5)					
Yes	33	18.2 (12.9, 24.6)	61	23.8 (18.7, 29.5)	0.2
Severity of anxiety symptoms					
Mild	13	7.2 (3.9, 12.0)	26	10.2 (6.7, 14.5)	0.1 [†]
Moderate	-	-	4	1.6 (0.4, 4.0)	
Positive anxiety symptoms screen (cut-off ≥5)					
Yes	13	7.2 (3.9, 12.0)	30	11.7 (8.0, 16.3)	0.1
Positive screen for comorbid depressive and anxiety symptoms					
Yes	8	4.4 (1.9, 8.4)	26	10.1 (6.7, 14.5)	0.03

95% CI 95% confidence interval; [†] based on Fisher's exact test. Note - Note: The number of respondents reported in this table (181 for HIV-negative adults) and 256 (for OALWH) is slightly lower than the overall sample size (183 for HIV-negative and 257 for OALWH) because the 3 participants were dropped from the analysis due to incomplete data.

4.4.4 Association between HIV status and common mental disorders

In univariate and multivariate logistic regression analyses, HIV seropositivity was not significantly associated with depressive or anxiety symptoms (Table 4.4). However, HIV seropositivity was significantly associated with higher odds of a positive screen for depressive and anxiety symptoms co-occurrence in univariate but not in the multivariate model.

4.4.5 Determinants of CMDs in OALWH

Table 4.5 presents results from logistic regression analyses exploring the determinants of CMDs among OALWH.

4.4.5.1 Depressive symptoms: In the multivariable logistic regression model, factors significantly associated with higher odds of depressive symptoms among OALWH were functional disability, ageism, sleeping difficulties, chronic fatigue, increasing household HIV burden, and perceived HIV-related stigma. Easier access to HIV care was significantly associated with lower odds of depressive symptoms.

4.4.5.2 Anxiety symptoms: In the multivariable analyses, age ≥ 70 , perceived loneliness, functional disability, ageism, and sleeping difficulties were significantly associated with higher odds of anxiety symptoms among OALWH .

4.4.5.3 Comorbid depressive and anxiety symptoms: In the multivariable analyses, perceived functional disability, and ageism were significantly associated with higher odds of comorbid depressive and anxiety symptoms. Easier access to HIV care was significantly associated with lower odds of comorbid depressive and anxiety symptoms.

4.4.6 Determinants of CMDs in HIV-negative older adults

The current work largely focused on OALWH. As such, we only provide a summary of the factors associated with CMDs among the HIV-negative older adults using the available data, particularly focusing on mild depressive symptoms whose prevalence was relatively high in the current sample, i.e. $>10\%$. In multivariable analyses, (supplementary table 4.1), sleeping difficulties, perceived loneliness, and increasing medication burden were significantly associated with higher odds of a positive screen for depressive symptoms among HIV-negative older adults. Greater sedentary behaviour and higher monthly household income were significantly associated with lower odds of depressive symptoms.

Table 4.4 Association between HIV status and common mental disorders across the whole sample of older adults

Covariate	Positive screen for depressive symptoms		Positive screen for anxiety symptoms		Comorbid depressive and anxiety symptoms	
	Crude analysis OR (95% CI)	Adjusted analysis aOR (95% CI)	Crude analysis OR (95% CI)	Adjusted analysis aOR (95% CI)	Crude analysis OR (95% CI)	Adjusted analysis aOR (95% CI)
HIV status						
<i>Seronegative</i>	Ref	Ref	Ref	Ref	Ref	Ref
<i>Seropositive</i>	1.40 (0.87, 2.25)	0.54 (0.27, 1.07)	1.72 (0.87, 3.39)	0.46 (0.18, 1.19)	2.46* (1.09, 5.57)	0.74 (0.25, 2.22)
Sex						
<i>Male</i>		Ref		Ref		Ref
<i>Female</i>		1.68 (0.84, 3.38)		2.49 (0.95, 6.54)		1.93 (0.67, 5.56)
Age (years)						
<i>50 – 59</i>		Ref		Ref		Ref
<i>60 – 69</i>		0.89 (0.46, 1.70)		1.78 (0.71, 4.47)		1.72 (0.59, 4.98)
<i>Above 70</i>		0.56 (0.19, 1.69)		3.99* (1.08, 14.71)		3.94 (0.92, 16.94)
Marital status						
<i>Never married</i>		Ref		Ref		Ref
<i>Separated/Divorced/Widowed</i>		0.14* (0.03, 0.69)		0.40 (0.06, 2.75)		0.83 (0.06, 11.27)
<i>Married/cohabiting</i>		0.12* (0.02, 0.62)		0.48 (0.07, 3.53)		1.26 (0.09, 18.17)
Asset Index score		0.77* (0.60, 0.98)		1.06 (0.77, 1.46)		0.91 (0.63, 1.32)
Sexually active						
<i>No</i>		Ref		Ref		Ref
<i>Yes</i>		2.61* (1.24, 5.47)		0.96 (0.38, 2.43)		0.81 (0.28, 2.29)
Functional disability score		1.18** (1.09, 1.28)		1.14* (1.05, 1.24)		1.14* (1.04, 1.24)
Loneliness score		1.12* (1.03, 1.22)		1.16* (1.04, 1.30)		1.12 (0.99, 1.27)
Ageism score		1.10** (1.04, 1.16)		1.16** (1.08, 1.24)		1.16** (1.08, 1.25)
Caring for a sick family member		2.08* (1.08, 4.02)		3.50* (1.32, 9.28)		3.07* (1.03, 9.20)
Chronic fatigue		3.14** (1.46, 6.72)		1.80 (0.69, 4.67)		1.86 (0.66, 5.24)
Sleeping difficulties for the past month						
<i>None</i>		Ref		Ref		Ref
<i>Sometimes</i>		4.62** (2.38, 8.98)		3.64* (1.47, 9.03)		4.69* (1.59, 13.88)

Most of the time/always		10.89** (3.57, 33.24)		4.89* (1.35, 17.63)		7.30* (1.76, 30.27)
Number of the final model		431		431		431
Hosmer-Lemeshow Test		X ² = 433.90; P=0.25		X ² = 307.20; P=0.99		X ² = 338.67; P=0.99
Variance explained		35.0%		36.4%		38.8%

GAD Generalized anxiety disorder, CMD Common mental disorder, OR odds ratio, aOR adjusted odds ratio, Ref reference group

* – *p*-value < 0.05, **– *p*-value <0.001

Table 4.5 Univariate and multivariable analysis of correlates of common mental disorders among OALWH

Covariate	Positive screen for depressive symptoms		Positive screen for anxiety symptoms		Comorbid depressive and anxiety symptoms	
	Univariate analysis OR (95% CI)	Multivariable analysis aOR (95% CI)	Univariate analysis OR (95% CI)	Multivariable analysis aOR (95% CI)	Univariate analysis OR (95% CI)	Multivariable analysis aOR (95% CI)
Age (years)						
50 – 59	Ref	Ref	Ref	Ref	Ref	Ref
60 – 69	0.77 (0.41, 1.44)	0.55 (0.23, 1.32)	1.18 (0.51, 2.72)	2.03 (0.66, 6.20)	1.12 (0.45, 2.76)	0.73 (0.19, 2.84)
≥70	1.35 (0.44, 4.15)	1.00 (0.19, 5.24)	4.19** (1.27, 13.80)	7.43** (1.25, 44.36)	4.55** (1.37, 15.09)	4.76 (0.70, 32.55)
Sex						
Male	Ref	Ref	Ref	Ref	Ref	Ref
Female	1.34 (0.73, 2.45)	1.36 (0.58, 3.19)	1.79 (0.76, 4.19)	2.17 (0.58, 8.08)	1.73 (0.70, 4.29)	2.59 (0.64, 10.45)
Marital status						
Never married	Ref	–	–	–	–	–
Separated/Divorced/Widowed	0.19** (0.04, 0.82)	–	–	–	–	–
Married/cohabiting	0.16** (0.04, 0.73)	–	–	–	–	–
Education level						
None	Ref	–	Ref	–	Ref	–
Primary	0.80 (0.41, 1.57)	–	0.51* (0.22, 1.19)	–	0.52* (0.22, 1.25)	–
Secondary	0.78 (0.34, 1.80)	–	0.38* (0.11, 1.24)	–	0.20** (0.04, 0.96)	–
Tertiary	0.16* (0.02, 1.28)	–	0.28 (0.03, 2.30)	–	0.31 (0.04, 2.59)	–
Monthly household income (Ksh)						
≤10,000	Ref	–	Ref	–		
Above 10,000	0.33*** (0.12, 0.86)	–	0.13* (0.02, 1.02)	–	0.16* (0.02, 1.22)	–
Living arrangements						
Multiple generational families	–	–	–	–	Ref	–
Single generational families	–	–	–	–	2.11* (0.77, 5.78)	–
Alone	–	–	–	–	1.05 (0.29, 3.82)	–
Number of dependents, mean (SD)	–	–	0.87* (0.74, 1.04)	–	–	–

Caring for a sick family member						
<i>No</i>	Ref	–	–	–	–	–
<i>Yes</i>	0.63* (0.33, 1.16)	–	–	–	–	–
Food insecurity (lack of food in the past week)						
<i>Never</i>	Ref		Ref	–	Ref	–
<i>Sometimes</i>	2.92*** (1.55, 5.49)	–	4.21*** (1.75, 10.14)	–	5.95*** (2.18, 16.20)	–
<i>Most of the times/always</i>	2.9** (1.11, 7.62)	–	6.21** (1.96, 19.70)	–	9.56*** (2.76, 33.15)	–
Loneliness score, mean (SD)	1.21*** (1.12, 1.32)		1.29*** (1.16, 1.43)	1.16** (1.01, 1.34)	1.28*** (1.15, 1.42)	
Functional disability score, mean (SD)	1.25*** (1.15, 1.35)	1.15** (1.04, 1.28)	1.19*** (1.10, 1.28)	1.10** (1.01, 1.20)	1.18*** (1.10, 1.27)	1.12** (1.03, 1.22)
Ageism score, mean (SD)	1.14*** (1.08, 1.19)	1.10** (1.04, 1.17)	1.17*** (1.10, 1.24)	1.14*** (1.06, 1.23)	1.17*** (1.11, 1.24)	1.23*** (1.13, 1.33)
Hours spent in sedentary behaviours in a day, mean (SD)	–	–	–	–	1.13* (1.00, 1.28)	–
Sexually active						
<i>No</i>	–	–	Ref	–	Ref	–
<i>Yes</i>	–	–	0.44* (0.18, 1.06)	–	0.44* (0.17, 1.15)	–
Sleeping difficulties in the past month						
<i>None</i>	Ref	Ref	Ref	Ref	Ref	–
<i>Sometimes</i>	6.59*** (3.18, 13.66)	3.51** (1.38, 8.89)	10.17*** (3.29, 31.47)	6.41** (1.73, 23.83)	11.75*** (3.28, 42.0)	–
<i>Most of the times/always</i>	25.60*** (9.00, 72.99)	8.82*** (2.33, 33.37)	18.25*** (4.94, 67.40)	6.18** (1.26, 30.22)	20.31*** (4.80, 85.96)	–
Chronic fatigue						
<i>No</i>	Ref	Ref	Ref	–	Ref	–
<i>Yes</i>	7.90*** (3.66, 17.02)	5.41** (1.78, 16.38)	2.68** (1.09, 6.62)	–	3.36** (1.33, 8.46)	–
Number of medications participants are currently using, mean (SD)	–	–	–	–	1.24* (0.94, 1.64)	–
HIV status disclosure						

Yes	Ref	—	—	—	—	—
No	2.40* (0.73, 7.85)	—	—	—	—	—
Household HIV burden, mean (SD)	1.30** (1.09, 1.55)	1.37** (1.08, 1.74)	1.20* (0.98, 1.47)	—	1.21* (0.98, 1.49)	—
cART regimen change/interruption since HIV diagnosis						
No	—	—	Ref	—	Ref	—
Yes	—	—	2.13* (0.97, 4.68)	—	1.88* (0.82, 4.34)	—
Access to HIV care						
Not easily accessible	Ref	Ref	Ref	—	Ref	Ref
Easily accessible	0.47** (0.26, 0.85)	0.35** (0.15, 0.83)	0.36** (0.16, 0.78)	—	0.29** (0.12, 0.68)	0.16** (0.04, 0.60)
Perceived HIV-stigma score, mean (SD)						
Personalized stigma	1.21** (1.04, 1.41)	1.27** (1.02, 1.59)	1.16* (0.96, 1.42)	—	1.25** (1.02, 1.54)	—
Disclosure concerns	—	—	—	—	—	—
Concerns about public attitudes	1.23** (1.06, 1.42)	—	1.29** (1.06, 1.57)	—	1.23** (1.00, 1.51)	—
Negative self-image	1.22** (1.06, 1.40)	—	1.20** (1.00, 1.44)	—	1.36** (1.12, 1.66)	—
Overall stigma	1.11*** (1.05, 1.18)	—	1.10** (1.02, 1.20)	—	1.13** (1.04, 1.23)	—
n for the final model		251		252		245
Variance explained		41.7%		41.0%		42.0%
Hosmer-Lemeshow test		X ² = 241.96; p-value = 0.35		X ² = 210.85; p-value = 0.79		X ² = 176.09; p-value = 0.99
cvMean AUC (95% CI)		0.91 (0.87, 0.96)		0.88 (0.82, 0.95)		0.92 (0.89, 0.96)

Only a priori variables (age, sex), as well as those with p-value < 0.15 in the univariate analysis or multivariable $p < 0.05$ are presented here
OR odds ratio, aOR adjusted odds ratio, Ref reference group, cvMean AUC cross-validated mean area under the curve for the final multivariable model
10 independent variables were fitted for the multivariable model on depressive symptoms, 7 variables for both the anxiety symptoms and CMD comorbidity
* - p value < 0.15, ** - p value < 0.05, *** - p value < 0.01

4.5 Discussion

4.5.1 Summary of findings

To our knowledge, this is the first study in Kenya and among the first reports from SSA investigating CMDs among OALWH compared to their HIV-negative peers. Our study found a relatively high burden of mild depressive and anxiety symptoms; however, HIV status was not independently associated with these symptoms. The correlates of CMDs in our study were predominantly psychosocial factors, many of which are potentially modifiable, thus highlighting the need to address the psychosocial needs of these adults alongside their biomedical needs. Overall, our findings address a significant gap in the literature of CMDs among OALWH in SSA which is very limited, especially regarding anxiety. Our study has presented comprehensive correlates of CMDs, some of which (e.g. ageism) have not been reported elsewhere in the literature of OALWH in SSA – thus opening the space for further enquiry on these issues in the region and beyond. Our study also points to preliminary evidence of shared and unique risk indicators of CMDs among OALWH and their uninfected counterparts. Future studies can corroborate this finding and guide the extent of both targeted and comprehensive services for these populations in the region.

4.5.2 Comparison of present findings with previous research

Our finding of no significant differences in the prevalence of CMDs between OALWH and their HIV-negative peers is dissimilar to other emerging reports in SSA. In rural Uganda, OALWH on cART had a significantly lower prevalence of probable depression than their HIV-negative peers (254), similar to what was reported in rural South Africa (253). Our finding also offers an interesting contrast to the predominant findings in HICs showing that OALWH present with worse CMDs than their HIV-negative peers (166). The observed variation could reflect contextual differences across settings e.g. healthcare systems, informal support systems and mental health resources that are likely to alter the risk profile of these adults. Nonetheless, this finding needs to be interpreted with caution given the sampling differences between OALWH and their uninfected peers in the study. Future studies will provide more clarity on this.

HIV status was not found to be an independent predictor of CMDs in our study. This observation is consistent with previous findings from South Africa (266) and Uganda (242) but contrasts common research findings in HICs (166). It is possible that the significant differences observed in demographic factors between OALWH and their uninfected counterparts could have exerted significant effects on this association. This notwithstanding, our study may be part of an emerging body of evidence in SSA showing that the psychological health of OALWH is not worse than among those without HIV.

HIV-related stigma was significantly associated with higher odds of depressive symptoms among OALWH in our study. These findings are consistent with previous findings in the literature (115, 240, 267) and provide additional evidence of the critical role of addressing intersecting stigma in improving the mental wellbeing of OALWH. Existing research has noted a significant paucity of intervention studies on HIV stigma and discrimination, especially in non-HIV specific healthcare settings and the few available interventions have targeted discrimination from providers outside HIV-specific care or the people living with HIV themselves (268). Some of the existing programmes include information-based, skills building, structural, contact-based and biomedical interventions. Further research is warranted on this issue. Relatedly, ageism was also significantly associated with higher odds of depressive symptoms, anxiety symptoms and their co-occurrence among OALWH. This finding is consistent with previous research conducted outside SSA (269). Ageism could have an adverse impact on the mental health of OALWH through psychological, behavioural and physiological pathways (270). Interventions addressing both ageist and HIV-stigmatizing attitudes at the community level will potentially improve the mental health of OALWH.

Increasing household HIV burden was significantly associated with higher odds of depressive symptoms among OALWH in our study. This may be related to the high caregiving burden often experienced by OALWH caring for HIV-positive children. This observation concurs with previous findings in the study setting (271).

Loneliness is common among older adults in general (272). In this study, higher perceived loneliness was significantly associated with elevated odds of anxiety symptoms among OALWH and depressive symptoms among HIV-negative older adults. Our finding is consistent with previous studies from HICs (115, 273). Theoretical models suggest that loneliness has cognitive, biological and social consequences that could potentially heighten the risk of subsequent CMDs (274). Higher perceived functional disability was also strongly associated with higher odds of depressive symptoms, anxiety symptoms and their co-occurrence among OALWH in the current study, consistent with previous findings (242, 275, 276). Since functional disability occurs frequently among OALWH, there is a need for early identification to help preserve functional independence.

Sleep disturbance is a prominent symptom in people with CMDs, especially depression, and was formerly regarded as a main secondary indicator of depression (277). Nonetheless, multiple prospective studies have identified insomnia as an independent risk indicator for emerging or recurrent depression, suggesting that sleep problems are not necessarily secondary effects of CMDs but a predictive prodromal symptom (278, 279). In this study, persistent sleep problems were significantly associated with higher odds of depressive symptoms, anxiety symptoms and their co-occurrence among OALWH and higher odds of depressive symptoms among HIV-negative older adults. This finding is consistent with previous findings (277, 280, 281). A combination of pharmacological and nonpharmacological intervention for sleep disturbances may effectively reduce and possibly prevent CMDs (282).

Chronic fatigue was also significantly associated with increased odds of depressive symptoms among OALWH in our study, similar to what has been reported elsewhere (283, 284). Fatigue is a vital indicator of ageing-related declines in health and functioning (285). Fatigue management strategies such as adequate rest and sleep is likely to improve the mental health of OALWH. Among HIV-negative older adults, an increased medication burden was also significantly associated with higher odds of depressive symptoms, consistent with previous findings (286). While the exact mechanism for this association is unknown, we know that the use of medication increases as the number of

medical conditions rise. Multiple medications, which is easily detected by clinicians, can provide an important clue to healthcare providers to further investigate depression in their clients.

Among sociodemographic factors, old age (≥ 70 years) was significantly associated with higher odds of anxiety symptoms in OALWH while higher monthly household income was significantly associated with lower depressive symptoms among HIV-negative older adults. Mixed findings have been reported on these factors previously (287).

Easier access to HIV care was the only protective indicator for CMDs in OALWH in the current study. Given that many OALWH in Kenya face unique challenges with seeking HIV care services (171), programmes aimed at strengthening HIV care access or financial support have the potential to improve OALWHs' mental wellbeing. Further decentralizing HIV care into the community possibly utilizing community health workers may also be beneficial.

Among HIV-negative older adults, an increasing number of hours on sedentary activities was significantly associated with lower odds of depressive symptoms. More studies are needed to better understand the mechanism involved. Emerging data suggest that passive sedentary behaviours e.g. television watching increase the risk of depression while mentally active sedentary behaviours e.g. reading may be protective against depression (288).

Most of our data (about 84%) were collected after the onset of the covid-19 pandemic. Some studies have reported elevated levels of loneliness, depression, anxiety, and insomnia among older adults following the outbreak of COVID-19 (289-291), while others have reported no changes before and during the pandemic despite increased loneliness during the pandemic (292). Other studies have shown that younger populations have had higher rates of CMDs compared to older adults (293-296). While it is possible that the emergence of the pandemic may have created an environment where the determinants of poor mental health could have been exacerbated, our study found low prevalences of

CMDs, similar to previous research suggesting higher resilience to the mental health effects of COVID-19 (297). The long-term impacts of the pandemic remain unclear, especially in SSA where data on older adults' mental health is very scarce. More studies are needed to elucidate these findings.

4.5.3 Strengths and limitations

The strengths of the current study include the focus on a neglected but rapidly growing population of OALWH, use of a comparison group and sufficient sample size. Nonetheless, the cross-sectional nature of the study precludes any conclusion on causality. We recruited our OALWH from public HIV clinics, as such, our findings may not be readily generalizable to OALWH who may be out of care or attending private or urban HIV clinics or recruited from the community. Relatedly, given the significant sociodemographic differences observed between OALWH and their uninfected counterparts, our findings should be interpreted cautiously. We also utilized self-report screening measures which could be subject to reporting bias. Relatedly, the mental health screening measures do not give a clinical diagnosis of the studied CMDs, hence, we only report the symptomatology of these conditions.

4.5.4 Implications

Despite the outlined limitations, this study has important implications in the care of older adults in our setting. We observed substantial levels of mild depressive and anxiety symptoms in both OALWH and their HIV-negative peers, highlighting the need for culturally appropriate mental health interventions in these older adults, regardless of their HIV status. Routine screening for CMDs should be strengthened to identify those at-risk. Risk indicators for depressive symptoms, anxiety symptoms and their co-occurrence in this study were predominantly psychosocial factors. Unfortunately, there is a paucity of research on psychosocial interventions among OALWH (201) and those in the general population (298), especially in SSA. Our findings highlight the need to strengthen the evidence base for interventions for CMDs among older adults in low-resource settings like Kenya.

4.6 Conclusions

Ambulatory, out-patient OALWH and their HIV-negative peers from the community have similar levels of mild depressive and anxiety symptoms. Additionally, living with HIV is not predictive of CMDs in this setting. Our study provides an initial understanding of the determinants of CMDs from a low-resource setting. Modifiable risk factors such as ageism, HIV-related stigma, loneliness, functional disability, and sleeping difficulties represent a target for preventive interventions through psychosocial interventions at the family, community, and clinical levels. Future studies can explore whether a higher cut-off on PHQ-9 and GAD-7 (translating into a moderate or severe levels of CMDs) has a different phenomenon in relation to the correlates of these conditions.

4.7 Competing interests

The authors have no competing interests to disclose.

4.8 Authors' contributions

PNM, CRN, and AA conceptualized the study. PNM, CRN, RGW and AA designed the study. PNM and CN programmed the study questions on tablets and managed study data for the entire study period. PNM analyzed the data. PNM, CN, RGW, CRN and AA contributed to the interpretation of the data. PNM wrote the first draft of the manuscript and all the authors reviewed the subsequent versions and approved the final draft for submission.

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4.11 Data availability

Application for data access can be made through the Data Governance Committee of the KEMRI Wellcome Trust Research Programme who will review the application and advise as appropriate ensuring that uses are compatible with the consent obtained from participants for data collection. Requests can be sent to the coordinator of the Data Governance Committee using the following email dgc@kemri-wellcome.org.

Supplementary Table 4.1. Univariate and multivariable analysis of the correlates of depressive symptoms among HIV-negative older adults

Covariate	Univariate analysis OR (95% CI)	Multivariable analysis aOR (95% CI)
Age (years)		
50 – 59	Ref	Ref
60 – 69	1.21 (0.55, 2.69)	1.18 (0.42, 3.27)
≥70	0.63 (0.17, 2.37)	0.19 (0.02, 1.51)
Sex		
Male	Ref	Ref
Female	2.00* (0.91, 4.42)	1.00 (0.34, 2.96)
Monthly household income (Ksh)		
≤10,000	Ref	Ref
Above 10,000	0.31*** (0.14, 0.68)	0.33** (0.11, 0.94)
Number of dependents, mean (SD)	1.11* (0.96, 1.29)	–
Caring for a sick family member		
No	Ref	–
Yes	1.93* (0.86, 4.33)	–
Food insecurity (lack of food in the past week)		
Never	Ref	–
Sometimes	2.42** (1.08, 5.42)	–
Most of the times/always	2.97 (0.26, 34.43)	–
Loneliness score, mean (SD)	1.22*** (1.09, 1.37)	1.23** (1.05, 1.44)
Functional disability score, mean (SD)	1.13** (1.01, 1.26)	–
Ageism score, mean (SD)	1.10** (1.02, 1.19)	–
Hours spent in sedentary behaviours in a day, mean (SD)	0.69*** (0.56, 0.86)	0.72** (0.55, 0.94)
Sleeping difficulties in the past month		
No	Ref	Ref
Yes	5.87*** (2.62, 13.14)	6.91*** (2.38, 20.08)
Chronic fatigue		
No	Ref	–
Yes	3.32** (1.25, 8.84)	–

Number of medications participants are currently using, mean (SD)	1.48** (1.02, 2.14)	1.37** (1.01, 1.89)
n for the final model	–	178
Variance explained	–	34.5%
Hosmer-Lemeshow test	–	$\chi^2 = 200.21$; p-value = 0.22
cvMean AUC (95% CI)	–	0.83 (0.79, 0.88)

Only a priori variables (age, sex), as well as those with p-value < 0.15 in the univariate analysis or multivariable $p < 0.05$ are presented here. *OR* odds ratio, *aOR* adjusted odds ratio, *Ref* reference group, *cvMean AUC* cross-validated mean area under the curve for the final multivariable model

* - p value < 0.15, ** - p value < 0.05, *** - p value < 0.01

Chapter 5

Prevalence and factors associated with frailty among older adults living with HIV compared to their uninfected peers from the Kenyan coast

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5.0 Preamble

This chapter presents the second set of results from the quantitative phase of the study whose primary aim was to document the prevalence and associated factors (demographic, psychosocial and biomedical) of CMDs and frailty among OALWH compared to their uninfected peers. The previous chapter identified relatively high levels of mild symptoms of CMDs among participants and also documented several factors (largely psychosocial) that were associated with an increased risk of CMDs – many of these factors were also reported in the qualitative phase of the study in Chapter 2 of the thesis. The current chapter builds on the previous work by documenting the prevalence and associated factors of frailty from the same quantitative sample – and hence clarify whether the burden is similar or different from the already reported outcomes e.g. extent of problems and correlates. Likewise, the chapter is a reproduction of the published article on frailty.

5.1 Abstract

Objectives: a) To document the prevalence and correlates of frailty among older adults living with HIV (OALWH) and their uninfected peers, and b) Investigate HIV status as an independent predictor of frailty.

Methods: This cross-sectional study was conducted between 2020 and 2021 at the Kenyan coast among 440 older adults aged ≥ 50 years (257 OALWH). Frailty was assessed using the Reported Edmonton Frail Scale. Logistic regression was used to examine the correlates of frailty.

Results: The prevalence of frailty was significantly higher among OALWH (24%) than their uninfected peers (13%), P -value < 0.01 . HIV seropositivity was not independently associated with frailty in multivariable analysis. Sleeping difficulties, ageism, higher waist/hip ratio, visiting traditional healers, HIV treatment change/interruption, prolonged illness following HIV diagnosis, and self-reported diabetes were significantly associated with higher odds of frailty. Residing in larger households, having higher income, having

friends, being male and light physical activities were significantly associated with reduced odds of frailty.

Conclusions: The prevalence of frailty is elevated among OALWH; however, factors other than HIV are predominant, particularly biomedical and psychosocial factors. Multicomponent interventions are needed to prevent/delay and manage frailty in this setting.

Keywords: HIV; aging; frailty; correlates; sub-Saharan Africa

5.2 Introduction

Recent years have witnessed a remarkable rise in the population of older adults in developing countries, including Kenya, making caring for the elderly a public health priority (299). A better understanding of the factors that influence healthy ageing is crucial for designing appropriate therapies to prevent functional decline, maintain independence, and preserve the quality of life of these adults. In this context, increasing attention has been paid to geriatric syndromes, especially frailty, as a potential explanation of the health diversity among older adults (300). Although a universal definition is still lacking, frailty is commonly conceptualized as the increased vulnerability to external and internal stressors resulting from a significant loss of physiologic reserve (301). Several pathophysiological pathways, including cellular senescence, mitochondrial dysfunction, oxidative stress, and dysregulation of inflammatory processes, underlie the frailty syndrome (302). Growing evidence from systematic reviews also links frailty with adverse health outcomes, including emergency hospital admissions (140), disability (137), poor quality of life (303), dementia (138), and premature mortality (139). Given the high burden, negative impacts on older adults, and the dynamic nature of frailty, identifying the determinants of frailty is imperative, especially among vulnerable older adults such as those ageing with HIV.

Frailty has been examined extensively in recent years; however, most work has been conducted in older populations in high-income countries (HICs). Some work has been conducted in LMICs, but this has been confined to Brazil, Mexico, China (304) and South Africa (305-308). So far, results indicate that the prevalence of frailty is highly variable, both between countries and between populations within a country, due to differences in the populations studied and the measurement of frailty. A recent meta-analysis of European studies showed a frailty prevalence of 12% among community-based studies and 45% in non-community-based studies (309). In Latin America, the prevalence of frailty among community-dwelling older adults was 20%, with a range of 8% to 43% in the studies reviewed (310). Among OALWH, the global prevalence of frailty ranges from 5 to 29% (128). In SSA, there has been growing attention to the risks of frailty in the ageing population, both in the general population and among people living with HIV (PLWH). To our knowledge, about a dozen studies on frailty have been conducted among older adults in the general population in SSA: South Africa (305-308), Tanzania (311-313), Ghana (307, 308), Nigeria (314), and Burkina Faso (315) with prevalence estimates ranging from 5.4% (305) to 63.3% (314). Only two studies have focused on OALWH (129), with prevalence estimates ranging from 2.8% to 14.7%.

Identifying the risk and protective factors of frailty may be useful for developing interventions designed to prevent and/or lower the burden that frailty places on a person and provide future directions for public health policy. Indeed, numerous studies have focused on identifying the factors associated with frailty, including the role of biological, lifestyle, and psychological factors [18]. Among older adults in the general population, sociodemographic factors (e.g. being female, older age, low education levels, low income, living alone), physical factors (e.g. obesity, malnourishment, hearing loss, visual impairment, persistent pain), lifestyle factors (e.g. smoking, alcohol consumption, sedentary behaviours) and psychological factors (e.g. depressive symptoms, and sleeping problems) have been identified as risk factors for frailty (316-325). Most of these studies have focused on sociodemographic factors. However, recently published studies have focused more on lifestyle-related, psychological, and biological factors associated with frailty, which may reflect a growing interest in potentially modifiable factors for frailty. Among OALWH, less research on risk and protective factors has been

conducted. In a past systematic review (128), the predictors of frailty included older age, comorbidities, diagnosis of acquired immunodeficiency syndrome (AIDS) and low current CD4⁺ cell count. The impact of specific initial or ongoing ART drugs on the development of frailty is difficult to assess and require further investigations. Previous studies have suggested that protease inhibitors and specific non-nucleoside reverse transcriptase inhibitors e.g. efavirenz might be associated with increased risk of frailty (326, 327).

Like many parts of SSA, Kenya's population of older adults is increasing rapidly. In the most recent population census of 2019, the proportion of older adults aged ≥ 50 years was about 11%, representing approximately 5.2 million individuals (328). Kenya is also witnessing an increase in chronic age-related conditions (234), which coincides with a high prevalence of HIV among those aged ≥ 50 years (233). Hence, establishing the current burden and determinants of frailty is essential if health and social care services are to meet the needs of Kenya's ageing population. The present study aims to: a) determine the prevalence of frailty among OALWH compared to their uninfected peers; b) investigate HIV status as an independent predictor of frailty in the older adults; and c) investigate the determinants of frailty among the older adults at the coast of Kenya.

5.3 Methods

5.3.1 Study design and setting

This was a cross-sectional study carried out at the Kenyan coast in Mombasa and Kilifi counties between 2020 and 2021. With an estimated population of about 1.5 million people (329), most Kilifi residents are rural inhabitants of the Mijikenda tribe, whose primary source of livelihood is subsistence farming and small-scale trading. In Kilifi, the prevalence of HIV in adults is 4.5% (252). Mombasa County borders Kilifi to the north and hosts Mombasa City, the second-largest city and chief port of Kenya. It has a population of about 1.2 million residents (329). Given its urban nature, the county is made up of the local (Mijikenda and Swahili) and immigrant communities from other parts of Kenya. At about 60%, the formal sector provides the majority of employment in Mombasa County (330). The prevalence of HIV in adults in Mombasa is about 7.5% (252).

5.3.2 Study participants and recruitment

5.3.2.1 Older adults living with HIV (OALWH)

We recruited the OALWH from two public HIV-specialized clinics in Mombasa and Kilifi counties (one in each). We specifically selected the two clinics because of their wide client catchment area and their large volume of potential participants. To be included, clients had to be aged ≥ 50 years of age, have a confirmed HIV seropositivity status, be on HIV treatment, and be willing and able to provide informed consent for their involvement.

In both HIV clinics, two community health volunteers or healthcare providers assisted us in reviewing existing records to identify potential clients. Efforts were made to contact all potential clients who had contact details (in alphabetical order) to invite them to participate in our study. Study introductions were conducted in person by a research assistant before any enrolment. Participant recruitment began in Mombasa County; however, it was interrupted by the onset of the COVID-19 pandemic after recruiting and assessing only 72 OALWH. Upon resumption of study activities, the recruitment and assessment of remaining clients ($n=368$) took place in Kilifi County.

5.3.2.2 HIV uninfected older adults

All the older adults without HIV were recruited from Kilifi County. The Kilifi Health and Demographic Surveillance System (KHDSS) was used to identify families with eligible older adults. Subsequently, potential participants aged ≥ 50 years were randomly identified from the existing database and followed up at their homes using Global Positioning System (GPS) coordinates by our trained research assistants. Study information was shared with all individuals who expressed interest in participation. As inclusion criteria, individuals had to be ≥ 50 years old, inhabitants of Kilifi county, and provide consent to their involvement, including willingness to be tested for HIV using a rapid HIV testing kit (OraQuick) for a confirmation of their HIV seronegative status.

5.3.3 Sample size calculations

We calculated our sample size using a previous study (331), which reported significant differences in the prevalence estimate of frailty between OALWH and their uninfected counterparts. Power analyses in Stata (using effect estimates and comparison of two group proportions) were conducted to estimate the required sample size. An overall sample of 310 was required to detect a difference in frailty between OALWH and uninfected peers at 80% power and a 5% level of statistical significance. A sample of 450 participants was deemed sufficient, allowing for missing data.

5.3.4 Measures

We programmed all our research instruments on Android tablets using the Research Electronic Data Capture (REDCap) platform (255) for face-to-face interviewer administration. The first author (the study coordinator) trained the research assistants for two weeks to facilitate the proper administration of the study tools. All study tools not previously adapted to the local language of Swahili underwent recommended adaptation procedures, that is, forward translation, forward translation review, back translation, harmonization by a panel of experts, pilot testing, pilot testing review, and proofreading (265).

5.3.4.1 Sociodemographic and asset index form

Sociodemographic characteristics, including participants' age, sex, marital status, educational level, occupational status, household size, income, living arrangements and number of dependents, were captured in REDCap. We also collected information on individual and family ownership of disposable assets for asset index computation as a proxy for socioeconomic status. The participants also provided information on their food security in the past week, access to social support, social network of close friends, the number of people living with HIV in the household, and whether they were taking care of sick family members at the time and visiting traditional healers.

5.3.4.2 General health information

We also gathered the participants' anthropometric details (such as height, weight, blood pressure, waist, and hip circumference), hours spent on sedentary activities in a day, sexual activity, number of medications one was using, self-reported comorbidities, past medical history, and common complaints, e.g., fatigue, pain, sleeping difficulties, visual and hearing problems.

For OALWH, we also asked HIV-specific questions relating to the disclosure of HIV status, access to the HIV clinic, and past medical history, e.g., cART regimen change/interruption and prolonged illness after HIV diagnosis. Information pertaining to their current ART regimen and overall duration on ART were extracted from their medical records. We also collected 10 ml of venous blood samples from the OALWH for viral load measurement.

5.3.4.3 Psychosocial measures

Psychosocial variables included HIV-related stigma, functional disability, loneliness, and age-related discrimination (ageism). All these constructs were assessed using interviewer-administered Likert scales, the brief 12-item HIV stigma scale (256), the 12-item World Health Organization Disability Assessment Schedule 2 (257), UCLA 8-item loneliness scale (258), and the 20-item ageism survey (259). In each scale, a higher score translates into a greater level of impairment.

5.3.4.4 Measures of frailty

We assessed frailty using the modified Reported Edmonton Frail Scale (332). It assesses nine domains of frailty: cognition, general health status, functional independence, social support, medication use, nutrition, mood, continence, and self-reported functional performance. Each domain comprises a set of questions examining the construct. Test scores range from 0 – 18, and participants are classified conventionally into 5 categories, with a higher score representing a higher degree of frailty: 0 – 5 (not frail), 6 – 7 (apparently vulnerable), 8 – 9 (mild frailty), 10 – 11 (moderate frailty) and 12 – 18 (severe frailty). In the current study, we collapsed these categories into three: 0 – 5 (non-frail), 6 – 7 (pre-frail) and 8 – 18 (frail) to enable

meaningful analysis of the correlates of frailty (333, 334). The decision to use the modified Reported Edmonton Frail Scale was based on its brevity (it can be administered in less than 10 minutes), ease of administration (it does not require specialized training), and stable psychometric properties. These properties make the tool a good candidate for clinical use in our settings.

5.3.5 Data analysis

We conducted all our analyses in STATA version 15.0 (StataCorp LP, College Station, Texas, USA). We utilized descriptive statistics to summarize sample characteristics. Specifically, independent Student's t-test and Chi-square test were used to compare differences in independent variables. Proportions were used to estimate the prevalence of frailty among OALHW and their uninfected peers. To examine HIV status as an independent predictor of frailty, we used logistic regression analyses adjusting for relevant exposure variables that accounted for differences in frailty. Examination of the correlates of frailty applied logistic regression models to explore univariate associations between the binary outcome variables (frailty) and the various exposure variables. Exposure variables with a p-value <0.15 in the univariate analysis were then entered into the multivariable models using forward selection. In all models, collinearity was checked, and for all hypothesis tests, a two-tailed p-value <0.05 was deemed statistically significant. We checked the overall fit of the final models using Hosmer and Lemeshow's goodness of fit, where a p-value of >0.05 was considered a good fit.

5.4 Results

5.4.1 Sample characteristics

Our sample comprised 440 participants, 257 (58%) of whom were OALWH. An overall response rate of 90% was achieved at recruitment. Among the respondents, 6 (1.4%) did not complete the outcome measure. Table 5.1 gives the details of the demographic and biopsychosocial information of these participants. In brief, the mean age of the respondents was 60.1 (SD=6.9) years and 58.6% were female. The majority of the participants were unemployed (65.5%), had a monthly household income of less than

10,000 Kenyan shillings – about \$90 (63.4%), lived in multigenerational households (81.6%), and had caregiving responsibilities (66.4%). Moreover, close to half of them reported being sexually active, and a similar proportion reported that they were not accessing/receiving adequate social support. Adults living with HIV were likely to be younger, unmarried, more educated, have lower monthly household income, live alone, and have fewer dependents.

Table 5.1: Characteristics of the study population by HIV status, *n* = 440 (Kenyan coast. 2020 & 2021)

Characteristic	Total sample <i>n</i> = 440	HIV status		
		<i>HIV uninfected older adults, n = 183</i>	<i>HIV-infected older adults, n = 257</i>	<i>p-value</i>
Age (years)				
50 – 59	227 (51.6)	84 (45.9)	143 (55.6)	
60 – 69	171 (38.9)	74 (40.4)	97 (37.7)	0.02
≥70	42 (9.5)	25 (13.7)	17 (6.6)	
Sex				
Female	258 (58.6)	98 (53.6)	160 (62.3)	0.07
Male	182 (41.4)	85 (46.4)	97 (37.7)	
Marital status				
Never married	12 (2.8)	4 (2.2)	8 (3.1)	
Separated/Divorced/Widowed	181 (41.1)	45 (24.6)	136 (52.9)	<0.001 [†]
Married/cohabiting	247 (56.1)	134 (73.2)	113 (44.0)	
Education level				
None	162 (36.8)	90 (49.2)	72 (28.0)	
Primary	182 (41.4)	65 (35.5)	117 (45.5)	<0.001 [†]
Secondary	73 (16.6)	22 (12.0)	51 (19.9)	
Tertiary	23 (5.2)	6 (3.3)	17 (6.6)	
Employment				
Unemployed	288 (65.5)	126 (68.9)	162 (63.0)	
Employed	116 (26.3)	39 (21.3)	77 (30.0)	0.1
Retired	36 (8.2)	18 (9.8)	18 (7.0)	
Household size				
One to two people	69 (15.7)	15 (8.2)	54 (21.0)	
Three to six people	297 (67.5)	131 (71.6)	166 (64.6)	0.001
Above seven people	74 (16.8)	37 (20.2)	37 (14.4)	
Monthly household income (Ksh)				
≤10,000	279 (63.4)	69 (37.7)	210 (81.7)	
Above 10,000	161 (36.6)	114 (62.3)	47 (18.3)	<0.001
Living arrangements				
Multiple generational families	359 (81.6)	169 (92.3)	190 (73.9)	
Single generational families	41 (9.3)	6 (3.3)	35 (13.6)	<0.001 [†]
Alone	40 (9.1)	8 (4.4)	32 (12.5)	

Number of dependents, mean (SD)	3.2 (2.6)	3.6 (2.5)	2.9 (2.7)	0.01
Caring for a sick family member, OM = 2				
Yes	291 (66.4)	104 (57.1)	187 (73.1)	0.001
No	147 (33.6)	78 (42.9)	69 (26.9)	
Social network of close friends (yes or no question) OM=1				
None	19 (4.3)	4 (2.2)	15 (5.9)	
Yes	420 (95.7)	179 (97.8)	241 (91.4)	0.1 [†]
Access to instrumental/social support				
None	199 (45.2)	93 (50.8)	106 (41.2)	
Sometimes	215 (48.9)	83 (45.4)	132 (51.4)	0.07
Most of the time	26 (5.9)	7 (3.8)	19 (7.4)	
Seeking the services of traditional healers OM=4				
No	399 (91.5)	166 (90.7)	233 (92.1)	0.6
Yes	37 (8.5)	17 (9.3)	20 (7.9)	
History of cerebrovascular accident OM=4				
No	427 (97.9)	178 (97.3)	249 (98.4)	0.5 [†]
Yes	9 (2.1)	5 (2.7)	4 (1.6)	
Food insecurity (lack of food in the past week), OM = 3				
Never	293 (67.1)	134 (73.6)	159 (62.4)	
Sometimes	119 (27.2)	45 (24.7)	74 (29.0)	0.002 [†]
Most of the time/always	25 (5.7)	3 (1.7)	22 (8.6)	
Asset index score ^a – mean (SD)	2.3 (1.5)	1.9 (1.2)	2.5 (1.6)	<0.001
Body mass index ^c – mean (SD), OM = 11	24.9 (6.0)	24.7 (6.1)	25.0 (5.9)	0.7
High waist-hip ratio				
No	202 (46.3)	77 (42.1)	125 (49.4)	0.1
Yes	234 (53.7)	106 (57.9)	128 (50.6)	
Loneliness score ^b – mean (SD), OM = 3	13.9 (3.7)	13.0 (3.4)	14.6 (3.7)	<0.001
Functional disability score ^c – mean (SD), OM = 2	2.5 (4.3)	1.5 (3.0)	3.1 (4.9)	<0.001
Ageism score ^d – mean (SD)	4.2 (5.9)	3.0 (4.4)	5.0 (6.6)	<0.001
Hours spent in sedentary activities in a day, mean (SD), OM = 12	4.5 (2.6)	4.3 (2.1)	4.6 (2.9)	0.3
Days spent doing light activities in the past week, mean (SD), OM=5	5.6 (2.4)	4.6 (3.0)	6.4 (1.6)	<0.001
Sexually active, OM=4				
Yes	206 (47.3)	105 (57.4)	101 (39.9)	<0.001
No	230 (52.7)	78 (42.6)	152 (60.1)	

Sleeping difficulties in the past month, OM = 4				
<i>None</i>	276 (63.3)	125 (68.3)	151 (59.7)	
<i>Sometimes</i>	131 (30.1)	53 (29.0)	78 (30.8)	0.01 [†]
<i>Most of the time/always</i>	29 (6.6)	5 (2.7)	24 (9.5)	
Frequent bodily pain				
<i>No</i>	334 (75.9)	134 (73.2)	200 (77.8)	0.3
<i>Yes</i>	106 (24.1)	49 (26.8)	57 (22.2)	
Self-reported hearing ability OM=4				
<i>Very good</i>	360 (82.6)	151 (82.5)	209 (82.6)	0.90
<i>Averagely/very bad</i>	76 (17.4)	32 (17.5)	44 (17.4)	
Self-reported Hypertension, OM=4				
<i>No</i>	322 (73.9)	138 (75.4)	184 (72.7)	0.5
<i>Yes</i>	114 (26.1)	45 (24.6)	69 (27.3)	
Self-reported diabetes, OM=4				
<i>No</i>	412 (94.5)	175 (95.6)	237 (93.7)	0.4 [†]
<i>Yes</i>	24 (5.5)	8 (4.4)	16 (6.3)	
Number of medications participants are currently using, mean (SD), OM = 8	1.6 (1.6)	0.4 (1.2)	2.4 (1.2)	<0.001

All numbers are reported as frequencies with percentages unless otherwise stated

p-values are for the difference between OALWH and their uninfected peers by sample characteristic

[†] based on Fisher's exact test; *SD* standard deviation; *OM* observation with missing value; *Ksh* Kenya shillings ^a – score range = 0 to 8, higher scores indicate better socioeconomic status; ^b – score range = 8 to 27, higher scores indicate greater loneliness; ^c – score range = 0 to 33, higher scores indicate increasing disability; ^d – score range = 0 to 34, higher scores indicate increasing agism

5.4.2 HIV-related characteristics of older adults living with HIV

All the OALWH were receiving HIV treatment, most (90%) of whom were on a first-line cART regimen. Most (95.3%) of them had disclosed their HIV status. The mean (SD) duration of HIV treatment was 11.4 (4.3) years. Additionally, nearly all of them (98.1%) had suppressed viral load (≤ 1000 copies/mL). Further details are highlighted in Table 5.2.

Table 5.2: HIV-related, clinical, and psychosocial characteristics of OALWH, *n* = 257 (Kenyan coast. 2020 & 2021)

Characteristic	Mean (SD) or Frequency (%)
HIV status disclosure	
<i>Yes</i>	245 (95.3%)
<i>No</i>	12 (4.7%)
Household HIV burden, mean (SD); OM = 5	1.4 (1.6)
cART regimen	

<i>First line</i>	233 (90.7%)
<i>Second line</i>	23 (8.9%)
<i>Third line</i>	1 (0.4%)
cART regimen change/interruption since HIV diagnosis	
<i>Yes</i>	110 (42.8%)
<i>No</i>	147 (57.2%)
Duration on cART (years), mean (SD), OM = 10	11.4 (4.3)
Viral suppression, OM = 45	
<i>Yes</i>	208 (98.1%)
<i>No</i>	4 (1.9%)
Access to HIV clinic, OM =4	
<i>Easily accessible</i>	169 (66.8%)
<i>Not easily accessible</i>	84 (33.2%)
History of a neurological condition, OM =4	
<i>No</i>	236 (93.3%)
<i>Yes</i>	17 (6.7%)
History of prolonged illness following HIV diagnosis, OM=6	
<i>No</i>	223 (88.8%)
<i>Yes</i>	28 (11.2%)
Perceived HIV-stigma score, OM = 1	
<i>Personalized stigma</i> ^a – mean (SD)	5.0 (1.9)
<i>Disclosure concerns</i> ^b – mean (SD)	8.6 (2.0)
<i>Concerns about public attitudes</i> ^c – mean (SD)	7.6 (2.2)
<i>Negative self-image</i> ^d – mean (SD)	6.4 (2.1)
<i>Overall stigma</i> ^e – mean (SD)	27.5 (5.4)

^a – score range = 3 to 12, higher scores indicate greater stigma; ^b – score range = 3 to 12, higher scores indicate greater stigma; ^c – score range = 3 to 12, higher scores indicate greater stigma; ^d – score range = 3 to 12, higher scores indicate greater stigma; ^e – score range = 12 to 44, higher scores indicate greater stigma; OM observation with missing value; cART combination antiretroviral therapy

5.4.3 Frailty prevalence estimates

The overall prevalence of frailty across the sample was 19.4% (95% CI: 15.7 – 23.4). Groupwise, older adults living with HIV presented with a significantly higher prevalence of frailty (23.9%) than their uninfected peers (12.8%), $p < 0.01$ (Table 5.3).

Table 5.3: Prevalence of frailty in OALWH versus their uninfected peers (Kenyan coast. 2020 & 2021)

	Older adults without HIV, $n = 179$		Older adults living with HIV, $n = 255$		Total sample, $n=434$		<i>p-value (between groups)</i>
	Number	Prevalence (95% CI)	Number	Prevalence (95% CI)	Number	Prevalence (95% CI)	
Not frail	119	66.5 (59.1 – 73.3)	140	54.9 (48.6 – 61.1)	259	59.7 (54.9 – 64.3)	0.02
Prefrail	37	20.7 (15.0 – 27.3)	54	21.2 (16.3 – 26.7)	91	21.0 (17.2 – 25.1)	0.9
Frail	23	12.8 (8.3 – 18.7)	61	23.9 (18.8 – 29.6)	84	19.4 (15.7 – 23.4)	<0.01

95% CI - 95% confidence interval

Note: The number of respondents reported in this table (434) is slightly lower than the overall sample size (440) because 6 participants were dropped from the analysis due to incomplete data on the frailty tool

5.4.4 Association between HIV status and Frailty

In univariate logistic regression analyses (Table 5.4), HIV seropositivity was significantly associated with higher odds of frailty (*OR* 2.13; 95% *CI* 1.26, 3.60). However, in the multivariable logistic regression model (Table 5.4), HIV seropositivity was not significantly associated with frailty (*aOR* 1.26; 95% *CI* 0.60, 2.63).

Table 5.4: Association between HIV status and frailty among older adults (Kenyan coast. 2020 & 2021)

Covariate	Positive screen for frailty	
	Crude analysis OR (95% CI)	Adjusted analysis aOR (95% CI)
HIV status		
<i>Seronegative</i>	Ref	Ref
<i>Seropositive</i>	2.13** (1.26, 3.60)	1.26 (0.60, 2.63)
Sex		
<i>Female</i>		Ref
<i>Male</i>		1.29 (0.62, 2.70)
Age (years)		
<i>50 – 59</i>		Ref
<i>60 – 69</i>		1.26 (0.64, 2.50)
<i>Above 70</i>		1.20 (0.40, 3.61)
Abnormal waist-hip ratio		
<i>No</i>		Ref
<i>Yes</i>		2.75** (1.41, 5.37)
Household size		
<i>One to two people</i>		Ref
<i>Three to six people</i>		0.37* (0.17, 0.82)
<i>Seven and above</i>		0.36 (0.12, 1.04)
Monthly household income (Ksh)		
<i>≤10,000</i>		Ref
<i>Above 10,000</i>		0.49 (0.22, 1.08)
Social network of close friends		
<i>No</i>		Ref
<i>Yes</i>		0.34 (0.10, 1.17)
Caring for a sick family member		
<i>No</i>		Ref
<i>Yes</i>		0.51* (0.27, 0.97)
Functional disability score		1.05 (0.98, 1.12)
Ageism score		1.08** (1.03, 1.13)
Sleeping difficulties for the past month		
<i>None</i>		Ref
<i>Sometimes</i>		3.70** (1.93, 7.10)
<i>Most of the time/always</i>		2.94 (0.99, 8.76)
Sexually active		
<i>No</i>		Ref
<i>Yes</i>		0.54 (0.26, 1.10)
Seeking the services of traditional healers		
<i>No</i>		Ref

Yes		2.95* (1.24, 7.05)
Self-reported hearing		
Very good		Ref
Averagely/very bad		1.58 (0.78, 3.22)
History of cerebrovascular accident		
No		Ref
Yes		5.87 (0.85, 40.68)
Number of individuals in the final model		427
Hosmer-Lemeshow Test		$\chi^2 = 402.62$; $P=0.36$
Variance explained		30.81%

CI Confidence Interval, OR odds ratio, aOR adjusted odds ratio, Ref reference group

* – p-value < 0.05, **– p-value < 0.01

Note: The number of individuals in the final model (427) is slightly lower than the actual sample size (440) because some of the observations had missing values

5.4.5 Determinants of Frailty in older adults living with HIV

Table 5.5 presents results from univariate and multivariate logistic regression analyses exploring the determinants of frailty among older adults living with HIV.

In the multivariable logistic regression model, factors significantly associated with higher odds of frailty among OALWH were sleeping difficulties in the past month, increasing ageism scores, visiting traditional healers, high waist-to-hip ratio, a history of cART regimen change/interruption, and a history of prolonged illness after HIV diagnosis. On the other hand, having a social network of close friends, a larger household, a higher household income ($\geq 10,000$ Ksh; about \$86) and taking part in light physical activities such as walking in the past week were significantly associated with lower odds of frailty.

Table 5.5: Univariate and multivariable analysis of correlates of frailty among OALWH (Kenyan coast. 2020 & 2021)

Covariate	Positive screen for frailty by mod-REFS	
	Univariate analysis OR (95% CI)	Multivariable analysis aOR (95% CI)
Age (years)		
50 – 59	Ref	Ref
60 – 69	0.96 (0.53, 1.76)	1.58 (0.63, 3.96)
≥ 70	0.66 (0.18, 2.41)	0.33 (0.05, 2.05)
Sex		
Female	Ref	Ref
Male	1.09 (0.60, 1.99)	1.32 (0.52, 3.39)
Monthly household income (Ksh)		
$\leq 10,000$	Ref	Ref
Above 10,000	0.26*** (0.09, 0.76)	0.13** (0.03, 0.60)
Household size		

<i>One to two</i>	Ref	Ref
<i>Three to six</i>	0.33*** (0.17, 0.63)	0.35** (0.12, 0.99)
<i>Above seven</i>	0.26*** (0.09, 0.73)	0.26 (0.06, 1.15)
Caring for a sick family member		
<i>No</i>	Ref	–
<i>Yes</i>	0.13*** (0.07, 0.24)	–
Having close friends (social network)		
<i>No</i>	Ref	Ref
<i>Yes</i>	0.09*** (0.03, 0.31)	0.13*** (0.03, 0.56)
Access to instrumental/social support		
<i>Not accessing</i>	Ref	–
<i>Sometimes</i>	2.53*** (1.33, 4.84)	–
<i>Most of the time/always</i>	1.48 (0.44, 5.05)	–
Food insecurity (lack of food in the past week)		
<i>Never</i>	Ref	
<i>Sometimes</i>	2.36*** (1.27, 4.40)	–
<i>Most of the time/always</i>	1.25 (0.43, 3.67)	–
Asset index, mean (SD)	1.16* (0.97, 1.38)	–
Waist hip ratio		
<i>Normal</i>	Ref	Ref
<i>Abnormal</i>	2.23*** (1.22, 4.06)	3.67*** (1.48, 9.10)
Self-reported Hypertension		
<i>No</i>	Ref	–
<i>Yes</i>	0.37*** (0.19, 0.74)	–
Loneliness score, mean (SD)	1.15*** (1.06, 1.24)	–
Functional disability score, mean (SD)	1.13*** (1.06, 1.20)	–
Ageism score, mean (SD)	1.14*** (1.08, 1.19)	1.11*** (1.04, 1.18)
Days spent doing light activities in the past week, mean (SD)	0.69*** (0.58, 0.82)	0.77*** (0.61, 0.98)
Hours spent in sedentary behaviours in a day, mean (SD)	0.79*** (0.70, 0.90)	–
Sexually active		
<i>No</i>	Ref	–
<i>Yes</i>	0.60* (0.33, 1.11)	–
Sleeping difficulties in the past month		
<i>None</i>	Ref	Ref
<i>Sometimes</i>	5.44*** (2.77, 10.71)	2.80** (1.14, 6.87)
<i>Most of the time/always</i>	7.82*** (3.04, 20.15)	1.92 (0.49, 7.43)
Seeking the services of traditional healers		
<i>No</i>	Ref	Ref
<i>Yes</i>	5.60*** (2.17, 14.46)	9.86*** (2.45, 39.68)
HIV status disclosure (family/relatives)		
<i>No</i>	Ref	–
<i>Yes</i>	3.55*** (1.91, 6.61)	–
History of a neurological condition		
<i>No</i>	Ref	–
<i>Yes</i>	5.15*** (1.87, 14.21)	–
Prolonged period of illness following HIV diagnosis		

No	Ref	Ref
Yes	3.72*** (1.66, 8.35)	6.58*** (2.13, 20.33)
ART Regimen		
1 st line	Ref	–
2 nd line	3.07*** (1.27, 7.38)	–
Mean HIV duration (SD)	1.05* (0.98, 1.13)	–
Viral suppression		
Yes	Ref	–
No	8.56* (0.87, 84.01)	–
cART regimen change/interruption since HIV diagnosis		
No	Ref	Ref
Yes	6.86*** (3.55, 13.26)	3.36*** (1.43, 7.91)
Access to HIV clinic		
Not easily accessible	Ref	–
Easily accessible	1.77* (0.90, 3.52)	–
Perceived HIV-stigma score, mean (SD)		
Personalized stigma	0.85* (0.72, 1.00)	–
Disclosure concerns	1.37*** (1.16, 1.62)	–
Concerns about public attitudes	1.18** (1.02, 1.36)	–
Overall stigma	1.05** (0.99, 1.11)	–
n for the final model		248
Variance explained		43.35%
Hosmer-Lemeshow test		X ² = 235.00; p-value = 0.07
cvMean AUC (95% CI)		0.90 (0.86, 0.95)

Only a priori variables (age, sex) and those with p-value < 0.15 in the univariate analysis or multivariable $p < 0.05$ are presented here. OR odds ratio, aOR adjusted odds ratio, Ref reference group, cvMean AUC cross-validated mean area under the curve for the final multivariable model

* - p value < 0.15, ** - p value < 0.05, *** - p value < 0.01

Note: The number of individuals in the final model (248) is slightly lower than the actual sample size for older adults living with HIV (257) because some of the observations had missing values

5.4.6 Determinants of Frailty in older adults without HIV

In multivariable analyses (Table 5.6), sleeping difficulties in the past month, self-reported diabetes, and light physical activities in the past week were significantly associated with higher odds of frailty among the HIV uninfected older adults.

Conversely, being male was significantly associated with reduced odds of frailty in these adults.

Table 5.6: Univariate and multivariable analysis of correlates of frailty among HIV-uninfected older adults (Kenyan coast, 2020 & 2021)

Covariate	Positive screen for frailty by mod-REFS	
	Univariate analysis OR (95% CI)	Multivariable analysis aOR (95% CI)
Age (years)		
50 – 59	Ref	Ref
60 – 69	1.73 (0.62, 4.81)	0.91 (0.26, 3.22)
≥70	3.38** (1.02, 11.24)	4.61 (0.95, 22.29)
Sex		
Female	Ref	Ref
Male	2.29* (0.89, 5.86)	0.26** (0.07, 0.94)
Monthly household income (Ksh)		
≤10,000	Ref	–
Above 10,000	0.51* (0.21, 1.24)	–
Number of close family members/friends one interacted with at least once in the past month, mean (SD)	0.90* (0.81, 1.01)	–
Loneliness score, mean (SD)	1.11* (0.97, 1.26)	–
Functional disability score, mean (SD)	1.13** (1.00, 1.27)	–
Ageism score, mean (SD)	1.08* (0.99, 1.17)	–
Days spent doing light activities in the past week, mean (SD)	1.25** (1.03, 1.52)	1.29** (1.01, 1.66)
Sexually active		
No	Ref	–
Yes	0.27*** (0.11, 0.70)	–
Sleeping difficulties in the past month		
None	Ref	Ref
Sometimes	6.27*** (2.35, 16.70)	4.30** (1.41, 13.07)
Most of the time/always	11.05** (1.58, 77.26)	14.72** (1.11, 194.78)
Self-reported hearing		
Very good	Ref	–
Averagely/very bad	4.69*** (1.83, 11.99)	–
Frequent bodily pain		
No	Ref	–
Yes	2.39* (0.97, 5.89)	–
Self-reported diabetes		
No	Ref	Ref
Yes	8.00*** (1.85, 34.64)	8.35** (1.23, 56.92)
Self-reported hypertension		
No	Ref	–
Yes	3.29** (1.33, 8.11)	–
Number of medications participants are currently using, mean (SD)	1.38* (0.98, 1.93)	–
n for the final model		177
Variance explained		30.33%
Hosmer-Lemeshow test		X ² = 110.02; p-value = 0.97
cvMean AUC (95% CI)		0.87 (0.79, 0.94)

Only a priori variables (age, sex) and those with p-value < 0.15 in the univariate analysis or multivariable $p < 0.05$ are presented here. OR odds ratio, aOR adjusted odds ratio, Ref reference group, cvMean AUC cross-validated

5.5 Discussion

We report here the frailty prevalence and its associations in a hospital sample of OALWH and community-based sample of older persons without HIV. The two samples were significantly different with respect to several demographic factors (e.g. educational level, household income, living arrangements and food insecurity). Therefore, while the difference in frailty prevalence was significant, we focus instead on the associations within each sub-group. To our knowledge, there have been only two previous studies of frailty among OALWH in SSA. The first one, a cross-sectional sample of 145 OALWH (67% female) on ART and a median age of 57 years in Tanzania, reported a low prevalence of frailty (2.8%) (335). The other one, a population-based cohort of 614 older adults (292 OALWH) in South Africa, reported a frailty prevalence of 17.7% in OALWH compared to 14.7% in their uninfected peers (336). The variations in frailty prevalence could partly be attributed to differences in frailty measurement and the fact that older adults are a highly heterogeneous group, having different genetic backgrounds, medical profiles, and biological, as well as social-environmental factors at different stages of life, thus highlighting the need for country-specific frailty data using tools validated within the country or region of interest. Our finding of a higher prevalence of frailty in OALWH than their uninfected peers is consistent with previous evidence, which has demonstrated both higher frequency of frailty in OALWH and the development of frailty at earlier ages for OALWH than for individuals without HIV (128). Many factors may predispose OALWH to elevated rates of frailty, including the effects of persistent inflammation from HIV (even in well-controlled viraemia), toxic effects of earlier cART regimens, delayed initiation of ART, and higher rates of multimorbidity (337).

Literature suggests that it is a constellation of environmental, disease-specific, and biological factors that contribute to frailty (128, 316-325), though most of the evidence is concentrated in HICs. In the present study, the factors significantly associated with

frailty were predominantly psychosocial, many of which are potentially modifiable with appropriate programs and interventions. Consistent with previous studies (325, 338), our study showed that sleeping difficulties were associated with higher odds of frailty in OALWH and their uninfected peers. Sleep problems may impact frailty in numerous ways, including decreased energy expenditure, elevated inflammatory response, disturbed hormonal pathways, tissue growth and repair (338). These mechanisms may explain the associations observed. Interventions targeting sleeping problems – such as exercise and mindfulness-based stress reduction, may have potential clinical implications for OALWH and their uninfected peers.

Increasing ageism scores were also significantly associated with elevated odds of frailty in OALWH in our study. Ageism, commonly conceptualized as the stereotyping, prejudice and discrimination against people based on age, is becoming increasingly important in older adults (339). Very few studies have examined the possible association between frailty and ageism. Our finding is consistent with the limited previous research (340). Persistent exposure to ageism could lead to the internalization of the ageist messages by the OALWH, thus becoming part of their unconscious beliefs. In some cases, the adults may act subconsciously to fulfil the ageist stereotypes, even if detrimental to their health and wellbeing, e.g., physiologic stress response, and physical functioning performance, which may influence frailty. The observed association could also be explained by the health status and higher educational levels among OALWH.

A higher waist/hip ratio was also significantly associated with elevated odds of frailty among OALWH in our study, consistent with previous findings of a positive association between central/abdominal obesity and frailty (341, 342). As HIV infection has become a manageable chronic illness, it has been progressively accompanied by a growing prevalence of overweight and obesity (343). Moreover, long-term treatment with cART may contribute to lipodystrophy, often characterized by fat redistribution with a relative increase in abdominal fat (344). Lipid depositions and infiltration in muscle fibre may bring about frailty by decreasing mobility and increasing loss of muscle strength. Interventions to minimize obesity and sedentary behaviour could potentially be beneficial in addressing frailty.

Visiting traditional healers was significantly associated with elevated odds of frailty among OALWH in our study. We are not aware of previous research that has examined this relationship. Plausibly, frail individuals visit the healers to have their frailty symptoms addressed, especially when the primary care services fail to address these concerns. A previous qualitative exploration of the health and wellbeing of OALWH in the study setting has linked seeking help or treatment from traditional and certain faith healers with poor health outcomes, including defaulting HIV treatment and unsuppressed viral load (159). Healthcare providers have a reason to be concerned, given the observed impacts of untreated or improperly treated HIV on the development of frailty among OALWH.

Only two HIV-related factors were associated with elevated odds of frailty in our sample: a history of cART regimen change/interruption and prolonged illness following HIV diagnosis. These factors may be indicators of virological failure, ART toxicity or late HIV diagnosis, commonly associated with poorer health outcomes and risk of severe disease. Indeed, previous research has revealed an independent positive association between AIDS diagnosis, viral-load non-suppression, low CD4 count and frailty (128, 345). Many of the OALWH who have lived with HIV for several years may be significantly impacted by the legacy of the early years of the epidemic, thus predisposing them to a heightened risk of frailty. These adults will more likely require additional support to manage the challenges of ageing with HIV successfully. The timing of the ART interruption and early illness may need to be explored in future studies.

Several social factors, e.g. social isolation, social networks, socioeconomic status, social support, social engagement, and social capital, have the potential to influence the health of older adults (346). In our study, higher monthly household income, residence in a larger household, and having a social network of close friends were all associated with reduced odds of frailty among OALWH, thus confirming previous research (128, 323) and highlighting the importance of promoting positive social factors to aid healthy ageing in older adults living with HIV. These factors may, directly and indirectly, affect frailty, e.g., food security, energy expenditure, and better health-seeking behaviours.

Physical activities have the potential to promote physical function, prevent falls and improve general health, hence delaying the onset and progression of frailty. In our study, participating in light physical activities such as walking was associated with reduced odds of frailty among OALWH, confirming previous research (347). Exercise may also have positive effects on obesity, stress, loneliness in the case of group activities and muscular strength, which have been identified as potential risk factors for the incidence of frailty. However, light physical activities were associated with elevated odds of frailty among the HIV uninfected older adults in our study. This was a surprise finding, inconsistent with previous investigations (348-350). This warrants more exploration in the study setting.

Self-reported diabetes was also associated with higher odds of frailty among HIV uninfected older adults in our study, consistent with previous reports (351). Prospective evidence suggests that unhealthy behaviours and obesity may partly explain the association, and to a larger extent, by poor glucose control and altered serum lipid profile among individuals with diabetes, suggesting that diabetes nutritional therapy may reduce the risk of frailty (351). Individuals with diabetic neuropathy are particularly at an increased risk of early-onset frailty (352). Prevention programmes in the pre-frail states through appropriate exercise, nutrition and glycemic control may delay the development of frailty in these adults.

Similar to previous studies, this study showed that males are less likely to be frail than females, suggesting that being male is a protective factor against frailty (316). Differences in physical activity, muscle mass and higher fat percentages may explain sex discrepancies in frailty. This may also be a question of selection – a classical observation in gerontological research where women live longer but in poorer health (353). In this respect, men experience more life-threatening chronic conditions compared to women who experience more “non-life-threatening” conditions associated with more morbidity – as such the men who survive are those who tend to have better health status. Still, our observation may be related to social stigma of males appearing/acting/reporting weakness, that is, social preference bias, given the self-reported nature of the construct.

5.5.1 Implications

The prevalence of frailty in this study was relatively high for both OALWH and their uninfected peers. Preventing, delaying, or treating frailty is more critical in this setting, given its high burden and the fact that frailty is a known predictor of future disability and dependency. Within the clinical practice, an easy-to-use frailty score will allow the easy identification of those at risk, thus allowing planning of future health and social care needs of these adults. Our study also highlighted some of the correlates of frailty in this setting. Many of the factors identified, such as sleeping difficulties, social engagement, ageism, and visiting traditional healers, are potentially modifiable with appropriate programs. Our findings provide the foundation for developing culturally appropriate interventions and healthcare strategies to prevent, delay and manage frailty and its consequences to improve the health and functional status of older adults at risk of frailty. Individual, community-based, or clinic-based interventions such as comprehensive geriatric assessment, physical activity, promoting social engagement, addressing discrimination, and proper management of comorbidities, e.g., diabetes, may benefit older adults. Wider public health approaches, including proactive testing of older adults to avoid late diagnosis and advanced immunosuppression, will benefit OALWH. Our results also highlight the need for well-designed prospective studies to establish the incidence, pathophysiology, predictors of transition and outcomes of frailty in this population and assess potential interventions.

5.5.2 Strengths and limitations

Our study is among the very few reports on frailty in SSA and the first one in Kenya. It extends the existing evidence base regarding the prevalence and correlates of frailty in low-resource settings like Kenya. A further strength is the use of a relatively large sample size of people ≥ 50 years living with HIV. We also collected detailed information on sociodemographic, physical, lifestyle and psychological factors, which helped us examine the correlates of frailty in this population. The primary limitation, nonetheless, was the use of a cross-sectional design, which precludes any conclusions on causality. Besides, our sample was predominantly from a rural setting; thus, our participants' experiences may differ from those in urban places. Also, the OALWH were invited to

participate from a health facility (i.e. not a population-based sample) and may not be entirely representative of all OALWH in this area. For instance, the sample of OALWH in the study had very high levels of cART treatment and viral suppression, and our observations would probably be different in individuals not seeking care (either because they are unaware of their status or don't believe they need treatment). Relatedly, given the significant sociodemographic differences observed between OALWH and their uninfected counterparts, our findings should be interpreted cautiously.

5.6 Conclusions

In this cross-sectional study, we found a significantly higher prevalence of frailty among OALWH compared to their uninfected peers, however, HIV seropositivity was not significantly associated with frailty in the multivariable analyses. Several factors, mostly biomedical and psychosocial, were also identified as significant correlates of frailty in the two sub-groups of participants. Notably, these factors appeared to differ by HIV status. These findings add to the literature on frailty among OALWH in SSA, which is currently grossly understudied. Our findings on frailty correlates provide ideal targets for future plans on interventions to prevent, delay, or treat frailty in this setting. Further prospective work is required to investigate the directionality and potential mediators of the association between frailty and the observed correlates.

5.7 Declarations

5.7.1 Ethics approval and consent to participate

Ethical approval for this study was granted by the Kenya Medical Research Institute Scientific and Ethics Review Unit (Ref: KEMRI/SERU/CGMR-C/152/3804). Permission to undertake the study in the two Counties was granted by the research office Kilifi (Ref: HP/KCHS/VOL.X/171) and Mombasa (Ref: COH/Msa/RSC/04). All clients provided written informed consent for their participation.

5.7.2 Availability of data and materials

Application for data access can be made through the Data Governance Committee of the KEMRI Wellcome Trust Research Programme who will review the application and advise

as appropriate, ensuring that uses are compatible with the consent obtained from participants for data collection. Requests can be sent to the coordinator of the Data Governance Committee using the following email dgc@kemri-wellcome.org

5.7.3 Competing interests

The authors have no competing interests to disclose.

5.7.4 Funding

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Chapter 6

Assessing neurocognitive functioning among adults
ageing with and without HIV at the Kenyan Coast:
Measurement issues and correlates

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6.0 Introduction

Findings from the initial stages of this PhD (systematic review and qualitative phase) confirmed that cognitive impairment is an important health outcome for OALWH with potential adverse impacts on the wellbeing of these adults. Nonetheless, screening for this outcome is not done in the study setting and many parts of SSA, partly due to measurement challenges, e.g., inadequately validated tools. The current paper addresses this gap by adapting and validating the Oxford cognitive screen plus tool among the cross-sectional phase participants of this PhD study and provides an initial understanding of the cognitive performance of these adults.

6.1 Abstract

Background: Cognitive impairment is one of the most prevalent complications of HIV infection, with significant medical and functional consequences. However, valid, and reliable assessment tools are lacking for the newly emergent ageing population of people living with HIV (PLWH) in many parts of sub-Saharan Africa (SSA), including Kenya. Without these tools, defining the burden of cognitive impairment in this context is not possible. To bridge this gap in Kenya, we adapted the Oxford Cognitive Screen Plus (OCSPlus), a tablet-based cognitive assessment tool designed for low-literacy settings, with adults ageing with HIV ≥ 50 years and their uninfected peers. The study examines the acceptability, reliability, and validity of the OCSPlus tool among older adults and provides an initial understanding of the cognitive performance of these adults (by HIV status) and the biopsychosocial factors associated with their cognitive performance.

Methods: In a cross-sectional sample of 440 older adults (257 living with HIV), we administered the OCSPlus tool alongside the Ravens Standard Progressive Matrices (RSPM), the International HIV Dementia Scale (IHDS), and health and sociodemographic assessments.

Results: Generally, post-test survey responses revealed a high level of acceptability of OCSPlus from both participants and test administrators. However, a few participants found the tablet hard to use. On average, study participants took 17 minutes to complete the different OCSPlus sub-tasks. OCSPlus demonstrated moderate test-retest

reliability. Acceptable correlations between individual OCSPlus sub-tasks and conventional tests (RSPM and IHDS) were also observed for convergent validity. Regarding cognitive performance, older adults living with HIV (OALWH) presented with significantly lower mean scores on language, executive function, and the IHDS overall score compared to their uninfected peers. However, OALWH performed significantly better on memory. There were no differences in non-verbal intelligence, attention, and processing speed. Cognitive performance was significantly associated with behavioural and lifestyle factors (physical activity, sleeping difficulties, obesity, and sexual activity), sociodemographic factors (age, sex, educational status, household income, household size and asset index), medical or treatment factors (self-reported urinary incontinence, hearing problems, history of tuberculosis, seeking services of traditional healers, antiretroviral therapy [ART] regimen change, being on 3rd line ART treatment) and psychosocial factors including ageism and food insecurity.

Conclusions: We demonstrated the feasibility of OCSPlus administration by trained lay persons, its acceptability, and preliminary reliability and validity among low-literacy older adults on the Kenyan coast. Generally, older adults living with HIV had lower cognitive scores compared to their uninfected peers. Cognitive performance was associated with several biopsychosocial factors spanning behavioural/lifestyle, sociodemographic, psychosocial, medical and treatment factors. Further adaptation and validation studies and epidemiological research are needed to understand better the psychometric properties and utility of the OCSPlus tool and the cognitive function of these adults ageing with HIV.

Keywords: Older Adults, HIV, Cognition, Kenya, OCSPlus, determinants

6.2 Background

Cognitive impairment is one of the most frequently witnessed complications of HIV infection, affecting about 50% of people living with HIV (PLWH) globally and has important medical, functional, and public health consequences (354). Besides, the number of PLWH getting to 60 years is rapidly increasing, an age at which dementia

prevalence begins to rise in the general population. Given that age is an important risk factor for dementia (355), even small effects of premature, accelerated, or accentuated neurocognitive ageing in PLWH may have serious public health consequences for dementia risk globally. Among existing studies, evidence for premature cognitive ageing is inconsistent while evidence for accelerated cognitive ageing appears consistent, but based on limited studies (356). Evidence for accentuated cognitive ageing is rarely examined (356). Hence, stronger evidence is urgently needed to inform healthcare providers about cognitive impairment risk among PLWH to properly facilitate targeted screening, prevention and treatment among adults ageing with HIV.

Prevalence estimates of cognitive impairment among Africa's 25.6 million PLWH (357) range from 14% to 88% depending on geographical location, study design, measurement tools and participants' antiretroviral therapy (ART) status (95). These rates are similar to estimates observed in high-income countries (HICs) (354). Cognitive deficits in HIV, known as HIV-associated neurocognitive disorder (HAND), typically cause impairments in various cognitive domains, including learning, memory, executive function, language, attention, processing speed and motor functions (97). The pathogenesis of HAND is multifactorial and is generally classified into HIV viral factors, antiretroviral factors and individual factors (97, 358). HAND ranges in severity from asymptomatic and mild forms to severe dementia-type forms (97). There are significant medical and functional impacts associated with having cognitive impairments, such as a higher risk of mortality, increased likelihood of developing a more severe impairment, limitations in activities of daily living, decreased quality of life, poor decision making and increased HIV transmission risk behaviours, placing many PLWH at risk for worse health outcomes including reduced adherence to ART due to memory impairment (359-364).

Recent findings from several settings suggest that the cognitive profile of PLWH has evolved. The advent of combination antiretroviral treatment (cART) has lessened the severity but not the frequency of these impairments (97, 365, 366). Noticeably, there has been a sharp drop in the severe forms of HAND and an increase in milder forms (97). Besides, the current manifestations of HAND show a subtle subcortical

involvement and more cortical involvement compared to the progressive subcortical dementia with marked deterioration of cognitive speed and motor functions observed in the pre-cART era (367). Findings also show a change in the cognitive domains most affected - from largely motor skills, processing speed, and verbal fluency in the pre-cART era to predominantly memory, learning and executive functioning in the cART era, suggesting possible domain-specific effects of HIV or cART (368). Hence, understanding the domain-specific effects of HIV on cognition may extend our understanding of the mechanism of HAND, potentially guiding future research and care.

As life expectancy of PLWH approaches that of people without HIV, PLWH become more vulnerable to age-associated cognitive impairment (366). Ageing and comorbidities elevate the risk for cognitive impairment in older adults. Given the rapid increase in chronic, age-related conditions in many parts of Africa, which also coincides with increasing prevalence of HIV among older adults, it is imperative to understand the cognitive profile of this vulnerable population to guide the design and implementation of health programs and policies in this population. In many countries in sub-Saharan Africa (SSA), older adults living with HIV often begin ART with severe levels of immunosuppression (369). The long period of untreated HIV infection, particularly in the context of advanced immunosuppression, likely causes legacy brain effects which are often inactive, permanent and hence not amenable to treatment (370). Such clinical or disease-specific or biological characteristics – in addition to the wide range of sociocultural factors, e.g., available support systems to provide care and assistance to older people could lead to different distributions of cognitive impairments in SSA compared to other contexts – hence the need for country-specific data on cognition.

Targeted screening for those with clear cognitive symptoms and functional decline is critical for good holistic care and treatment strategies (371). This strategy is more practical and finds more relevancy in SSA where many of the healthcare systems are struggling to meet the diverse needs of its people. Healthcare providers can then have the opportunity of minimizing the effects of HAND, determine when to adjust cART regimen and educate clients in timely fashion about the effects of cognitive impairment (371-373). Nonetheless, targeted screening is rarely done in SSA as it faces numerous

challenges, including few locally developed tests and a lack of expert personnel to administer the tests (182, 374), thus missing critical opportunities to intervene for the millions of PLWH in the region. Additionally, many of the conventional screening measures take a binary view of cognition, relying on global scores with a single cut-off value for impairment. They are also subject to ceiling effect, low sensitivity and are inappropriate for populations with low literacy and low numeracy (375-377). In the current study, we use the Oxford Cognitive Screen Plus (OCSPlus) (149) and two other conventional tests (the International HIV Dementia Scale – IHDS, and the Ravens Standard Progressive Matrices (RSPM) to assess the cognitive function of older adults. The OCSPlus is a novel tablet-based cognitive performance tool designed for low-literacy settings. Unlike many conventional tests, which rely on reading and numeracy skills, the OCSPlus relies more on visual abilities, with literacy and numeracy are not required to complete the test (148, 149). This study focuses on Kenya, a country experiencing simultaneous demographic and epidemiologic transitions (328). To our knowledge, no study in Kenya has examined the cognitive function of older adults living with HIV. To address this gap, our study seeks to a) report the initial reliability and validity of the OCSPlus tool in a low-literacy Kenyan setting. b) document the cognitive performance by HIV status of older adults ≥ 50 years of age and c) examine the psychosocial factors associated with cognitive performance among the older adults.

6.3 Methods

6.3.1 Study design and setting

This work is part of a larger cross-sectional study, the HIV-Associated Neurocognitive Disorders (HAND) study, examining different neuropsychological outcomes, e.g., cognition, mental health, and psychosocial functioning in adults aged ≥ 50 years at the Kenyan coast in Mombasa and Kilifi counties (159, 161, 378, 379). Data collection for this study took place between 2020 and 2021. Kilifi County has approximately 1.5 million residents, most of whom are rural dwellers and belong to the Mijikenda ethnic group (329). Recent data indicates that Kilifi has an adult HIV prevalence of 4.5% (252). Mombasa County, on the other hand, borders Kilifi to the north and has an estimated

population of 1.2 million people (329) and an adult HIV prevalence of 7.5% (252). More details have been provided elsewhere (161).

6.3.2 Participants recruitment

6.3.2.1 Older adults living with HIV

Older adults living with HIV (OALWH) were recruited from two public HIV-specialized clinics: the Comprehensive Care and Research Clinic (at the Kilifi County Hospital) and the Comprehensive Care Clinic at the Coast General Teaching and Referral Hospital in Mombasa. The two clinics were chosen because of their wide client catchment area and large volume of potential respondents. To participate in the study, individuals had to be at least 50 years old, have a confirmed HIV seropositivity status, be on routine HIV treatment, and be willing and able to provide informed consent for their participation.

Two community health volunteers helped us in reviewing existing records at the HIV clinics to identify potential participants. We tried to contact all potential respondents with contact details to invite them to participate in our study. Subsequently, a research assistant introduced the study to potential clients before enrolment. We started the participant recruitment in Mombasa County; however, it was interrupted by the COVID-19 pandemic after having recruited and assessed only 72 OALWH. The remaining participants (n=368) were recruited in Kilifi County upon resumption of study activities.

6.3.2.2 Older adults without HIV

We used the Kilifi Health and Demographic Surveillance System (KHDSS) to identify families with eligible older adults. Potential participants were randomly identified from the existing database and approached at their homesteads using Global Positioning System (GPS) coordinates by a trained research assistant. Study information was shared with all persons who expressed interest in participating. To be included in the study, clients had to be aged at least 50 years, be resident of Kilifi County, and be willing and able to provide written informed consent, including willingness to be tested for HIV using a rapid HIV testing kit (OraQuick) for a confirmation of their HIV seronegative status.

6.3.3 Sample size calculations

Power analyses in Stata (using effect estimates and proportions) from previous studies were conducted to estimate the required sample size to identify important correlates of cognitive performance in the sample. A sample of 400 participants was deemed adequate to conduct multiple regression analyses to explore correlates of cognitive function among these adults (380). The sample size computation also took into account sufficient numbers required to conduct stable estimates of reliability and internal consistency (381).

6.3.4 Measures

Our research instruments were programmed on Android tablets using the Electronic Data Capture (REDCap) platform (255) for face-to-face interviewer administration. The first author (PNM) trained the research assistants over two weeks. The training comprised various components, including familiarization with study procedures, infection prevention and control, test administration rules and neuropsychological testing techniques. All measures not previously adapted to the local language (Swahili) underwent adaptation procedures that comprised forward translation, forward translation review, back translation, back translation review, harmonization by a panel of experts, pilot testing, pilot testing review and proofreading (265).

6.3.4.1 Sociodemographic information

We captured various sociodemographic characteristics, including participants' age, sex, marital status, educational level, household size, household income, and living arrangements. Additional information included individual/family ownership of disposable assets (for asset index calculation as a proxy for socioeconomic status). Participants also gave information about food security, social support, caregiving responsibilities and whether they were utilizing traditional medicine.

6.3.4.2 General health data

This information included participants' anthropometric details (e.g., height, weight, blood pressure, waist, and hip circumference), sexual activity, levels of physical activity,

number of medications one was using, self-reported comorbidities, past medical history, and common complaints, e.g., pain, fatigue, sleeping problems, visual and hearing problems.

For older adults living with HIV, we also asked HIV-specific questions, e.g., disclosure of HIV status, access to HIV services, cART regimen, past HIV medical history such as regimen interruption, and prolonged illness after HIV diagnosis. Information regarding the current ART regimen and overall ART duration were extracted from their clinic medical records. Additionally, we collected 10 milliliters of venous blood samples from the OALWH for viral load testing.

6.3.4.3 Psychosocial data

Psychosocial variables included HIV-related stigma, functional disability, loneliness, and ageism. These constructs were assessed using interviewer-administered Likert scales: the brief 12-item HIV stigma scale (256), the 12-item World Health Organization Disability Assessment Schedule 2 (257), the UCLA 8-item loneliness scale (258), and the 20-item ageism survey (259). For each scale, a higher score translates into greater impairment.

6.3.4.4. Neuropsychological evaluation

We used various measures to evaluate cognitive function, including:

International HIV Dementia Scale (IHDS). The IHDS is a conventional, brief, 3-minute screening tool comprising tasks that assess verbal memory, motor and psychomotor performance (374, 382). The highest possible score is 12, with higher scores indicating better cognitive performance. A score of ≤ 10 shows a reasonable sensitivity (64–74%) and specificity (55–66%) in identifying moderate to severe HIV-associated neurocognitive impairment (383).

Ravens Standard Progressive Matrices (RSPM) (384): The RSPM is a non-verbal standardized test of general intelligence (non-verbal intelligence) comprising five series with 12 items. The measure has previously been used in Kilifi, yielding good

psychometric properties (385). The maximum possible score is 60, with a higher score indicating better cognitive performance.

Oxford Cognitive Screen Plus (OCSPlus) (386): It is a novel tablet-based cognitive assessment tool designed for low-literacy, low-income settings. It is designed to tap into distinct cognitive domains, e.g., language, memory, attention, and executive functioning. Participants' performance and timing are automatically recorded and scored. Initial validation in rural South Africa yielded excellent construct and external validity (148). The adapted Swahili version, tapping into language, memory, attention, and executive functioning domains, was used in this study. Briefly, the memory domain included an orientation task assessing orientation in time and space, a 5-word immediate recall task, delayed recall (4- to 5-minute delay), and delayed word recognition, which tests the ability to recognize words not retrieved during free recall. The language domain was assessed by a picture naming task with four target pictures and a test of semantic knowledge (four objects). The executive function domain consisted of three versions of non-verbal trails task where participants were required to connect shapes using different rules: first circles, then squares, and then alternating between circles and squares. Processing speed was calculated as the sum of time taken on both versions of trails baseline tasks (circles or squares) divided by proportional accuracy. The attention domain was measured using a cancellation task. The participant selects drawings of fruit amongst drawings of common fruits and vegetables immediately followed with an invisible version of the same display.

OCSPlus was administered by two diploma-level research assistants who have several years' experience conducting psychological assessments at the KWTRP. The two assessors underwent one week of training at the beginning (and a subsequent refresher at mid-project) on how to conduct neurocognitive assessments including the OCSPlus. The training was led by a master's level mental health researcher with guidance from the tool developers. Following training, the team conducted pilot activities with adults in the community. To evaluate the acceptability and feasibility of the OCSPlus tool, clients and test administrators responded to post-test survey questions (both closed and open-ended questions) about their experience using the tool. Clients were asked to indicate

their ease of using the tool e.g. their interactions with the tablet, and the degree of difficulty of the battery of tests. Test administrators feedback included noting how easy/difficult it was for clients to understand instructions, and as well as their own experience with the tool. Assessors also gave their general recommendations as test administrators. Test-retest participants were randomly selected from the pool of assessed participants (1 month after the initial assessment) by the data manager and recontacted to come for the follow up assessments at the KWTRP.

6.3.5 Data analysis

All analyses were conducted in STATA version 15.0 (StataCorp LP, College Station, TX, USA). We used descriptive statistics (chi-square tests and student t-tests) to summarize sample characteristics. Test-retest reliability was assessed using intra-class correlations. To examine convergent validity between the OCSPlus tests and the conventional tests, Pearson correlation coefficients were computed for each OCSPlus test. We aimed for correlations above 0.3 to demarcate convergence (387) but also cautiously interpreted correlations >0.19 (149). We also used Student's t-test to compare cognitive performance between older adults living with HIV and their uninfected peers. We conducted multiple linear regressions to examine the association between OCSPlus raw scores and biopsychosocial variables among participants. To do this, univariable linear regression analyses were conducted to identify factors associated with OCSPlus raw scores and all factors having a p-value of ≤ 0.20 (388) were then entered into a multivariable linear regression model to examine the independent correlates through a back-ward elimination process (389). Statistical significant was considered at $p < 0.05$.

6.3.6 Ethical considerations

Ethical approval for this study was granted by the Kenya Medical Research Institute Scientific and Ethics Review Unit (Ref: KEMRI/SERU/CGMR-C/152/3804). Permission to conduct the study in the two Counties was granted by the research office Kilifi (Ref: HP/KCHS/VOL.X/171) and Mombasa (Ref: COH/Msa/RSC/04). All clients provided written informed consent for their participation.

6.4 Results

6.4.1 Sample characteristics

The final sample comprised 440 older adults (58% living with HIV), with a mean age of 60.1 (SD = 6.9) years and a participant response rate of 90%. Female participants were slightly more (58.6%) than males. A majority of the participants (63.2%) had formal education (an average of 4.8 years of formal schooling), 65.5% were unemployed, and 81.6% were living in multigenerational households. All adults living with HIV were on HIV treatment with a mean (SD) duration of HIV treatment of 11.4 (4.3) years. Most of the OALWH had disclosed their HIV status (95.3%) and were on first-line cART treatment (90%). Further details of the sample characteristics have been described previously (161).

6.4.2 Preliminary psychometrics

6.4.2.1 Acceptability of the OCSPlus tool

Ninety-four percent (n=407) of participants reported never using a computer. Only twenty-two percent (n=88) had used a smartphone before. Only two percent (n=10) reported using a tablet before. Fifty-three percent of the sample reported that the study tablet was "very easy" to "somewhat easy" to use, while the rest (47%) felt the study tablet was "somewhat difficult" to "very difficult to use".

Table 6.1 highlights respondents' perceived degree of difficulty or ease on the different OCSPlus subtests. The trail making test was reported to be the most challenging test by 96 (22%) of the respondents. On the other hand, the selection visible OCSPlus task was considered the easiest by 349 (79%) of the participants. On average, study participants took 17 minutes to complete the different OCSPlus sub-tasks.

Further details on the different OCSPlus subtasks are highlighted in Table 6.1.

Table 6.1. Perceived degree of difficulty or ease on various OCSPlus tests from respondents (n= 440)

OCSPlus subtest	Number (%) of respondents who reported that the test was difficult	Number (%) of respondents who reported that the test was easy
Picture naming (OM=5)	35 (8%)	270 (61%)
Semantics (OM=12)	39 (9%)	267 (61%)
Orientation (OM=5)	31 (7%)	268 (61%)
Word encoding 1 (OM=17)	68 (15%)	239 (54%)
Word encoding 2 (OM=4)	59 (13%)	242 (55%)
Trail making (OM=5)	96 (22%)	244 (55%)
Delayed word recall (OM=5)	71 (16%)	236 (54%)
Incidental memory (OM=15)	30 (7%)	249 (57%)
Selection visible (OM=6)	48 (11%)	349 (79%)
Selection invisible (OM=6)	67 (15%)	306 (70%)

Note: OM=Observations missing

Feedback from the test administrators was generally positive. Administrators rarely encountered any technical problems when administering the test. In three instances, the tablet froze; however, restarting the tablet was able to fix the problem. The other reported challenges included eyesight difficulties and hand tremors, which were experienced by 8 (2%) participants.

6.4.2.2 Reliability

A group of 46 older adults living with HIV were re-tested on the OCSPlus tool on average 30 days after the initial test. The window of time between test administrations (1 month) was deemed long-enough to minimize practice effects. Intra-class correlations were computed to examine test-retest reliability for the different OCSPlus subtasks highlighted in Table 6.2. Reliability coefficients were generally of acceptable quality, ranging from 0.51 to 0.79.

Table 6.2. Intra Class Correlations for the different OCSPlus subtasks

Measure	Reliability coefficients
Picture naming	0.78
Semantics	0.68
Orientation	0.79
Word encoding 1	0.60
Word encoding 2	0.61
Word recall - total	0.51
Trails circles	0.57
Trails squares	0.51
Trails baseline	0.68
Cancellation	0.68

We also calculated Cronbach alphas for the different OCSPlus domains; most alpha values were low (Table 6.3). However, performance on these items was stable over time.

Table 6.3. Cronbach alphas for some of the OCSPlus subtasks

Measure	Cronbach alphas
Picture naming	0.58
Semantics	0.57
Orientation	0.67
Word encoding	0.56
Word recall	0.53

6.4.2.3 Convergent validity

To examine convergent validity between the OCSPlus tests and the conventional tests, Pearson correlation coefficients were computed for each OCSPlus test. Table 6.4 displays the correlation matrix between OCSPlus and the conventional tests. Generally, statistically significant correlations between the OCSPlus and conventional tests were observed for the majority of the tests.

Table 6.4. Correlations between OCSPlus and the conventional tests (n=440)

OCSPlus subtasks	Ravens total score	IHDS total score
Picture naming	0.1	0.3**
Semantics	0.3**	0.2**
Orientation	0.5**	0.2**
Word recall total score	0.3**	0.3**
Incidental memory	0.2**	0.2**
Trails circle	0.5**	0.2**
Trails squares	0.5**	0.3**
Trails mixed	0.2**	0.3**
Trails processing speed	-0.3**	-0.2**
Selection visible targets	0.3**	0.3**
Selection invisible targets	0.3**	0.4**

Notes: ** p<0.01

6.4.3 Cognitive performance on conventional and OCSPlus measures

Table 6.5 displays mean scores for the OCSPlus sub-tasks and the conventional cognitive measures (RSPM and the IHDS), adjusted for age, educational levels, sex, and asset index. Older adults living with HIV presented with significantly lower mean scores on language, executive function, and the conventional screening measure (IHDS) compared to their uninfected counterparts. On the contrary, OALWH performed significantly better on memory. There were no differences in non-verbal intelligence, attention, and processing speed.

Table 6.5. Cognitive profile on conventional and OCSPlus cognitive tests, according to HIV status (*adjusted means, n=440*)

Domain	Test	Older adults living with HIV (n=257)	Older adults without HIV (n=183)	
		Adjusted Mean (SD)	Adjusted Mean (SD)	P-value
OCSPlus sub-tests				
Language (A higher score is better cognitive performance)	Picture naming task	3.8 (0.4)	4.0 (0.4)	0.001
	Semantics task	2.3 (0.7)	2.3 (0.7)	0.4
Memory (A higher score is better cognitive performance)	Orientation task	3.0 (0.9)	2.4 (0.9)	<0.001
	Word encoding task 1	2.9 (1.0)	3.0 (1.1)	0.6
	Word encoding task 2	4.0 (1.0)	3.9 (0.9)	0.3
	Word recall - free score	2.3 (1.3)	2.0 (1.2)	0.03
	Word recall - total score	3.3 (1.1)	3.2 (1.2)	0.6
	Incidental - memory	2.6 (0.8)	2.6 (0.8)	0.9
Executive functioning	Trails - Baseline trails	8.1 (3.8)	8.4 (3.9)	0.4
	Trails - Executive score	0.8 (1.0)	1.1 (0.9)	0.001
Processing speed (A lower score is better cognitive performance)	Trails - processing speed score (milliseconds)	207053.9 (293190.7)	205446.3 (295192.2)	0.9
Attention (A higher score is better cognitive performance for taps on targets, and the opposite is true for taps on distractors)	Selection visible task - Number of unique taps on targets	22.6 (8.1)	23.4 (8.1)	0.3
	Selection visible task - Number of unique taps on distractors	5.2 (8.7)	6.45 (8.7)	0.1
	Selection invisible task - Number of unique taps on targets	17.7 (8.4)	19.0 (8.6)	0.1
	Selection invisible task - Number of unique taps on distractors	2.9 (5.9)	4.0 (5.9)	0.06
Conventional measures				
Non-verbal intelligence	Ravens standard progressive matrices	18.0 (5.5)	17.4 (5.5))	0.2
verbal memory, motor, and psychomotor performance (A higher score is a better cognitive performance)	International HIV Dementia Scale	7.4 (1.8)	8.3 (1.7)	<0.001

Notes: cognitive domains with significant differences ($p < 0.05$) are indicated with bolded p-values. When using the OCSPlus tool – language, memory and attention tasks had 253 complete observations; while executive and processing speed tasks had 254 complete observations. Among older adults without HIV; language, memory had 182 complete observations and the rest had 181 complete observations. For IHDS tool, we had 255 complete observations among OALWH and 179 complete observations among those without HIV.

6.4.4 Association of OCSPlus raw scores with biopsychosocial variables

Table 6.6 highlights the biopsychosocial variables associated with OCSPlus raw scores among older adults living with HIV. The most consistent finding in this group was the significant positive association of education with OCSPlus mean scores across all cognitive domains. Female sex was significantly associated (negatively) with all but one (attention) of the five cognitive domains tested. Moreover, as expected, older age was significantly associated (negatively) with memory, executive functioning, and attention scores. Asset index (a proxy measure of socioeconomic status) was positively associated with memory scores, while greater food insecurity was negatively related with the same domain. Monthly household income and being sexually active were positively associated with executive scores, while self-reported urinary incontinence was negatively associated with the same domain. Doing light physical activities was positively associated with language scores, while sleeping difficulties were negatively associated with the same domain. Self-reported hearing problems, ART regimen change and seeking services of traditional healers were negatively associated with attention scores. Ageism was negatively associated with executive function and attention scores. Caring for a sick family member was positively associated with language and attention scores. An increasing number of dependents was negatively associated with language, executive function and processing speed scores. Being on third-line HIV treatment was negatively associated with language and memory scores.

Table 6.7 highlights the biopsychosocial variables associated with OCSPlus raw scores among HIV uninfected older adults. Among HIV uninfected older adults, education was significantly associated (positively) with memory, executive and processing speed domains. Female sex was significantly associated (negatively) with language and memory scores. Older age was negatively associated with language, processing speed and attention scores. Asset index was positively associated with language scores. Increasing number of dependents was negatively associated with memory scores. Self-reported hearing problems were negatively associated with executive scores. A history of TB was negatively associated with attention scores. Increased food insecurity was

negatively associated with attention scores. Being overweight and frequent fatigue were negatively associated with processing speed scores.

Table 6.6. Multiple linear regression model showing the association of OCSPlus raw scores with biopsychosocial variables among OALWH

Independent variables	β-coefficient (95% CI) of cognitive domains as dependent variables											
	Language		Memory				Executive Function			Processing speed	Attention	
	Picture naming	Semantics	Orientation	First immediate word recall	Delayed word recall	Incidental memory	Trails, circles	Trails, squares	Trails, mixed	Trails – processing speed score	Selection, visible	Selection, invisible
Female sex (ref: male)	-0.1 (-0.2;0.04)	-0.3*** (-0.5;-0.2)	-0.5*** (-0.7;-0.2)	-0.1 (-0.4; 0.2)	-0.2 (-0.5; 0.1)	-0.03 (-0.2; 0.2)	-0.8** (-1.4;-0.2)	-0.7** (-1.3;-0.2.)	1.2 (-0.1;2.4)	72298.4** (1463.9; 143132.9)	-0.2 (-2.4; 2.1)	-1.3 (-3.3; 0.6)
Age (ref: 50–59 years)												
60 – 69 years	-0.04 (-0.2; 0.1)	0.02 (-0.2; 0.2)	-0.01 (-0.2; 0.2)	-0.1 (-0.4; 0.2)	-0.6*** (-0.9 –0.3)	0.1 (-0.1; 0.3)	-0.1 (-0.7; 0.5)	-0.6** (-1.1 –0.1)	0.6 (-0.5;1.7)	14190.6 (-54615.9; 82997.1)	-1.6 (-3.6; 0.4)	-2.2** (-4.2; –0.3)
≥70 years	-0.2 (-0.5;0.04)	0.03 (-0.3; 0.4)	-0.2 (-0.6; 0.3)	-0.1 (-0.7; 0.4)	-1.0*** (-1.5 –0.5)	-0.3 (-0.7;0.05)	-0.8 (-2.0; 0.4)	-1.3** (-2.3 –0.3)	1.6 (-0.5;3.8)	74949.1 (-64132.2; 214030.4)	-6.0*** (-10.1; –1.9)	-6.0*** (-9.9; –2.1)
Education (ref: none)												
Primary level (upto completion)	-0.2 (-0.3; 0.0)	0.2 (-0.01;0.4)	1.0*** (0.8; 1.3)	0.4** (0.03; 0.7)	0.6*** (0.3; 0.9)	0.4*** (0.2; 0.6)	1.9*** (1.2; 2.6)	0.9*** (0.3; 1.6)	1.6** (0.4; 2.8)	-149863.4*** (-230170.3; -69556.5)	1.7 (-0.7; 4.0)	3.0** (0.7; 5.4)
Secondary level (upto completion)	-0.1 (-0.3; 0.1)	0.3** (0.001;0.5)	1.2*** (0.9; 1.6)	0.5** (0.03; 0.9)	0.5*** (0.1; 0.9)	0.5*** (0.2; 0.8)	2.9*** (2.0; 3.8)	1.9*** (1.1; 2.7)	2.5*** (1.0; 4.1)	-200253.8*** (-302309.7; -98198.0)	4.8*** (1.8; 7.8)	4.3*** (1.3; 7.3)
Tertiary level (upto completion)	-0.3 (-0.5; 0.0)	0.4** (0.04; 0.8)	1.1*** (0.6; 1.6)	0.8*** (0.2; 1.4)	1.1*** (0.1; 0.7)	0.4** (0.03; 0.8)	2.8*** (1.6; 4.0)	1.5** (0.4; 2.6)	2.6** (0.4; 4.8)	-244202.9*** (-387041.2; -101364.5)	0.8 (-3.2; 4.7)	3.9 (-0.1; 7.9)
Asset index score	–	–	0.1*** (0.1; 0.2)	0.1*** (0.04; 0.2)	–	–	–	–	–	–	–	–
Monthly household income >10,000 Ksh (ref: ≤10,000 Ksh)	–	–	–	–	–	–	–	1.1*** (0.4; 1.8)	2.5*** (1.2; 3.9)	–	–	–
Food insecurity in the past week (ref: never)												
Sometimes	–	–	–	–	-0.3** (-0.6; 0.03)	–	–	–	–	-19886.4 (-93226.0; 53453.2)	–	–
Most of the time	–	–	–	–	-0.2 (-0.6; 0.2)	–	–	–	–	140935.2*** (27179.5; 254691.0)	–	–
Sexual intercourse (ref: no)	–	–	–	–	–	–	–	–	1.8*** (0.6; 2.9)	–	2.0 (-0.3; 4.2)	–
Days spent doing light activities in the past week	0.1*** (0.02; 0.1)	–	–	–	–	–	–	–	–	–	–	–
Self-reported hearing (ref: good)	–	–	–	–	–	–	–	–	–	–	-2.9** (-5.3; –0.5)	–

	Language		Memory				Executive Function			Processing speed	Attention	
Independent variables	Picture naming	Semantics	Orientation	First immediate word recall	Delayed word recall	Incidental memory	Trails, circles	Trails, squares	Trails, mixed	Trails – processing speed score	Selection, visible	Selection, invisible
Sleeping difficulties in the past month (ref: none)												
Sometimes	–0.1** (–0.3;0.03)	–	–	–	–	–	–	–	–		–	–
Most of the time	–0.2 (–0.4;0.01)	–	–	–	–	–	–	–	–		–	–
Access to social support (ref: none)	0.2 (–0.02;0.5)	–	–	–	–	–	–	–	–		–	–
Ageism scores	–	–	–	–	–	–	–	–0.1*** (–0.1; 0.03)	–		–	–0.2*** (–0.4; –0.1)
Caring for a sick family member (ref: no)	0.3*** (0.2; 0.5)	–	–	–0.2 (–0.5;0.1)	–	–	–	–	–		8.6*** (6.4; 10.7)	8.4*** (5.9; 10.9)
Number of dependents	–	–0.04** (–0.1;0.01)	–	–	–	–	–0.1** (–0.2;0.04)	–0.1*** (–0.2; 0.03)	–	16146.7*** (4199.0; 28094.5)	–	–
Number of drugs the client currently uses	–	–	–	–	–	–	–	–	–	33344.3*** (6694.2; 59994.4)	–	–
cART regimen (ref: 1 st line)												
2 nd line	–	0.04 (–0.3; 0.3)	0.3 (–0.03;0.7)	–	–	0.2 (–0.1; 0.5)	–	–	–	–	–	–
3 rd line	–	–1.7** (–3.1; 0.4)	–0.8 (–2.4; 0.9)	–	–	–1.6** (–3.0; 0.1)	–	–	–	–	–	–
History of cART change (ref: no)	–	–	–	–	–	–	–	–	–	–	–	–4.6*** (–6.8; –2.4)
History of frequent body pain (ref: no)	–	–	–	–	0.4*** (0.1; 0.7)	0.3** (0.1; 0.5)	–	–	–	–	–	–
History of stomach upsets	–	–	–	–	–	–	–	–	–	–	–	–2.6 (–7.3;2.1)
Mid-upper arm circumference	–	–	–	–	–	–	0.1** (0.01; 0.1)	–	–	–	–	–
Incontinence - urinary (ref: no)	–	–	–	–	–	–	–	–	–2.2** (–3.9; 0.4)	–	–	–
Seeking services of traditional healers (ref: no)	–	–	–	–	–	–	–	–	–	–	–4.5** (–8.0; –1.0)	–
n, final model	246	249	253	247	252	249	250	254	250	247	248	248
R-squared, final model	28.1%	14.2%	47.5%	17.3%	28.3%	14.7%	30.6%	32.1%	16.8%	21.3%	31.5%	41.9%

Notes: ** p<0.05; *** p<0.01

Table 6.7. Multiple linear regression model showing the association of OCSPlus raw scores with biopsychosocial variables among HIV uninfected older adults

Independent variables	β-coefficient (95% CI) of cognitive domains as dependent variables										
	Language	Memory				Executive Function			Processing speed	Attention	
	Semantics	Orientation	First immediate word recall	Delayed word recall	Incidental	Trails, circles	Trails, squares	Trails, mixed	Trails – processing speed score	Selection, visible	Selection, invisible
Female sex (ref: male)	-0.6*** (-0.8; 0.3)	-0.4*** (-0.8; -0.1)	0.2 (-0.2; 0.5)	-0.2 (-0.6; 0.2)	-0.1 (-0.4; 0.1)	-0.3 (-1.1; 0.5)	-0.2 (-0.9; 0.6)	0.4 (-1.2; 2.0)	18254.2 (-76428.8; 112937.2)	-0.7 (-3.1; 1.7)	-0.5 (-2.9; 1.8)
Age (ref: 50–59 years)											
60 – 69 years	-0.03 (-0.3; 0.2)	0.1 (-0.3; 0.4)	-0.01 (-0.4; 0.3)	-0.2 (-0.6; 0.2)	-0.1 (-0.4; 0.2)	-0.6 (-1.3; 0.2)	-0.5 (-1.2; 0.2)	0.5 (-1.0; 2.0)	89259.2** (4521.5; 173996.8)	0.1 (-2.2; 2.3)	-1.1 (-3.3; 1.1)
≥70 years	-0.4** (-0.7; 0.02)	0.2 (-0.3; 0.7)	0.1 (-0.4; 0.6)	-0.5 (-1.1; 0.1)	-0.3 (-0.7; 0.2)	0.3 (-0.8; 1.3)	-0.6 (-1.7; 0.5)	0.1 (-2.2; 2.3)	154362.1** (28638.9; 280085.3)	-2.0 (-5.4; 1.3)	-4.2** (-7.6; -0.8)
Education (ref: none)											
Primary level	-0.05 (-0.3; 0.2)	1.1*** (0.8; 1.5)	0.6*** (0.2; 1.0)	0.5** (0.04; 0.9)	0.2 (-0.1; 0.5)	1.0** (0.2; 1.9)	1.4*** (0.6; 2.2)	2.5*** (0.8; 4.2)	-119893.2** (-213755.6; -26030.7)	1.3 (-1.3; 3.8)	
Secondary level	0.1 (-0.3; 0.5)	1.8*** (1.2; 2.3)	0.8*** (0.3; 1.3)	1.0*** (0.4; 1.6)	0.3 (-0.1; 0.8)	3.1*** (1.9; 4.3)	2.8*** (1.5; 4.0)	3.7*** (1.3; 6.1)	-244097.7*** (-378665.5; 109529.9)	2.4 (-1.4; 6.2)	2.2 (-0.3; 4.7)
Tertiary level	0.02 (-0.6; 0.6)	0.8 (-0.1; 1.8)	0.2 (-0.8; 1.2)	0.5 (-0.5; 1.5)	-0.1 (-0.8; 0.6)	2.6*** (0.7; 4.5)	2.2** (0.3; 4.2)	3.9** (0.02; 7.8)	-181528 (-398055.6; 34999.7)	3.0 (-3.0; 9.0)	3.4 (-0.1; 7.0)
Asset index score	0.1*** (0.04; 0.2)	–	–	–	–	-0.1 (-0.4; 0.2)	-0.02 (-0.3; 0.3)	–	–	0.6 (-0.3; 1.6)	4.2 (-2.3; 10.7)
Employment (ref: none)											
Employed	–	0.1 (-0.3; 0.5)	0.1 (-0.3; 0.5)	–	–	–	–		–		
Retired	–	0.5 (-0.1; 1.0)	0.6 (-0.03; 1)	–	–	–	–		–		
Number of dependents	–	–	–	-0.1** (0.2; 0.02)	–	–	–		–		
Self-reported hearing (ref: good)	–	–	–	–	–	–	–	-2.0** (-3.8; -0.2)			
Monthly household income >10,000 Ksh (ref: ≤10,000)	–	–	–	–	–	–	–	–	0.3 (-0.05; 0.6)		

	Language	Memory				Executive Function			Processing speed	Attention	
	Semantics	Orientation	First immediate word recall	Delayed word recall	Incidental	Trails, circles	Trails, squares	Trails, mixed	Trails – processing speed score	Selection, visible	Selection, invisible
Past history of TB (ref: no)	–	–	–	–	–	–	–	–	–	–15.9** (–29.8; –2.0)	–
Food insecurity in the past week (ref: never)											
Sometimes	–	–	–	–	–	–	–	–	79050.4 (–9371.8; 167472.6)	–	–2.5** (–4.8; –0.1)
Most of the time	–	–	–	–	–	–	–	–	–446.6 (–231369.1; 230475.8)	–	–6.6 (–14.9; 1.7)
BMI Categories (ref: normal)											
Underweight	–	–	–	–	–	–	–	–	51386.0 (–88180.5; 190952.4)	–	–
Overweight	–	–	–	–	–	–	–	–	126147.0 *** (34067.3; 218226.7)	–	–
Obese	–	–	–	–	–	–	–	–	5823.6 (–119896.6; 131543.8)	–	–
Frequent fatigue	–	–	–	–	–	–	–	–	176293.6 *** (55624.7; 296962.4)	–	–
n, final model	179	182	175	181	176	181	181	181	181	181	180
R-squared, final model	21.9%	44.8%	13.4%	15.0%	5.5%	20.6%	19.3%	12.2%	27.4%	9.3%	13.8%

Notes: ** p<0.05; *** p<0.01

6.5 Discussion

Although HIV-associated neurocognitive impairments are mostly mild in patients successfully treated with modern antiretroviral therapy, ageing is likely to exacerbate severe forms of impairment with greater impacts on activities of daily living and health-related quality of life. Unfortunately, valid and reliable screening tools for these impairments are lacking in many parts of SSA, including Kenya. To bridge this gap, our study provides preliminary evidence for the acceptability, reliability, and validity of the Oxford Cognitive Screen Plus (OCSPlus) tool, a brief, tablet-based, domain-specific cognitive assessment designed for low-literacy settings in a hospital sample of adults ageing with HIV (≥ 50 years) and their uninfected peers at the Kenyan coast. Additionally, our study documents the cognitive performance of these adults (by HIV status) and reports the factors associated with their cognitive performance.

Our findings demonstrate the feasibility of layperson-administered, older adults cognitive testing with the OCSPlus in a low-literacy Kenyan setting. All of the administered tasks had $>90\%$ valid data. There was also good level of acceptability of OCSPlus by the participants, even with substantially low previous use of computer tablets. Performance on most of the OCSPlus subtasks correlated well with the conventional cognitive tests. The OCSPlus was also found to have moderate test-retest reliability.

Regarding cognitive performance, OALWH had significantly lower scores in language, executive function and one of the conventional screening measures (IHDS) compared to their uninfected peers. However, OALWH performed better in the memory domain. Cognitive performance among OALWH (on OCSPlus domains) was associated with a host of biopsychosocial variables ranging from sociodemographic factors (female sex, age, educational level, asset index, monthly household income, number of dependants), psychosocial factors (food insecurity, sleeping difficulties, ageism, physical activity, sexual activity), biomedical (self-reported urinary incontinence, hearing problems) and treatment-related factors (ART regimen change, being on third-line HIV treatment, and seeking the services of traditional healers). All the observed associations were in the *a priori* hypothesized direction. Similar associations were also seen among HIV

uninfected older adults. Our findings extend the evidence on cognitive screening instruments among older adults in the region and pave the way for further research on the utility and application of the OCSPlus tool in the region and similar settings.

To the best of our knowledge, this is the second study in SSA that has attempted to validate the OCSPlus tool among older adults. The initial validation was conducted in a population of older adults (aged at least 40 years) in rural South Africa against standard questionnaires and in relation to associations with several variables, including physical and mental health, age, education, and alcohol consumption (for external validity) (148). The authors reported high task compliance and good construct and external validity of the OCSPlus in their large, low formal education, low-income population sample from the rural South African community of Agincourt (390). Unlike the South African study, the OCSPlus in our study was validated among older adults ≥ 50 years, and our sample was relatively smaller (440 older adults), comprising OALWH in routine HIV care and HIV-uninfected older adults from the surrounding communities. Besides our study assessed the reliability and convergent validity of the OCSPlus unlike the South African one – which focused on construct and external validity. Generally, our findings confirm the convergent validity of the OCSPlus tool among low-literacy, low-income populations in SSA. Notably, our study also provides preliminary evidence of the tool's reliability in Kenya with moderate test-retest results.

A variant of the OCSPlus tool known as the Oxford Cognitive Screen: Executive Function (OCS-EF) has also been validated in SSA, albeit among adolescent females in rural South Africa. The results indicated that the tool can be administered by trained lay people and is valid for assessing cognition at scale among adolescents (391). Outside SSA, the OCSPlus has also been validated among 320 neurologically healthy older adults from a pooled English and German normative sample where performance on several OCSPlus subtasks correlated with performance on standard measures, though some of the convergent validity was relatively low (149). The OCSPlus was also found to have good test-retest reliability despite the wide-ranging test-retest intervals. Similar to our study, values for some subtasks were low due to inherent low variance. In terms of validity, similar to our findings, many of the comparisons had relatively low (<0.5)

correlation coefficients, possibly due to low variance in ceiling-type performance. Nonetheless, in terms of the size of the convergent correlations, majority were at or above an acceptable level of convergence observed in validations of other commonly used screens, that is, >0.20 (392). While the performance on OCSPlus subtasks and conventional tests is significantly associated, these tests are not exactly identical nor have very few lower-range scores to give perfect estimates.

In our second objective, OALWH presented significantly lower cognitive scores on language and executive function (for OCSPlus) and on the IHDS. However, the same adults performed significantly better in the memory domain of the OCSPlus. Our findings differ from those of a population-based cross-sectional study of older adults in rural South Africa (393). When using a conventional battery (assessing orientation, word recall, and numeracy skills), the authors observed significantly higher cognitive scores among PLWH. Nonetheless, when cognitive function was evaluated using OCSPlus, the authors found no significant differences in cognitive function according to HIV and ART status. Our finding however needs to be interpreted cautiously given that the South African study used summative OCSPlus scores while we used domain-specific raw scores. Plausibly, the discrepancy in findings may be due to differences in the samples of OALWH studied (population-based vs. hospital sample), tools used (conventional ones), participants' age (≥ 50 in our study vs ≥ 40 in the South African study) or other contextual differences. The OCSPlus tool assesses several domains of cognitive function, and some of these domains may be especially sensitive to HIV-related brain changes.

Our study identified several variables associated with cognitive performance (across OCSPlus subtasks). These factors ranged from behavioural and lifestyle factors (physical activity, sleeping difficulties, obesity, and sexual activity), sociodemographic factors (age, sex, educational status, household income, household size and asset index), medical or treatment factors (self-reported urinary incontinence, hearing problems, history of TB, seeking services of traditional healers, ART regimen change, being on 3rd line ART treatment) and psychosocial factors including ageism and food insecurity. The observed associations were in the expected direction, consistent with

previous literature. Notably, many of these factors are modifiable, hold great promise for promoting cognitive health, and may lend themselves to developing effective interventions in this population. Our findings, however, do not infer causality; and further research with suitable study designs, e.g., longitudinal studies, is needed to understand the results further. Similar findings on some of these variables have been reported elsewhere in West Africa (394, 395) and South Africa (396).

6.5.1 Limitations and future research

The OCSPlus tool, in its current state, is designed to briefly measure more detailed cognitive performance metrics that can be used to make informed clinical decisions and not to separate the spectrum of cognitive deficits into impairment categories. Normative performance data have not been established for OCSPlus in the Kenyan setting, making generalization of performance on it difficult. Also, the conventional tests used in our study (the Ravens standard progressive matrices and the international HIV dementia scale) assessed limited cognitive domains compared to the OCSPlus, and this may explain some of the low correlation coefficients for the convergent validity. Future validation studies should expand the conventional neuropsychological battery. Despite these limitations, we believe OCSPlus offers researchers and clinicians a brief, easy-to-use solution to screen for cognitive function among older adults living with HIV and other patients with brain-involving pathologies. However, more research is required to validate the tool as a screening tool for neurocognitive impairments. A larger sample, statistically powered to confirm internal and external validity, is essential for the tool scale-up. There is also scope for in-depth qualitative research with potential users of OCSPlus in clinical settings, e.g., clinicians and nurses, to assess the utility of the tool in these settings. We recruited our OALWH from public HIV clinics, as such, our findings may not be readily generalizable to OALWH who may be out of care or attending private or urban HIV clinics or recruited from the community. Relatedly, given the significant sociodemographic differences observed between OALWH and their uninfected counterparts, our findings should be interpreted cautiously.

6.6 Conclusions

Neurocognitive impairment is one of the most common complications of HIV infection, with serious medical and functional consequences. Valid and reliable assessments of HIV-related cognitive deficits are essential to advance research, yet challenging to implement in many settings where research is most urgently needed given that most existing tests were designed to detect only the severe forms of impairments, have poor psychometric properties, require additional equipment (e.g., stopwatches, pens, test forms) and many require highly trained professionals to administer, score and interpret – resources not readily available in SSA. Mobile technologies offer potent solutions to neurocognitive screening by making testing more accurate and potentially robust (e.g. the timing and direction of trails can be recorded by the tablet compared to the paper-based version of the same test), efficient, affordable, accessible to those who need testing, especially in low-resource settings. Our study provides preliminary evidence for the reliability and validity of OCSPlus, an innovative, domain-specific, and domain-general tablet-based approach to cognition assessment, among a clinic sample of OALWH and their uninfected peers in a low-literacy Kenyan setting. The results show that OCSPlus has promise as a brief cognitive screen in this population, showing good test-retest reliability and convergent validity. Our study also provides an initial understanding of the cognitive performance of older Kenyans by HIV status and the factors associated with the cognitive performance of these adults on the Kenyan coast. Further validation and epidemiologic studies are needed to understand better the utility of the tool and the cognitive function of older adults in the region.

Chapter 7

Integration of key results across the PhD thesis
manuscripts and General Discussion

7.1 Chapter outline and broad discussion points

The extensive use of cART has led to a markedly increased life expectancy in PLWH and, thereby, to a growing population of older adults living with HIV across the world (42). Along with the increasing life expectancy of the population of PLWH, HIV is also increasingly being diagnosed at older ages (32, 33), further contributing to the rise of a sub-population of older adults living with HIV, who have unique health challenges, including late HIV diagnosis, multiple psychosocial challenges, early-onset geriatric syndromes, and multimorbidity (10, 11, 53, 55). Therefore, a better understanding of the factors that influence healthy ageing for OALWH is crucial for designing appropriate programs to address these challenges, especially for those living in SSA, where older people are often neglected. The main objective of this thesis was to contribute to a better understanding of the health and wellbeing of OALWH, more so, their mental, cognitive, and functional health outcomes in a low-literacy Kenyan setting. Using a qualitative inquiry, Chapters 2 and 3 of this thesis provided an understanding of the health challenges that OALWH experience and the coping strategies they use to confront these challenges, respectively. Building on this work, Chapters 4 and 5 then examined the burden and associated factors of CMDs and frailty among OALWH compared to their uninfected peers in the same setting. Chapter Six reports findings on the adaptation and validation of a cognitive screening instrument, OCSPlus, for use among these adults.

The relevance of the current chapter is threefold: first, to synthesize the overall findings from the 5 PhD thesis manuscripts in an integrative way while considering the broader body of literature; second, to present the overall implication of the findings in terms research, policy, and practice; and lastly to highlight the scholarly contribution and methodological reflections of this PhD study.

7.2 Key findings

7.2.1 Perceived biopsychosocial challenges confronted by OALWH on the coast of Kenya

Chapter Two of the thesis provided preliminary insights into the complex health challenges facing OALWH on the Kenyan coast, revealing that these older adults experience a range of physical, mental, and psychosocial challenges. These challenges were predominantly psychosocial and mental health problems, but physical health problems were also discussed. Additionally, many of the perceived risk factors for these challenges, e.g. financial insecurity, family conflicts, and food insecurity, were shown to overlap across the three health domains. Overall, the findings suggest that the priority health concerns for OALWH in Kenya are primarily non-HIV-related. We found little evidence that OALWH were particularly concerned about the effects of HIV on their health or longevity. Most of their health concerns centred around mental and physical wellbeing, which was frequently complicated by several psychosocial challenges, e.g. food insecurity. These challenges were closely intertwined, highlighting the urgent need for cohesive and collaborative responses by different stakeholders to adequately address these issues through age-friendly, multimodal, and multipronged interventions.

Many of the perceived risk factors for the biopsychosocial challenges overlapped across the three health domains suggests that older adults who experience the shared cumulative factors are more likely to have multiple health challenges. Further, it implies that the steps taken to address any or some of the underlying factors are likely to have a preventive spillover effect across multiple domains. Interestingly, some of the mental and psychosocial health challenges (HIV-related stigma, discrimination, poverty, food insecurity, symptoms of common mental health problems) reported by older adults living with HIV in this setting also overlapped with those earlier reported in other sub-populations of PLWH, including adolescents (12-17 years) (48), younger adults living with HIV (18 to 24 years) (47) and general adults (46). Essentially, this implies that similar intervention programmes could be used to reduce shared challenges across different age groups of PLWH. Programmes addressing mental and psychosocial challenges of adolescents and young adults living with HIV (46, 397-399) have been identified in the literature. These programmes include family-strengthening interventions, economic empowerment combined with family strengthening, sensitization of the family and general community, psychoeducation, and cognitive

behavioural strategies such as improved communication, assertiveness training, and informational support.

Beyond the shared mental and psychosocial challenges across the different age groups of PLWH, our findings show that OALWH experience other challenges unique to their age, including ageism, loneliness, caregiving responsibilities, multiple comorbidities (e.g. cognitive, somatic, and functional complaints), and multiple healthcare appointments. Given the unique challenges in these adults, innovative and focused programmes are needed to address their distinct needs. Unfortunately, different reviews of psychosocial, behavioral, and cognitive interventions targeting OALWH demonstrate a significant paucity of programmes in this population (201, 400, 401). Some of the few existing programs include re-engineering systems for primary care treatment of depression, home-based computerized cognitive training programs, cognitive appraisal, coping skills training, identifying and maintaining social support, physical activity counselling to improve physical function, autonomous motivation, depression, and quality of life (201, 400, 401). Nonetheless, most of the interventions have small to moderate effects in improving the psychosocial wellbeing of OALWH, and none of the existing studies originated from SSA (201, 400, 401). Within SSA, programmes to support the financial/economic empowerment of OALWH will go a long way in enabling them to access healthcare services (e.g. transportation costs and other services, such as investigations and routine monitoring), enhance food security in their homes, and help them navigate their caregiving responsibilities such as paying school fees for their dependents.

Health services and systems are also encouraged to utilize evidence-based frameworks to provide effective geriatric care to OALWH in SSA, given the complexity of health challenges facing OALWH (402, 403). At the moment, there are limited data about optimal geriatric models of care for OALWH and limited knowledge of the role of family, friends, and peers in enhancing the optimal components of geriatric models of care on patient outcomes. One clinic in Harare, Zimbabwe, Newlands Clinic, recently implemented an integrated HIV-geriatric clinic model geared towards establishing a differentiated care model for OALWH incorporating the management of chronic

conditions with the assessment of geriatric syndromes and development of personalized care plans which focus on the optimization of intrinsic capacity and functional ability (404). The clinic's geriatric model is based on the WHO's Integrated Care for Older People (ICOPE) guidelines (405). These guidelines represent an innovative, function-centered and person-centered (instead of disease-centered) approach to caring for older people. The comprehensive geriatric assessment in Newlands Clinic assesses physical, mental, and cognitive health, nutrition and dentition, eyesight and hearing, socioeconomic support, e.g. food support and bus fare assistance, mobility, falls and incontinence. Similarly, in Western Kenya, the Academic Model Providing Access to Healthcare (AMPATH) programme, a partnership between Moi University, Moi Teaching and Referral Hospital in Kenya and a consortium of North American Universities led by Indiana University, has collaborated with the Kenyan Ministry of Health to introduce comprehensive care services across Western Kenya (402). The integrated model introduced at AMPATH has reduced healthcare fragmentation (e.g. multiple clinic appointments) while, at the same time, addressing the underlying socioeconomic challenges with programmes such as creating community-based savings and loan groups that enhance access to capital, nutrition support programmes for food insecure adults, starting peer-based care delivery, and creating livelihood opportunities. These efforts are a step in the right direction, and other clinics in similar settings can learn from these programmes.

To the best of my knowledge, our qualitative study is the second in Kenya (171) to explore the health challenges confronted by OALWH directly, and among the few available qualitative studies in SSA (60-70). Many of our findings are consistent with what has been reported previously. However, some findings are unique to this study, e.g. skipping medications when one misses food, the potentially harmful effects of mixing biomedicine and traditional medicine, and high levels of ageism reported in this population. Moving forward, more qualitative studies are required to understand the health challenges in this rapidly expanding subpopulation of PLWH. It is also important that such studies identify and utilize local idioms/concepts of these problems for meaningful investigation. These findings, alongside the growing quantitative data on the burden and determinants of mental, cognitive and functional health problems among

OALWH in the region (129), will guide intervention efforts for OALWH, ideally informed by older adults.

7.2.2 Strategies for improving mental health and wellbeing used by adults ageing with HIV from the Kenyan coast

Older adults living with HIV are increasingly vulnerable to physical, mental, and social health challenges (8, 10, 105). However, intervention research designed to mitigate these challenges is non-existent in SSA (201, 401). Thus, it is unclear how the growing population of OALWH cope and age with HIV in the region given that there are limited transitional arrangements from adult to geriatric HIV care- and most health systems are largely unprepared to support the needs of OALWH (402). In Kenya, most HIV clinics for OALWH are held alongside other adults without any specialized services specific to OALWH. Given this context, it is critical to explore and understand how the expanding population of OALWH is coping with the numerous health challenges and identify areas that need strengthening in their coping mechanisms. In *Chapter Three* of this thesis, I presented the findings of a qualitative inquiry that was conducted to understand the strategies used by OALWH to improve their mental health and wellbeing at the coast of Kenya. Findings from this study reveal that OALWH are able to integrate various coping strategies into their lifestyle to address their mental health and wellbeing challenges. The study also revealed important maladaptive coping strategies among OALWH that have the potential to negatively impact their health and wellbeing if not addressed.

Five key coping strategies emerged from our study, namely self-care practices, social connectedness, religion and spirituality, generativity, identity, and mastery. Of these strategies, self-care and religiosity were the most predominantly discussed. The five strategies developed over time, and their application was associated with improved physical health (e.g. fitness, reduced somatic complaints), mental health (improved emotional states and sleep patterns) and social health (social inclusion, acceptance, disclosure, and improved income) in many of the OALWH. Many of these strategies, especially social connectedness, religiosity, identity and mastery, have been reported in other sub-populations of PLWH (47, 406-408) and the general population of older adults (409, 410); however, they are still emergent themes among OALWH, highlighting the

need for extended research for a more detailed understanding of these issues among OALWH, e.g. how best to maximize these strategies for optimal health outcomes. Given the nature of our study, intervention research will be needed to establish which of these strategies yield maximum and sustained positive effects in this setting. At the moment, the little existing research from outside SSA points to only modest evidence of the effectiveness of some of these strategies in this population (201, 219, 411).

In as much as these findings are promising and emphasize the importance of adaptive coping in the care of OALWH, our study revealed major gaps that need to be addressed to maximize the health benefits of adaptive coping and mitigating maladaptive strategies in this population. For instance, many of the coping strategies in our study, e.g. self-care practices such as physical exercises, were unstructured, irregular, and therefore likely unsustainable. Besides, the common sources of information for these strategies were often trial and error. For instance, some of the women engaged in make-shift weightlifting exercises that may be potentially harmful if not trained on the correct techniques. For OALWH to maximize the health benefits arising from self-care strategies, they need to receive additional knowledge, ideally from their healthcare providers, e.g. which strategies are helpful and when to stop engaging in a particular strategy if it's not working. Unfortunately, this is not the case in many countries in SSA, including Kenya. Most healthcare providers are not equipped to be in a position to build the capacity of OALWH on adaptive coping strategies. This was evident in our study where the providers reported to have insufficient skills and knowledge to handle the health issues of OALWH. This may partly explain why some of the OALWH engaged in maladaptive coping strategies such as skipping medications when they missed meals and mixing biomedical and traditional treatments leading to poor treatment outcomes, reliance on over-the-counter medications and delayed help-seeking. This may also be explained by the lack of community-based support organizations targeting OALWH or older adults in general, forcing OALWH to seek help in the wrong places or engage in unhealthy coping strategies. For meaningful application of coping strategies in this population, healthcare providers need to recognize and appreciate the important contribution of self-care in improving the health and wellbeing of OALWH. To this end, they need to be reoriented or trained on how to meet the unique needs of OALWH, and

after that, help motivate and build the capacity of OALWH and their caregivers to take part in their care actively. This care needs to be structured and regulated to address any challenges that OALWH may experience as they take part in enhancing their health. Other significant barriers, such as HIV-related stigma and ageism, also need to be addressed as they may prevent OALWH from benefiting from available services, e.g. religious and spiritual sources of support.

The research on coping strategies indicates that health status, age, socioeconomic status, and sex are all critical factors that shape and constrain a person's engagement in various health practices (412, 413). In our study, women were more likely to engage in self-care practices than men. This may be related to women's greater knowledge about health and alternative practices and gender socialization that encourages higher responsiveness to illness. Moreover, individuals with higher education levels and income tend to have more health-related knowledge and better access to alternative therapies. In our study, many OALWH delayed seeking help and support due to lack of finances, in which case it led to extended suffering.

Inherent challenges such as ageism and HIV-related stigma also need to be tackled, e.g. through sensitization campaigns in the community and legal frameworks for those found to discriminate or abuse OALWH, as they also prevent some of the OALWH from benefiting from available services, e.g. religious and spiritual sources of support. Some of the OALWH reported living in isolation or avoiding certain services or activities because of stigma and ageism.

To our knowledge, this is the first study in Kenya to explore this construct and among the very few studies in SSA (64, 414, 415). Although most research has focused on the experiences of children, adolescents and young adults living with HIV, our study adds to the growing literature on older adults' engagement with coping strategies. Our findings offer a preliminary understanding of how OALWH cope in the context of limited resources. Interventions intended to improve social connectivity, self-identity and mastery, positive religiosity, and personal capacity may potentially enhance mental health and wellbeing in this context, especially when done in collaboration with the caregivers and providers of OALWH.

7.2.3 The burden of common mental disorders among OALWH compared to their uninfected peers on the Kenyan coast

In *Chapter Four* of this thesis, an empirical cross-sectional study was conducted to measure the prevalence and factors associated with depressive and anxiety symptoms among OALWH aged ≥ 50 years compared to their HIV-uninfected peers at the coast of Kenya. We used locally validated, interviewer-administered, self-report measures of depression (88) and anxiety (89). Findings show that the burden of moderate and severe CMDs among older adults is low in this setting; however, both OALWH and their HIV-uninfected peers have a similar relatively high burden of mild anxiety and depressive symptoms.

The prevalence of moderate depressive and anxiety symptoms (cut-off of ≥ 10) among OALWH was found to be 3% and 2%, respectively. These estimates are below those reported in our systematic review of mental health outcomes among OALWH aged ≥ 50 years within SSA (129). These findings are also inconsistent with what is frequently observed in HICs (105). Our finding that depressive and anxiety symptoms were similar between OALWH and their uninfected peers is supported to some extent in the extant literature among OALWH within SSA (129); however, it is inconsistent with what has been reported among young adults living with HIV in the same region (92) and what has been frequently reported outside SSA (105). In our 2021 review, we identified six studies (199, 242, 253, 416-418) that compared the prevalence of depression among OALWH and a group of HIV-uninfected peers. Similar to our findings in the cross-sectional study, four of these five studies did not find a significant difference in the reported prevalence of depression between OALWH and their uninfected peers. In contrast, the remaining two studies reported significantly lower prevalence of depression among OALWH than their uninfected peers.

Our finding of no significant differences in the prevalence of CMDs between OALWH and their uninfected peers was not a surprise, considering the findings of our 2021 review (129). Our results add to the accumulating body of research demonstrating similar or improved physical and mental health outcomes among OALWH in SSA,

compared to their uninfected peers (253, 418, 419). The mechanisms responsible for this observation need further study but may include positive spillover effects of HIV programs, e.g. enhanced psychosocial support and comorbid health conditions, survivorship bias among those who access HIV care, and the direct effects of cART on HIV replication, inflammation, and downstream disease pathophysiology. Evidence from qualitative and cohort studies demonstrate that a longer duration of ART is associated with reductions in internalized stigma, which could also contribute to observed attenuation of CMDs symptom severity (420, 421). Relatedly, the normalization of knowledge of one's HIV status could also explain this observation, as demonstrated in the results of *Chapter Three* on the coping strategies used by OALWH to enhance their mental health and wellbeing (160). These findings also give a striking contrast to what is predominantly reported in HICs (105, 422, 423). This discrepancy suggests contextual differences in the drivers of CMDs across settings, including the role of engagement in HIV care among those with and without HIV, differences in healthcare systems, formal and informal support systems, mental health resources and profile of OALWH which may alter the risk profile of these adults.

While the difference between OALWH and their uninfected peers was an important focus of this analysis, our results also highlight a low prevalence of CMDs in our study setting compared to other studies of OALWH in SSA (129) as well as younger populations of PLWH (92, 183). In comparison to younger populations of PLWH, OALWH may have the benefit of "experience" or hardiness/resilience or grit than young PLWH given the longer duration of living with HIV and having survived a very traumatic period in the early years of the HIV epidemic. This observation could also be explained by survival bias – in that OALWH who have survived this long may have developed ways of coping with stressors (as demonstrated in our *Chapter Three* findings where many OALWH were able to integrate several strategies to cope with mental health challenges) in comparison to those who may not have been able to cope. Further inquiry is needed to explore to what extent the psychosocial services being offered at HIV clinics benefit older adults versus young adults. In my qualitative findings in *Chapter Three*, it came out strongly that morning talks (which included psychoeducation, opportunity for mentorship and prayers) and the usual camaraderie at the HIV clinics

was an essential source of support for OALWH, sometimes resulting in some to walk several kilometres to access this support opting to forgo services at clinics closer home in order to receive this support.

The limited number of comparative studies, less focus on anxiety and inconsistent findings relating to anxiety disorders make it difficult to compare and contrast our findings on anxiety symptoms directly. In the discussion of our 2021 systematic review (129), we recommended additional studies focusing on anxiety disorders among OALWH in SSA. The empirical study, reported in *Chapter Four*, was indeed timely in bridging this gap. It compares the burden of CMDs between older adults living with and without HIV on the Kenyan coast, focusing on depressive and anxiety symptoms. From this study, a need for psychosocial interventions at the family, community and clinic levels was identified to reduce the risks of mild symptoms of CMDs that were relatively high and known to be debilitating. Our findings also highlight the importance of integrating and implementing mental health screening services as part of the comprehensive geriatric care of OALWH, and older individuals more generally, on the Kenyan coast. This will be important in promptly recognizing those at risk of mental health problems and quickly initiate treatment and referral services for further management.

A range of factors are significantly associated with elevated odds of CMDs among OALWH on the Kenyan coast. Most of these factors are psychosocial factors, including HIV-related stigma, ageism, loneliness, functional disability, sleeping difficulties and higher household HIV burden. Virtually all of these factors were also raised as essential challenges in the qualitative inquiry with OALWH in *Chapter Two*. In *Chapter Four*, these factors increased the odds of CMDs among OALWH. Properly addressing CMDs among OALWH will need prioritizing of those at risk for mental health screening to enable prompt detection, management and referral along the care pathways. Most of these factors are modifiable with proper psychosocial programs, e.g. enhancing social networks, stigma/ageism sensitization campaigns, and comprehensive geriatric assessment implemented at the family, community, or clinic levels. Besides psychosocial factors, chronic fatigue and advanced age (>70 years) were also shown to

be significantly associated with higher odds of CMDs among OALWH, further highlighting the profile of OALWH at risk of CMDs and the need for them to be prioritized in mental health screening for early treatment. Easier access to HIV care was the only protective indicator against CMD among OALWH. In the qualitative inquiry reported in *Chapter Three*, easier access to HIV clinics, e.g. through support with fare to attend routine clinic appointments, was an important pillar of support amidst the challenges that OALWH confronted. Therefore, programs intended to increase access to services should be incorporated as part of the interventions addressing CMDs in OALWH.

Although the current work focused mainly on OALWH, the drivers of CMDs among HIV-uninfected older adults cannot be ignored. From available data, loneliness, sleeping difficulties and medication burden were significantly associated with elevated odds of depressive symptoms. In contrast, greater sedentary behaviour and higher monthly income were significantly associated with lower odds of depressive symptoms in these adults. Though more research is needed for further understanding of the determinants of CMDs among older adults in the general population (to accurately inform the planning of interventions), for a start, programmes that enhance social networks, promote good sleep, promote economic empowerment, and address older adults' pressing health needs are likely to improve their mental wellbeing.

When investigating the factors associated with CMDs among OALWH in the empirical quantitative study reported in *Chapter Four*, we found that none of the HIV-associated clinical factors was significantly associated with CMDs. In the current era of cART treatment for all PLWH regardless of CD4 count (424), the HIV care that OALWH receive at their respective clinics likely promotes better HIV outcomes, thus the reduced likelihood of having mental health challenges due to inadequate treatment and care. All of the OALWH in the empirical quantitative study were on routine HIV care, and the majority (95%) had disclosed their HIV status. Most (98%) of the OALWH had achieved viral suppression. Nonetheless, further studies are needed in this area given the limited number of studies among OALWH in SSA as a whole (129).

7.2.4 The burden of frailty among OALWH compared to their HIV-uninfected peers on the Kenyan coast

Frailty, one of the most common geriatric syndromes, is a significant public health priority (81, 98). Its occurrence is frequently associated with adverse health outcomes such as elevated disability, dependency, delirium, falls, longer durations of hospitalization, higher rates of institutionalization and mortality (137-140). Research predominantly carried out in HICs (101, 128), has documented a higher burden of frailty among OALWH, as well as an earlier presentation; hence efforts to understand this outcome and provide better services to a population with specific needs are already underway (81, 425). Unfortunately, within SSA, where more than two-thirds of OALWH reside, there are very few studies examining frailty, and there is limited awareness in the health and social services addressing this problem (129). The cross-sectional study (*Chapter Five*) that measured the prevalence and factors associated with frailty among OALWH aged ≥ 50 years and their HIV-uninfected peers bridges this gap in Kenya. Findings from this work reveal that the prevalence of frailty among OALWH (24%) is significantly higher compared to their uninfected peers (13%).

To the best of my knowledge, this study is the first in Kenya and the fourth in SSA to examine frailty among OALWH (129, 132). The prevalence estimate reported in our study is higher than that reported in the earlier studies: 9% in Ethiopia (132), 3% in Tanzania (426) and 18% in South Africa (336). The variation of the prevalence estimates of frailty among OALWH in SSA is consistent with findings outside SSA, where the prevalence of frailty has been shown to be highly variable, both between countries and between populations within a country, partly because of the differences in population studied as well as the frailty measures used (101, 128). In our study, we used the Reported Edmonton Frail Scale (332) to assess frailty among OALWH, given its brevity, ease of administration, and potential for clinical utility. In contrast, the Tanzanian cross-sectional study used three frailty tools: the Fried frailty phenotype (427), Clinical Frailty Scale (428) and Brief Frailty Instrument (429) to assess frailty, while the Ethiopian cross-sectional study utilized the Brief Frailty instrument. The South African population-based study used a modified version of the Fried Frailty Index. The

difference in measures and study populations could explain the variation in frailty prevalence estimates. This calls for country-specific studies of frailty in order to adequately investigate this outcome to guide appropriate intervention efforts. Older adults are a highly heterogeneous group with different medical profile, biological and social environmental factors, further emphasizing this point. The finding of a higher prevalence of frailty among OALWH compared to those without HIV in Kenya is consistent with research conducted in HICs (425). In this study, however, HIV seropositivity was not independently associated with frailty after adjusting for biopsychosocial factors, potentially highlighting the importance of other, non-HIV-related factors in this elevated risk.

My study also documented several factors that were significantly associated with higher odds of frailty among OALWH in the study setting. Similar to our findings on CMDs in *Chapter Three* of this thesis, most of these were psychosocial factors, including sleeping difficulties, ageism, and visiting traditional healers. All of these factors also came up in our qualitative inquiry in *Chapter Two*. Besides psychosocial factors, this study also identified biomedical factors that were associated with higher odds of frailty among OALWH, including higher waist/hip ratio (a surrogate measure of central obesity), self-reported diabetes, HIV treatment change or interruption and prolonged illness following HIV diagnosis. The findings in the present study highlight the importance of promoting early geriatric screening in OALWH to enable early detection and management of frailty in this population. There is some evidence from HICs suggesting that frailty is a potentially modifiable dynamic process, implying that specific interventions and health strategies could be applied to prevent, delay, or even reverse this condition (425). In a previous US study, higher education, employment, younger age, reduced comorbidity, higher CD4 nadir (>500 cells/ml), absence of a prior AIDS diagnosis and HIV virologic suppression were associated with reduced frailty progression and greater recovery from frailty (430). Many of the risk factors identified in our study, e.g. ageism, sleeping difficulties, visiting traditional healers, prolonged illnesses following HIV diagnosis, self-reported diabetes, and central obesity, are potentially modifiable with appropriate programs. Early HIV diagnosis and initiation of treatment, proper management of comorbidities such as diabetes and obesity,

engagement of traditional healers with biomedical treatment to maximize patient outcomes, and inclusion of psychosocial interventions in the care and treatment of OALWH could go a long way in mitigating the effects of frailty in this population. There is also growing consensus that interventions targeting the physical phenotype, e.g. mobility, strength, balance, nutrition, and physical activities, may potentially offer an opportunity to prevent, delay or reverse symptoms of frailty (431, 432). Living in large households, having higher income, having friends, having light physical activities and being male were significantly associated with reduced odds of frailty among OALWH in our study. Several of these factors, such as higher income, social network of friends and physical activities, were also identified as important coping strategies in the qualitative inquiry in *Chapter Three* of this thesis. Therefore, the incorporation of these factors as elements of interventions addressing frailty in OALWH will go a long way in mitigating frailty in this population.

The moderately higher prevalence of frailty among older adults without HIV cannot be overlooked. Studies documenting frailty among older adults in the general population in SSA are also scanty. The few available studies are concentrated in South Africa (305-308), Tanzania (311-313), Ghana (307, 308), Nigeria (314), and Burkina Faso (315). The correlates of frailty in these adults need to be documented and addressed. Though my study was primarily focused on OALWH, I attempted to examine this outcome among these adults. From the available data, sleeping difficulties, self-reported diabetes and light physical activities were associated with elevated odds of frailty in this population. Conversely, similar to OALWH, being male was significantly associated with reduced odds of frailty among these adults. Though further research is needed to articulate this outcome in the region, to accurately inform proper intervention planning, for a start, programs designed to promote better sleep management are likely to benefit these adults in mitigating frailty. The role of physical exercise needs to be studied further as it is inconsistent with previous research.

7.2.5 Local validation of the Oxford Cognitive Screen Plus tool among older adults

Cognitive health is an essential dimension of wellbeing in old age, but very few studies have investigated this outcome in SSA. One of the key hindrances to cognitive health research in SSA is the inadequacy of optimal measurement tools suited for LMICs (433). Most of the available cognitive health instruments have been developed and validated in HICs and may not be directly applied for clinical or research use in SSA. The use of such cognitive instruments outside HICs would need adequate adaptation to the new setting before being applied. An alternative would be for researchers in LMICs to develop cognitive health measures from the beginning, but this is usually resource and time constraining. In *Chapter Six* of this thesis, I present the findings of an empirical study that was conducted to adapt and psychometrically evaluate the Oxford Cognitive Screen Plus measure. The adapted measure was utilized to examine the neurocognitive function of OALWH and their HIV-uninfected peers. Our findings demonstrate the initial feasibility of adapting cognitive health measures developed in HICs for use in SSA using recommended steps (434) and that this locally adapted instrument holds promise for use in the study setting given its moderate levels of reliability and acceptable convergent validity. Our preliminary work sets the scene for further adaptation and validation of the tool in similar settings to address some of the limitations observed in the current study such as lack of OCSPlus norms, and borderline reliability coefficients. Future inquiries are also needed to establish the construct validity and other forms of reliability of the tool as they were not examined in this study.

To the best of my knowledge, this is the second study in SSA to locally validate the OCSPlus among older adults in general (147) and the first study in SSA to validate the OCSPlus tool among OALWH, hence setting the stage for future corroboration of the current findings. Our findings are in part consistent with the earlier validation of OCSPlus in South Africa (147), confirming the tools' convergent validity among low-literacy, low-income populations in SSA. Our findings also provide preliminary evidence of the tool's reliability (with moderate test-retest results) in the region. A larger sample, statistically powered to confirm the tool's internal and external validity, is essential for

the tool's scale-up. Currently, we lack normative performance data on the tool, making generalization of performance difficult. The validation of OCSPlus in my thesis was the first effort from SSA to adapt and validate cognitive screening measures suitable for the growing population of OALWH. None of the existing screening tools for HIV-associated neurocognitive impairments has been validated among OALWH in the region (374). Besides, most of the available screening tools for HAND in the region have inadequate psychometric properties, pointing out the need for further validation of existing tools and the development of new ones suitable for the changing patterns of neurocognitive function and possible impairment among OALWH. The adaptation and validation of OCSPlus in Kenya was thus timely in addressing this gap.

When OCSPlus was used to assess the cognitive function of older adults ≥ 50 years, OALWH presented with significantly lower cognitive scores on language and executive function compared to those without HIV; however, OALWH performed better in the memory domain. The OCSPlus evaluates multiple domains of cognitive function, and some of these domains may be sensitive to HIV-related brain changes. Our findings are generally consistent with what has been reported in HICs (435). Apart from our cross-sectional study, only one other study, a population-based cross-sectional study from rural South Africa, has evaluated cognitive function in OALWH using the OCSPlus. Our findings differ from the South African study that observed no significant differences in cognitive function by HIV and ART status. This difference may be attributed to differences in the profile of OALWH, conventional tools used, or other contextual differences. These observations call for more research to provide an in-depth understanding of the cognitive function of OALWH in the region. Several factors ranging from sociodemographic (sex, age, educational levels, income, household size and asset index), psychosocial factors (ageism, food insecurity, sleeping difficulties, seeking treatment from traditional healers), behavioural/lifestyle (physical activity, and sexual activity) to biomedical factors (obesity, urinary incontinence, hearing problems, history of tuberculosis, ART regimen change, being on 3rd line ART) were significantly associated with cognitive function among OALWH. Several of these factors were identified in qualitative inquiry (*Chapter Two*) of this thesis. Many of the factors are potentially modifiable and hold promise for promoting cognitive health. At the coast of Kenya,

several biopsychosocial factors influence the cognitive function of OALWH, suggesting the need for multicomponent interventions e.g. nutrition, cognitive training, cognitive rehabilitation, physical exercise, frequent social activity (436) to prevent, delay and mitigate cognitive impairment in this population. To date, we are not aware of any intervention research addressing cognitive impairments in OALWH in the region.

7.3 Scholarly contribution and Methodological reflections

My PhD study has addressed a critical research area on HIV and ageing in Kenya among a sub-population that is mostly neglected in research, policy, and practice. As much as mental, cognitive, and functional health outcomes are central to the healthy ageing of OALWH (437), quality research on the lived experiences of these adults and the burden and determinants of these outcomes is alarmingly scarce in SSA, and some of the available evidence appears mixed (129), emphasizing the need for more research on these issues in line with the WHO's global strategy and action plan for ageing and health (202). The region has witnessed some notable progress in the generation of quantitative data to characterize ageing and health, such as the Ibadan Study of Ageing in Nigeria (438), Health and Ageing in Africa, a longitudinal study of an INDEPTH community (HAALSI) in South Africa (439) and the World Health Organization Study of Global Ageing and Adult Health (SAGE) (440). Yet, there is still a need for more diverse research and national and sub-national studies in the context of HIV, given the lack of research in this area. For instance, few studies exist on anxiety disorders and frailty among OALWH in the region. Moreover, the correlates of mental, cognitive and functional health outcomes among OALWH have been investigated, and those examined are mostly sociodemographic, many of which are inconsistent (129). Many of the existing studies are also characterized by several weaknesses, including small sample sizes, varied age definitions and heterogeneous comparison groups, which limit the generalizability of existing findings and intervention planning efforts (129). To my knowledge, no study in Kenya has described the burden and determinants of these outcomes.

In this sense, my PhD work is timely in addressing some of the existing gaps in research on HIV and ageing outcomes and sets the stage for further work on this area

and the design of appropriate interventions to prevent, delay, and mitigate the health challenges confronted by OALWH in this setting. Unlike previous studies, my PhD work combined qualitative and quantitative methodologies to understand the challenges of ageing with HIV and coping strategies used by OALWH to confront these challenges and subsequently quantify the burden of CMDs and frailty among OALWH aged ≥ 50 years compared to a similar group of HIV-uninfected peers; and preliminarily adapt and validate a measure of cognitive function, the OCSPlus, to examine the cognitive function of OALWH aged ≥ 50 years compared to their HIV-uninfected peers at the coast of Kenya. The mixed methods design provides a holistic account of the burden and underlying factors of the studied outcomes. Apart from the OALWH themselves, the findings from the qualitative phase provided an account of how the health and wellbeing of OALWH is perceived by different stakeholders (informal caregivers and healthcare providers) and an understanding of the processes that generate risk and protective factors for mental, cognitive and frailty outcomes. Understanding such processes and circumstances played a complementary and explanatory role in various findings in the subsequent quantitative study on the prevalence and factors associated with CMDs, frailty, and cognitive function among OALWH.

This study was implemented in SSA, specifically in the coastal region of Kenya. SSA is a unique setting characterized by a high HIV burden and is currently experiencing a rapid ageing of its population, including OALWH. Nonetheless, the health issues of older adults are rarely prioritized in this region, and many of the health policies on older adults are seldom implemented (21). Stigma, discrimination, elder abuse, and poverty are pervasive (20, 22, 23, 441). These disparities are likely to play a crucial role in terms of the experience and healthcare modalities for both HIV as well as the mental, cognitive, and functional health outcomes of these adults. My PhD work is timely as it contributes to the increase of the much-needed body of evidence in an area that little is known about, i.e. HIV and ageing in Kenya and the region at large. Further strengths of this work include the inclusion of a comparative group of HIV-uninfected older adults and the use of locally adapted/validated measures.

Nonetheless, the studies included in this PhD do have some methodological limitations which should be considered in the interpretation of the presented findings. To begin with, the qualitative study in *Chapters Two and Three* was only conducted in a single geographical area of the Kenyan coast (Kilifi County). Relatedly, most of the participants in the quantitative arm of the study (*Chapters Four, Five and Six* of the thesis) were recruited from Kilifi County. Specifically, only 72 OALWH were recruited from Mombasa; the rest of the participants were recruited from Kilifi County. This was caused by the onset of the COVID-19 pandemic, which interrupted our participant recruitment and assessment in Mombasa County. Research activities had to be halted in light of the health and safety protocols instituted during the extended period of the pandemic. These circumstances also limit the generalizability of the study findings across the two study settings.

Secondly, all the empirical studies in *Chapters Four to Six* of the thesis were of cross-sectional design, which is known to possess some forms of bias, including social desirability and recall biases (442). In these studies, we utilized self-report measures, which may be subject to self-report bias (442). Also, given the cross-sectional nature of our studies, it was not possible to make conclusions on causality or direction of associations for the risk and protective indicators for CMDs, frailty and cognitive function reported in this thesis. Nonetheless, our empirical cross-sectional studies provided useful preliminary data for guiding policy and intervention efforts in the prevention, promotion, care, delay, care or management of mental and cognitive health impairments and frailty among older adults in SSA, particularly on the Kenyan coast, and more so those ageing with HIV.

7.4 Implications of study findings for future research, policy, and clinical practice

Despite the observed drawbacks, this thesis bears crucial implications for further research, policy, and clinical care of OALWH, as highlighted below.

7.4.1 Implications for further research

The qualitative study in my thesis was the first in SSA to directly interview OALWH, in addition to their caregivers and health care providers, about the biopsychosocial

challenges that OALWH face and the strategies they use to confront the challenges in the context of limited resources. I recommend additional studies of this design in SSA to enhance our understanding of the physical, mental, and psychosocial health and wellbeing of adults living with HIV as they transition to older ages and confront the realities of ageing with HIV. Qualitative methodologies will also provide crucial insights into the lived experiences of these adults as they are affected by their intrinsic capacity (cognition, psychological health, mobility, sensory and vitality) and the external environment (437). Local conceptualizations of these issues (e.g. noting and using local terms and idioms) would be important in studying this topic and are recommended as an initial step. In our qualitative research, it was pointed out that OALWH who sought the services of traditional healers were more likely to present with poorer health outcomes. This reality was corroborated in our quantitative arm of the study, where it was demonstrated that OALWH who sought the services of traditional healers, were at higher odds of being frail and were also associated with lower cognitive scores. Future studies can try to examine the scope of traditional healers, why OALWH visit these healers and explore how traditional medicine and biomedicine can co-exist and complement each other to maximize the health and wellbeing of OALWH. Further research can also include older adults without HIV to compare and contrast their health and wellbeing perspectives to those of OALWH, as this was not done in the present study. Additionally, we did not separate OALWH and their carers in our qualitative study due to constraints in time and resources. Future studies will do well to explore these groups separately and provide a deeper understanding of their unique health challenges and needs.

Findings of this PhD show that OALWH from the coastal region of Kenya, compared to those without HIV, have a higher burden of frailty. Additionally, OALWH also have a relatively high burden of mild symptoms of CMDs. Given that CMDs are rarely detected but can have serious health impacts on older people, it is important to assess for mild, moderate, and severe levels to get a comprehensive picture of the scale of the problem (251). Emphasizing only severe CMDs would leave many undiagnosed, untreated and at elevated risk of multiple morbidities. Prospective evidence suggests that assessment of CMDs, even mild levels in older adults, may have utility in predicting health declines,

e.g. cognitive health decline (251). Our findings on frailty and CMDs were complemented by our results from the qualitative inquiries where OALWH were reported to have numerous physical, mental, and psychosocial challenges.

Our results call for urgent testing of potential interventions addressing CMDs, frailty and promoting cognitive function among OALWH in this or similar settings within the SSA region, as the majority of OALWH live here. Such interventions and programs need to be older-adult friendly, transdiagnostic (to mitigate the numerous co-occurring mental, cognitive, and functional health problems) and have several contextually relevant elements that are based on known models of care. These interventions should leverage existing technological advancements and care delivery models that do not only rely on mental health experts but also consider other innovative models, such as task sharing and task-shifting, to increase access to these services in the region, given the enormous human resource gap in the region.

Given the emergent nature of HIV and ageing in the region, I would recommend more studies to investigate the burden and determinants of mental, cognitive, and geriatric syndromes in this population in the region. Our quantitative study in *Chapter Six* did not quantify the prevalence of cognitive impairment among the participants. As a whole, more research is still much needed to understand the burden of mental and cognitive health impairments and frailty among older adults living with HIV in this setting as well as provide important normative data, which would then allow for prevalence estimates. This is especially important as the emerging reports show contrasting findings within the region and when compared to those in HICs.

From the quantitative arm of thesis, three HIV-associated factors were significantly associated with some of our outcomes of interest (frailty and cognitive function but not CMDs) among OALWH. These factors were HIV treatment change/interruption, prolonged illness following HIV diagnosis and being on a third-line ART regimen. Previous studies on this subject from SSA report conflicting associations between HIV-related clinical factors. I therefore suggest further studies to be carried out in Kenya and the rest of SSA to gain a better understanding of the association between HIV-

associated clinical factors and cognitive, mental, and functional outcomes among OALWH in the current era of effective cART.

Our empirical quantitative studies identified numerous factors, largely psychosocial, that were associated with CMDs, frailty and cognitive function among OALWH at the coast of Kenya. Many of these factors e.g. sleeping difficulties, HIV-related stigma, and ageism, overlapped between symptoms and outcomes (e.g. CMDs and frailty). Essentially, this implies that addressing or targeting these shared risk indicators could improve multiple outcomes among OALWH. Additionally, our findings also suggest the presence of psychosocial phenotype that disproportionately impacts OALWH in this setting – hence emphasizing the need for specific targeted interventions. Future studies could assess the feasibility and potential effectiveness of transdiagnostic psychosocial interventions such as the WHO developed problem management plus intervention in this setting.

The cross-sectional design of our study precludes any conclusions on causality. Additional studies of appropriate design, such as longitudinal study design, will go a long way in establishing the cause-effect relationship as well as discern the dose-response association or rule out reverse causality for the observed associations reported in this PhD study. Our observation of a higher proportion of individuals who were separated/divorced and caring for a sick family member in the OALWH group was notable. Future studies could explore this further, particularly as it relates to resilience and loneliness when compared to individuals without HIV.

Although this PhD work focused mainly on OALWH, our findings also exhibit a relatively high burden of CMDs and frailty among older adults without HIV. The sample size of HIV-negative adults was relatively smaller, and the data collected from this group was not designed to comprehensively examine the correlates of CMDs, frailty and cognitive function. Hence, there is a need for additional studies to comprehensively examine the burden and drivers of these outcomes in the general population of older adults without HIV to guide their care adequately.

Notably, sleeping difficulties were associated with higher odds of both CMDs and frailty in the quantitative analyses. We recommend follow up studies, especially longitudinal designs, to better understand the nature of sleep disturbances, given the large effect

sizes and wide confidence intervals in our study. Given the difficulties in measuring sleep disturbances (443), implementing more biometric measures of sleep could be a valuable next step before assessing the feasibility of potential interventions in the study setting.

As data on ageing and health increases across SSA, investigators could also consider combining datasets and explore future hypotheses. Combining datasets will increase the sample size of participants and enable the study of important research questions, detect clinically significant changes, and also increase generalizability of findings. Nonetheless, this will need harmonization of tools so as to reduce potential heterogeneity and increase the researchers' choice of variables.

7.4.2 Implications for policy and clinical practice

According to the results from the qualitative phase of this PhD study, OALWH experience certain health challenges that are unique to their stage in the life course, such as ageism, loneliness, financial and food insecurity, multimorbidity and geriatric syndromes. Many of these factors, such as ageism and loneliness, were also corroborated in the quantitative phase of the study. In this sense, OALWH need to be recognized as a unique sub-population in need of targeted health and social services within the HIV care continuum to meet their special needs adequately. At the moment, the care of PLWH in the study setting is not age-differentiated, e.g. adolescents, emerging adults, general adults, and older adults. This structure is likely to disadvantage those in need of unique services such as the OALWH. For this reason, I recommend the disaggregation of PLWH into different age cohorts, including that of OALWH ≥ 50 years, to start highlighting and addressing their unique needs.

Relatedly, the current structure of HIV services in the study setting is not optimal for the needs of OALWH, as observed in our study. For instance, many of the healthcare providers we interviewed confirmed that they did not feel adequately trained (both prequalification and on the job training) to handle the complex health issues of OALWH in the study setting. The HIV clinics did not have any geriatric specialists, and the chronic care services, e.g. diabetes, hypertension, and psychiatric care, were not integrated, forcing the affected OALWH to have multiple healthcare appointments to

receive the necessary care. In part, this may have made some of the OALWH to rely on over-the-counter medications (perhaps because medications are the only available options to them) or wait for the symptoms to run their course while doing nothing (perhaps because of inadequate treatment or financial difficulties to access the relevant services) and seek for support from traditional healers, which was often associated with poorer health outcomes. To this end, I recommend that all healthcare providers of OALWH need to receive further training on the unique needs of OALWH through, e.g. continuous medical education, conferences, and workshops for them to confidently discharge their duties and champion optimal health outcomes in these adults, at least in the short term. In the long-term, however, policymakers need to advocate for the training of more geriatric specialists who are extremely scarce, with the few existing geriatricians in Kenya (and much of SSA) located in major cities. There is also a need for HIV care guidelines to be updated to recognize and capture the needs of OALWH, as the current guidelines are silent on this issue. One way to do this is by integrating the chronic care services for the affected OALWH to avoid multiple clinic visits. The services offered in the HIV clinics also need to be older-adult friendly, e.g. sensitive to how healthcare providers talk to and engage these adults. In our qualitative inquiry findings in *Chapter Two*, it was reported that some of the healthcare providers scolded and insulted OALWH, especially when they missed their clinic appointments or mixed up their HIV and non-HIV medications.

Different geriatric models of care have been recommended in HIV literature for the optimal care of OALWH (403). The utility of these models in SSA is limited, and there is inadequate understanding of the role of family, friends, and peers (i.e., informal care) in supporting the geriatric care of OALWH. As much as more research is required to determine the impact of optimal components of these geriatric models, especially in SSA, any model adopted should encourage the holistic care of these adults. One important element of these models is the comprehensive geriatric assessment, which comprises the identification of physical, mental, and psychosocial needs and the development of an integrated care plan to meet those needs. As my PhD work has shown, OALWH face numerous challenges, and an important step would be to put in place a comprehensive geriatric assessment plan. The locally adapted tools in this

study and previous studies in the setting can go a long way in helping to achieve this. Formative work is, however, required to examine their clinical utility following their research adaptation and validation. Also, policymakers need to examine the care pathway so that after the geriatric assessment, there are adequate mechanisms of support for these adults. The Kenyan government, through the Ministry of Health, already recommends the screening of depression in HIV clinics. Nonetheless, as noted in our qualitative study findings, this is rarely implemented in most HIV clinics. The obstacles to implementation need to be explored and addressed to improve uptake. Considering the health challenges facing OALWH, e.g. multiple conditions that co-exist, I would urge policymakers to consider including cognition, frailty, anxiety, and other aspects of comprehensive geriatric assessment as part of the guidelines. Screening priorities can be considered among OALWH at greater risk, such as those experiencing ageism, HIV-related stigma, loneliness, those with multimorbidity and those having suboptimal treatment adherence.

In our qualitative findings in *Chapter Three*, OALWH demonstrated the use of multiple strategies to enhance their mental health and wellbeing. While this is encouraging and highlights the critical role of actively involving OALWH in their care, our study also found maladaptive self-care strategies such as visiting traditional healers and reliance on over-the-counter medications. Many of the strategies resulted from trial and error, lacked structure, and were applied infrequently or not at all and did not result in positive health outcomes. Our finding highlights the need for OALWH to be capacitated, together with their caregivers, on how best they can undertake self-care/coping strategies, bearing in mind the extensive lack of resources in the region. Ideally, this should trickle down from providers who are themselves equipped on how to handle the unique needs of OALWH.

Relatedly, in this PhD work, visiting traditional healers was associated with poorer outcomes in both the qualitative and quantitative arms of the study, highlighting an important research and policy/practice gap. Previous research in SSA shows that traditional medicine is common among PLWH; however, our findings are the first in Kenya among OALWH. In a recent study in South Africa, out of 516 OALWH, about 16%

utilised traditional medicine, and the major reasons for its utilization included the perception of receiving better healthcare services and payment flexibility with goods instead of money (444). Taken together, these findings suggest that traditional healers interact with PLWH, including OALWH, across the HIV continuum in SSA, and there is a need for collaboration between traditional healers and biomedical health providers and facilities to maximize the health and wellbeing of OALWH. As a first step, the scope of traditional healers need to be identified, and consultative meetings held to understand how best to complement each other in the care of these adults. Existing frameworks for the incorporation of traditional healers into the national healthcare systems can be used as a model in Kenya (445).

My qualitative study also highlighted an array of psychosocial challenges that OALWH experienced, and some of these challenges were associated with elevated CMDs and frailty and cognitive function among OALWH. Some of these challenges confronted by OALWH are similar to those faced by other age groups of PLWH, such as adolescents and emerging adults in the study setting; hence, they can be addressed by the adaptation and implementation of previously identified programs (46, 446, 447). There is still scope for targeted psychosocial interventions unique to older adults living with HIV, given the dearth of research on this subject in SSA (201). Our data goes a long way in informing the development of preventive and treatment strategies in the study setting and similar contexts. Targeting psychosocial elements e.g. social support and stigma for those with mild symptoms of depression and anxiety for instance is crucial as they may have a larger impact than other more 'biological factors.'

7.5 Conclusion

This thesis has presented work from two empirical studies into the physical, mental, and psychosocial wellbeing of older adults ageing with HIV on the Kenyan coast. In the first study, a qualitative inquiry, I have presented the biopsychosocial challenges confronted by OALWH and the coping strategies they use to improve their mental health and wellbeing. In the second study, a cross-sectional descriptive study, I present the prevalence and correlates of CMDs and frailty, as well as the cognitive profile of

OALWH compared to a group of HIV-uninfected older adults. Findings from the qualitative phase of the study show that OALWH are vulnerable to physical and mental health problems that appear to be complicated by a range of psychosocial challenges. Our findings also present a picture of OALWH, who utilize several strategies in an attempt to address their mental health and wellbeing challenges. Using locally adapted measures of CMDs, our findings show that both OALWH and their HIV-uninfected peers have a similar, relatively high burden of mild depressive and anxiety symptoms. However, OALWH have a significantly higher burden of frailty compared to their HIV-uninfected peers. Our cross-sectional study also identified several correlates of CMDs, frailty and cognitive function among OALWH, many of which were also corroborated in the qualitative inquiries. We also demonstrated the feasibility of OCSPlus administration by trained laypersons, its reliability, and its validity among low-literacy older adults on the Kenyan coast. Overall, the findings from this thesis emphasize the urgent need for prioritization of research and interventions on physical, mental, and cognitive function among older adults living with HIV on the Kenyan coast. Given the emergent nature of this subject in Kenya, our findings provide an important roadmap for further investigation and preliminary intervention efforts to mitigate the risks of physical, mental, and cognitive problems identified. Future work in this setting or similar one in SSA should focus on the cause-and-effect association of the reported correlates and carry out formative work on the feasibility of potential interventions, e.g. reduce CMDs, and improve frailty symptoms. In doing so, we can improve the lives of older adults living with HIV at the Kenyan coast.

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Appendix

Ethics Approval

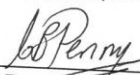
UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG



R14/49 Mr Patrick Nzivo Mwangala

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M220544

NAME: Mr Patrick Nzivo Mwangala
(Principal Investigator)
DEPARTMENT: School of Public Health
KEMRI-Wellcome Trust Research Programme
Kilifi Kenya
PROJECT TITLE: Ageing with HIV: Psychological Wellbeing and its
biopsychosocial determinants at the Kenyan coast
DATE CONSIDERED: 27/05/2022
DECISION: Approved unconditionally
CONDITIONS:
SUPERVISOR: Prof A. Abubakar, Dr R. Wagner and Prof C. Newton
APPROVED BY: 
Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL: 30/06/2022

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the Third Floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.** The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in **May** and will therefore be due in the month of **May** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature

Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

In-depth interview guides

1. In-depth Interview– Adults living with HIV, Healthcare Providers and Primary caregivers

- Greet the participant
- Introduce yourself
- Give background information about the study
- Carefully read through the informed consent form and answer any questions.
- Assure that the participant that s/he does not have to participate if s/he does not want to
- Tell the participant that s/he can stop the interview any time s/he wishes
- Assure confidentiality
- Give information about the interview/Explain the ground rules (length of the interview, active participation, all responses are welcome)
- Ask for approval to participate in the interview
- Make sure the participant knows what the tape-recording procedure is. Ask for approval.
- Ask if the participant has any questions before the interview
- If the participant agrees to take part please ensure s/he signs two copies of the consent form, give him/her a copy and keep one copy for our records.
- Check the tape-recording equipment
- Start the interview
- At the start of the interview, DO NOT record respondents name or any identifier;

For older adults living with HIV indicate:

- *the venue, date and time of interview*
- *gender, age, educational level (years in school), employment status (unemployed/retired/business/casual worker)*
- marital status
- the living arrangement of the respondent
- number of people in the household they are living – including dependents
- *years since first HIV diagnosis [before or after haart]. How long have you known your HIV status?*

- *How long did you take (after diagnosis) before starting using medications?*
- *currently taking HAART medications. (Yes/no).*

For Healthcare providers indicate:

- *the venue, date and time of interview*
- *gender, age, educational level (years in school) of the respondent*
- *Job title of participant*
- *Years in HIV services*

For Primary caregivers indicate:

- *the venue, date and time of interview*
- *gender, age, educational level (years in school), occupation of the respondent*
- *Relationship of the respondent with the adult living with HIV*

Older Adults living with HIV

1. Reactions to HIV diagnosis and disclosure

- To begin with, I would like to know **how you knew your HIV status**. Please tell me what happened that led to your testing?
- Could ***you please tell me about the time after the testing?*** What did you do? How did you feel? What was the turning point (to accepting your diagnosis?) Which people (how many people) have you **disclosed/shared your HIV status?**

2. Significant changes after being diagnosed

Since being diagnosed with HIV, what has changed in your life and family?

- *Intrapersonal/individual changes,*
- *Interpersonal activities,*
- *Community activities*
- Sex and sexuality:

3. Health challenges

- Do you think that it is harder living with HIV at your age, compared to other age groups?

- What are some of the hardest things that have happened since the HIV?
 - What are the pressing challenges that you face as an older adult living with HIV (compared to older adults without HIV? *Probes*
- a) **Mental health problems** - depressive symptoms, anxiety symptoms, suicidal ideations, drug and substance use,
 - b) **Cognitive (thinking/learning) problems** - Difficulty remembering things? Easily distracted? Postponing tasks/activities more than usual or starting others before finishing one? Difficulty paying attention.
 - c) **HIV-related stigma/discrimination and ageism** HIV-related stigma (felt/internalised, enacted, perceived and vicarious stigma) –
 - How is it like living with HIV in this community at your age?
 - Have you been *openly discriminated/treated differently because of your HIV status* (from **family members, friends, service providers, potential sexual partners, colleagues at work, religious gathering, in the community**) (*enacted stigma*).
 - Have you *felt ashamed or having expectations of discrimination from people if you* disclose your HIV status to them? (*felt/internalized/self-stigmatization*).
 - Have you felt discriminated (experienced in the imagination through the feelings or actions of another HIV infected person) (*vicarious stigma*).
 - How has the stigma experiences/feelings affected your health-seeking behavior, disclosure, medications and interaction with other people in the community, and other aspects of life.
 - How are older people (at least 50 years) treated in **your community/village/home/workplace/clinic**?
 - How are you treated as an older adult by those around you (home, work, or in the community).
 - How are older people living with HIV treated in your community/village/home/workplace compared to older adults without HIV?
 - Could you tell me about a time that you felt discriminated against or mistreated because of being older?
4. **Frequent hospitalisations and body's unpredictability and its consequences**
 5. **Physical and somatic symptoms as well as history of comorbid conditions**
 6. **Social isolation and loneliness**
 7. **Health seeking behavior and coping mechanisms**

- How often do you seek medical help for any of the problems identified above?
- Which services do you normally receive at your clinic?
- How accessible are these services – distance and cost, how many hospital visits in a month, any missed visits and why (transport, distance, health issues, siblings to take care of?
- What is satisfying about the HIV care services at the clinic?
- What is frustrating about the HIV care services at the clinic? Challenges in accessing medication and other healthcare services.
- How easy is it for you to talk to your clinician about some of the challenges you face?
- Do you have some specific needs that you feel are not being met at the healthcare facility?

Coping mechanisms/selfcare practices

- What do you do to keep yourself healthy or cope with these problems? At work, home, relationships, healthcare settings.
- Please describe to me any support that you have access to.
- What helps you the most to live with HIV at your age?
- What do you enjoy doing normally at home/work or in the community? (the things which make you happy while at it.
- What are your hopes for the future?

8. *Is there something else you would like to talk about on this subject?*

Healthcare providers

1. On average, **how many older adults** (those ≥ 50 years) do you attend to at your HIV clinic/organisation?
2. At what point do you interact with these older adults living with HIV?
3. In your experience, **what are the common challenges faced by older adults living with HIV?** How are these challenges different from those of other younger ages (children, adolescents and young adults)?
4. Based on your experience working in this HIV clinic, **what are the pressing healthcare problems or complaints in older adults living with HIV?**
5. **How do you manage/address these health problems?**
6. What are the **typical healthcare services** provided to **the older adults** living with HIV at this clinic?

7. Do **they know whether these services exist at the clinic?** How often do older adults seek the existing services apart from the normal HIV care they receive at the clinic? Which factors promote and discourage this?
 - The **current HIV management guidelines in Kenya (2018 version)** **recommend** the following package of care to all people living with HIV: ART therapy, positive health, dignity and prevention components (e.g. condom use, disclosure, adherence support, family testing), Specific opportunistic infection screening and prevention, Reproductive health services, Non-communicable diseases screening and management, Mental health screening and management, Nutritional services and Prevention of other infections.
 - Which aspects of this package are implemented?
 - What are the barriers and facilitators in implementing these guidelines?
8. Overall, **what challenges do you encounter in adequately addressing the needs of older** adults living with HIV in this clinic?
9. In **your opinion what should be done to optimise the care and support of older adults in our context?**

Primary caregivers

1. **How long have you known the HIV status of your significant other**
2. **What was your initial reaction on learning the HIV status of this adult?** And how has this changed over the course of your interaction?
3. **How would you describe your relationship/interaction with this adult?**
4. **How would you describe the relationship of this older adult with other family members,** neighbours and friends?
5. **In your capacity and experience living with/knowning this adult, what are the important healthcare challenges that this person faces**
6. **How frequently does this adult seek medical assistance/help for any of the problems** you have mentioned above? **Which services/help does this person seek?** How far do you go and how much do you pay to access these services?
7. In your **capacity as an individual, how do you do to support this adult in ensuring they have a good quality of life?**
8. In your opinion, **what should be done to enhance the quality of life of older adults living** with HIV?

Published papers

- 1) **Mwangala PN**, Mabrouk A, Wagner RG, Newton CR, Abubakar A. Mental health and well-being of older adults living with HIV in sub-Saharan Africa: a systematic review. *BMJ Open*. 2021 Sep 1;11(9):e052810.
doi: <https://doi.org/10.1136/bmjopen-2021-052810>
- 2) **Mwangala PN**, Wagner RG, Newton CR, Abubakar A. Navigating life with HIV as an older adult on the Kenyan coast: perceived health challenges seen through the biopsychosocial model. *International Journal of Public Health*. 2023;68:1605916.
doi: <https://doi.org/10.3389/ijph.2023.1605916>
- 3) **Mwangala PN**, Wagner RG, Newton CR, Abubakar A. Strategies for improving mental health and wellbeing used by adults ageing with HIV: a qualitative exploration. *Wellcome Open Research*. 2022;7(221):1.
doi: <https://doi.org/10.12688/wellcomeopenres.18212.2>
- 4) **Mwangala PN**, Nasambu C, Wagner RG, Newton CR, Abubakar A. Prevalence and factors associated with mild depressive and anxiety symptoms in older adults living with HIV from the Kenyan coast. *Journal of the International AIDS Society*. 2022 Sep;25:e25977. doi: <https://doi.org/10.1002/jia2.25977>
- 5) **Mwangala PN**, Nasambu C, Wagner RG, Newton CR, Abubakar A. Prevalence and Factors Associated With Frailty Among Older Adults Living With HIV Compared to Their Uninfected Peers From the Kenyan Coast. *International Journal of Public Health*. 2024;69:1606284. doi: <https://doi.org/10.3389/ijph.2024.1606284>

BMJ Open Mental health and well-being of older adults living with HIV in sub-Saharan Africa: a systematic review

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ABSTRACT

Objective In this systematic review, we aimed to summarise the empirical evidence on common mental disorders (CMDs), cognitive impairment, frailty and health-related quality of life (HRQoL) among people living with HIV aged ≥50 years (PLWH50+) residing in sub-Saharan Africa (SSA). Specifically, we document the prevalence and correlates of these outcomes.

Design, data sources and eligibility criteria The following online databases were systematically searched: PubMed, CINAHL, PsycINFO, Embase and Scopus up to January 2021. English-language publications on depression, anxiety, cognitive function, frailty and quality of life among PLWH50+ residing in SSA were included.

Data extraction and synthesis We extracted information, including study characteristics and main findings. These were tabulated, and a narrative synthesis approach was adopted, given the substantial heterogeneity among included studies.

Results A total of 50 studies from fifteen SSA countries met the inclusion criteria. About two-thirds of these studies emanated from Ethiopia, Uganda and South Africa. Studies regarding depression predominated (n=26), followed by cognitive impairment (n=13). Overall, PLWH50+ exhibited varying prevalence of depression (6%–59%), cognitive impairments (4%–61%) and frailty (3%–15%). The correlates of CMDs, cognitive impairment, frailty and HRQoL were rarely investigated, but those reported were sociodemographic variables, many of which were inconsistent.

Conclusions This review documented an increasing number of published studies on HIV and ageing from SSA. However, the current evidence on the mental and well-being outcomes in PLWH50+ is inadequate to characterise the public health dimension of these impairments in SSA, because of heterogeneous findings, few well-designed studies and substantial methodological limitations in many of the available studies. Future work should have sufficiently large samples of PLWH50+, engage appropriate comparison groups, harmonise the measurement of these outcomes using a standardised methodology to generate more robust prevalence estimates and confirm predictors.

PROSPERO registration number CRD42020145791.

BACKGROUND

All societies globally are experiencing an ageing population—some are in its early stages, and some are more advanced.¹

Strengths and limitations of this study

- This is the first comprehensive review of common mental disorders, cognitive impairment, frailty and quality of life among older adults living with HIV in sub-Saharan Africa, synthesising the current evidence regarding the prevalence and correlates of these outcomes.
- Our expanded search of five online databases and snowballing techniques minimised the risk of missing relevant studies.
- Meta-analysis was not conducted due to extensive heterogeneity across the studies in methods and presentation of results.
- We observed substantial methodological limitations in many of the included studies, for example, small sample sizes, making it difficult to characterise the real public health dimension of these impairments in the region.

Likewise, the proportion of people living with HIV (PLWH) aged ≥50 years (considered as older adults within the HIV literature) is growing rapidly across the globe,² demanding an increase in research, policy and practice to address the complex needs of this vulnerable group.³ In 2016, there were around 6 million PLWH50+ globally, representing 16% of the entire adult HIV population.² This proportion was projected to reach 21% by the end of 2020, with Southern and Eastern Africa containing the vast majority of PLWH50+.² The increase in older PLWH is mainly driven by two factors: effective antiretroviral therapy (ART) and new HIV infections among the elderly.⁴

This rapidly growing segment of PLWH50+ yields new challenges. Several HIV and ageing cohorts (mostly from high-income countries, HICs) are pointing out an elevated burden of physical conditions (eg, cardiometabolic diseases), mental morbidities (eg, depression, cognitive disorders), psychosocial challenges (eg, stigma, loneliness) and geriatric syndromes (eg, frailty)

among PLWH ≥ 50 years (PLWH50+) compared with their uninfected counterparts.⁴⁻⁶ Unfortunately, the mechanisms for the heightened risk of poor outcomes among PLWH50+ are not fully understood but span a host of disease-related factors, legacy of the early years of the HIV epidemic and host vulnerability factors.⁴ Frailty, common mental disorders (CMDs) such as depression and anxiety, and cognitive impairments are of particular concern in this population.⁴⁻⁶ Frailty is an important emerging indicator of vulnerability that is increasingly being evaluated among individuals ageing with HIV.⁷ It describes a state of physiological vulnerability that, in the presence of internal or external stressors, puts a person at an elevated risk of adverse clinical outcomes, such as hospitalisation, functional disability and mortality.^{8,9} Overall, mental morbidities and frailty are understudied in the literature despite their elevated burden and potential adverse impacts on HIV treatment and health-related quality of life (HRQoL).

Despite the apparent need to sharpen the focus on the needs of the growing cohort of PLWH50+, this population is being neglected in HIV care and prevention efforts, especially in low-income and middle-income settings of sub-Saharan Africa (SSA). In SSA, this concern is not just based on the close association between ageing and physical, cognitive, mental impairments, but also on the recognition that older adults are not considered to be a priority for policy issues. They are marginalised and increasingly vulnerable to greater poverty.^{10,11} Thus, the burden and determinants of physical and mental impairments in these adults in SSA, the region most affected by HIV globally, are largely undocumented.¹²

The course and implication of physical and mental morbidities among PLWH50+ are well described in HICs, but it is an emergent research area in SSA. However, since 2010, the SSA region has witnessed a rise in interest in HIV and ageing outcomes, evidenced by the establishment of cohort studies of older people in different parts of Africa.¹³⁻¹⁵ This is encouraging since data from HICs may not be readily generalised to SSA where differences in, for example, genetics, social environmental milieu, formal and informal support systems will almost certainly alter the risk profile and morbidity characteristics among PLWH50+. Therefore, the current review aims to summarise the existing empirical evidence on CMDs, cognitive impairment, frailty and HRQoL among PLWH50+ in SSA by addressing the following specific objectives.

1. Establish the prevalence of CMDs, cognitive impairment and frailty among PLWH50+ in SSA.
2. Identify the correlates of CMDs, cognitive impairment, frailty and HRQoL among PLWH50+ in SSA.

METHODS

We followed the Preferred Reporting Items for Systematic Reviews and Meta-analyses guidelines to report the study.¹⁶

Search strategy

Five online databases (PubMed, CINAHL, PsycINFO, Embase and Scopus) were searched for publications. The last search was conducted on 4 January 2021. The following search terms were used: (HIV OR HIV-1 OR HIV/AIDS OR HIV infections) AND (adult OR older adult OR older people OR older individual OR elderly) AND (Africa OR sub-Saharan Africa OR Africa South of the Sahara) AND (cognitive impairment OR neurocognitive impairment OR neurological complication OR HIV-associated neurocognitive disorder OR common mental disorder OR depression OR depressive symptoms OR depressive disorder OR anxiety OR anxiety disorder OR quality of life OR health-related quality of life OR grip strength OR hand strength OR frailty). We also searched through the reference lists of included articles to access additional articles. Details of the full search strategy are provided in online supplemental file 1.

Studies were considered eligible if they: (1) involved PLWH50+ or had participants whose mean/median age was ≥ 50 years or aggregated their outcomes of interest by age (including the ≥ 50 age category); (2) were conducted within SSA; (3) were empirical and published in a peer-reviewed journal and (4) reported any of our outcomes of interest (CMDs, cognitive impairment, frailty or HRQoL). We excluded studies that did not aggregate the outcomes of interest by HIV status. We also excluded studies that were published in non-English languages. Two of the authors (PNM and AM) independently screened the titles, abstracts and full articles for eligibility and reached consensus.

Data extraction and quality assessment

The two authors (PNM and AM) independently extracted the following study characteristics using a similarly designed extraction sheet: (1) first author; (2) country and the year of publication; (3) sample description; (4) how the outcome of interest was measured; (5) results reported; (6) key findings on the outcome of interest. For studies exclusively carried out among PLWH50+, we computed or extracted the reported percentages of the relevant outcomes. Similarly, for studies with middle-aged participants but whose mean/median age was ≥ 50 years, we also computed or extracted the reported percentages for the relevant outcomes for the whole sample. For the studies with middle-aged participants (but whose mean/median age was not at least 50 years), we computed percentages for participants who fell within the ≥ 50 category, which was usually provided in the papers. In some studies, it was impossible to calculate these percentages. Hence, the occurrence of a specific outcome was reported in the original effect measure, for example, OR, median or mean. Any disagreement between the reviewers during data abstraction was also resolved by consensus.

We evaluated the quality of included studies using the modified version of the Newcastle-Ottawa Scale.¹⁷ The scale uses five parameters (sample size, sample representativeness, comparability between respondents and

non-respondents, ascertainment of the outcome of interest, and quality of descriptive statistics reporting) to obtain a total score ranging from 0 to 5. A score ≥ 3 is considered a low risk of bias, while a score of <3 is regarded as a high risk of bias.

Data synthesis and analysis

A narrative synthesis approach was used to compare studies and describe the state of evidence on all reported outcomes; by describing the effect estimates, for instance, proportions, means with SD, and median with their IQRs. Where applicable, ranges were used to summarise the outcomes of interest reported. A meta-analysis could not be done due to a limited number of studies and substantial heterogeneity among studies.

Patient and public involvement statement

The accompanying manuscript is part of broader doctoral research work for the first author. During the conceptual phase of this work, community engagement through meetings with different stakeholders was carried out to contextualise the issues of ageing and HIV at the coast of Kenya (eg, in terms of priorities and preferences). These stakeholders included the Kilifi and Mombasa counties' departments of Health, subcounty health management teams, and hospital management teams of various health facilities at the study setting. The research team received and incorporated useful feedback from these meetings towards the design and implementation of the project. It also led to further elaborations regarding ongoing community engagement during and after the study, including disseminating any work arising from this project using these forums and others such as publications, hospital departmental meetings, patient groups and conferences as an essential way to discuss the implications of the findings. For this systematic review, patients were not involved in the conduct of the study. However, the results will be disseminated to the relevant patient groups within the HIV clinics through feedback meetings.

RESULTS

Characteristics of included studies

We identified 8741 articles from the 5 online databases and an additional 7 citations from snowballing. Of these, 2693 were duplicates. Hence, we screened 6055 titles and abstracts for initial eligibility, out of which 575 articles were identified. Full articles were obtained for these citations, of which 50 met the eligibility criteria (figure 1). The eligible studies were conducted between 2006 and 2021 among 15 SSA countries of Uganda (n=13), South Africa (n=12), Ethiopia (n=8), Tanzania (n=5), Nigeria (n=3), Cameroon (n=2), Côte d'Ivoire (n=2), Senegal (n=2), Kenya (n=2), Botswana (n=1), Zambia (n=1), Malawi (n=1), Namibia (n=1), Togo (n=1) and Burkina Faso (n=1). However, some of these studies were conducted in multiple countries. Figure 2 shows the geographical distribution of these studies across the SSA region. Virtually

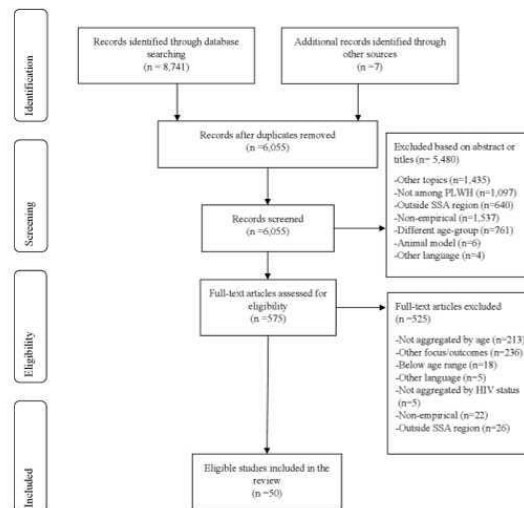


Figure 1 Identification of eligible studies. PLWH, people living with HIV; SSA, sub-Saharan Africa.

all the included studies were cross-sectional, except one that presented data from a randomised trial.¹⁸ Eighteen studies (36%) analysed baseline or follow-up data of different cohort studies.

About two-thirds of the included studies (n=35) recruited their HIV infected samples from clinical settings.^{18–52} The rest obtained their samples from the general population through household surveys and community samples. Additionally, many of the studies included samples of PLWH50 + lower than 100 (n=22). Overall, the samples of PLWH50 + per study ranged from 19 to 1048,^{36 53} while those for HIV uninfected older adults ranged from 17 to 4022.^{22 54}

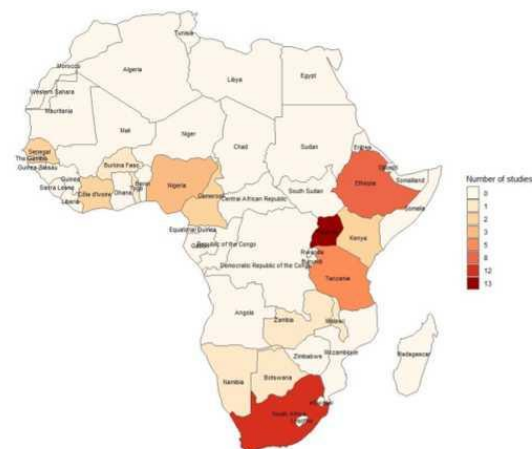


Figure 2 Geographical distribution of the included studies within SSA. SSA, sub-Saharan Africa.

Common HIV disease markers such as the duration of HIV infection, current/nadir CD4 +T cell count, duration of ART use, viral suppression level among PLWH50 + were reported in a few studies. However, there was extensive heterogeneity in how the information was reported and the level of detail given. In 42% of the included studies, all PLWH50 + were on ART. Six other studies included only ART naïve PLWH50+. Among ART users, viral suppression was reported in five studies where it was documented to range from 73% to 90%. Nadir CD4 +T cell count among PLWH50 + was reported in four studies where most of the participants (about 60%) had a count lower than 200. The duration of HIV infection among PLWH50 + ranged from 3.5 to 12 years (among the few studies that reported this variable).

Only eight studies examined the health outcomes of interest using an exclusively HIV infected older sample.^{25 33 40 45–49} Eighteen other studies used HIV uninfected older adults as comparison groups, while the rest included HIV infected young adults (the ages varied extensively).

Depression and anxiety

Depression was reported in 25 studies, while anxiety was reported in two studies. Notably, depression was assessed using multiple scales with diverse scoring systems. Six of the studies used the 9-item Patient Health Questionnaire (PHQ-9), while a similar number used the Centre for Epidemiological Studies Depression scale. Five other studies used the Mini International Neuropsychiatric Interview (MINI), while the rest utilised a host of different scales. On the other hand, anxiety was assessed using the Schedule for Clinical Assessment in Psychiatry and from clinical records.^{30 39} Nine of the depression studies^{19 29 44 49 51 55–58} reported major depressive disorders (MDD), while the remaining sixteen studies reported the prevalence of depressive symptoms. To synthesise and report the available evidence, depression (when ever used in this review) captures both the depressive symptoms (derived from brief screening measures) and Major Depressive Disorder (based on structured diagnostic interviews, for example, the MINI by specialised professionals or trained non-specialised workers). More information on this outcome is presented in the online supplemental table 1.

Prevalence of depression and anxiety

Overall, the prevalence of depression ranged from 6% to 59%. We found no clear pattern of over-reporting or under-reporting of depression prevalence in the included studies, considering the different cut-offs used. For instance, in studies using the PHQ-9, the prevalence of depression ranged from 47% to 49% (with a cut-off of ≥ 5) and 16% to 45% when using a cut-off of ≥ 10 . We also noted a similar observation when we took the ART status of PLWH into account. Specifically, the prevalence of depression ranged from 8% to 59% among studies whose participants were entirely on ART compared with

6% to 54% among studies with mixed or naïve PLWH. However, studies that used structured interviews such as the MINI, Composite International Diagnostic Interview (CIDI) and Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV) to assess for depression were noted to frequently report lower prevalence of depression among PLWH50+ (ranging from 6% to 30%)^{44 57} compared with studies that used brief screening scales such as the PHQ-9 (prevalence ranging from 8% to 59%).^{27 59}

Of note, eight studies documented higher prevalence of depression among PLWH50 + than their comparison groups.^{20 23 27 36 37 43 55 56} On the contrary, 11 studies reported a lower prevalence of depression among PLWH50 + than their comparison groups.^{19 24 28 29 31 32 44 50 51 58 59} In comparison, three other studies reported minimal or no differences in depression between PLWH50 + and their comparison groups.^{34 42 57} In one population-based study conducted in rural South Africa, neither diagnosis nor treatment of HIV was significantly associated with depression when compared with being uninfected.⁵⁴

Anxiety was reported in two studies.^{30 39} In one of them,³⁹ PLWH50 + on ART presented with the same proportion of anxiety symptoms with HIV uninfected older adults at 3%. In the other study,³⁰ the prevalence of anxiety disorders among PLWH50 + on ART was 21% compared with 22% in HIV infected young adults (18–50 years).

Reported correlates of depression

Correlates of depression among PLWH50 + were reported only in eight studies.^{27 28 46 48 51 54 55 58} Among sociodemographic variables, older age,^{27 54} declining socioeconomic status,⁵⁵ being unemployed,⁴⁶ being female,^{28 58} HIV status disclosure⁴⁸ and urban residency⁵⁸ were associated with an elevated risk of depression while being married, employed (full-time or part-time work),⁵⁴ old age,⁵¹ higher educational attainment⁴⁸ and belonging to the highest wealth quintile²⁸ were associated with reduced levels of depression. However, in some studies, household wealth quintile, education levels,⁵¹ and age²⁵ were not significant correlates of depression. In other studies, being a current/former smoker,⁴⁶ increasing disability scores, decreasing mean handgrip strength, reported back pain, not having hypertension,⁵⁵ HIV stigma⁴⁸ and caregiving (for adult children)⁵⁸ were significantly associated with elevated levels of depression. On the other hand, receiving a government grant⁵⁸ and resilience⁴⁸ were significantly associated with reduced levels of depression. Details of this data are presented in online supplemental table 1.

Cognitive and neurological functioning

These outcomes were reported by 13 studies, as highlighted in table 1. Of these, five studies quantified the prevalence of HIV-associated neurocognitive disorders (HAND) using different measures,^{25 35 38 40 49} two studies reported findings on dementia^{21 60} while five studies documented findings on cognitive function/

Table 1 Summary of prevalence estimates and correlates for cognitive impairment/neurological impairment

Author, publication year and country	Study design	Sample size	Treatment status of PLWH	Assessment tool used	Cut-off score or diagnosis criteria	Information on local tool validation	Prevalence estimates/ other results for PLWH50+	Correlates reported
Studies reporting the prevalence of HIV-associated neurocognitive disorders (HAND) or cognitive impairment								
Kelleit-Wright, ^{a,49} (2020); Tanzania	Cross-sectional	235 PLWH50+	95.5% on ART	International HIV Dementia Scale (IHDS) and (Six Item Dementia Screen, IDEA)	Frascati criteria with a detailed consensus panel discussion	Diagnostic accuracy (area under the receiver operating characteristic curve: 0.64–0.67 for IHDS and 0.65–0.71 for IDEA)	Prevalence of symptomatic HAND (MND and HAD) was 25.3%.	NR
Eaton, (2020); Tanzania ²⁵	Cross-sectional	253 PLWH50+	94.8% on ART	Comprehensive NP battery	Frascati criteria for classifying HAND		Prevalence of symptomatic HAND (HAD and MND) was 21.7%.	PLWH were at higher risk of having symptomatic HAND if they lived alone (OR 2.6), were illiterate (OR 3.2) or older at the time of HIV diagnosis (OR 1.1). HIV-specific factors were not related to symptomatic HAND. Vascular risk factors, such as smoking status, were not associated with symptomatic HAND.
Oumar, (2020); Burkina Faso ⁴⁰	Cross-sectional	102 PLWH50+	All on ART	Mini Mental State Examination (MMSE)	Frascati criteria for classifying HAND		23.5% had neurocognitive disorders	In a multivariate analysis, age (OR 4.6) and educational status (OR 2.6) were associated with neurocognitive disorders.

Continued

Table 1 Continued

Author, publication year and country	Study design	Sample size	Treatment status of PLWH	Assessment tool used	Cut-off score or diagnosis criteria	Information on local tool validation	Prevalence estimates/ other results for PLWH50+	Correlates reported
Mugendi, (2019); Kenya ³⁸	Cross-sectional	64 PLWH50+; 281 PLWH (20–49 years)	All on ART	Montreal Cognitive Assessment (MoCA) and IHDS	Combined scores of the two tools: a score of ≤ 26 on MoCA and ≤ 10 on the IHDS.	NR	Among PLWH50+, symptomatic HAND was 19.2% aggregated by age.	Reported correlates not aggregated by age.
Tsegaw, (2017); Ethiopia ³⁵	Cross-sectional	67PLWH56+; 526 PLWH (18–55 years)	All on ART	IHDS	≤ 9.5	NR	61.2% among PLWH56 + had HAND	Reported correlates not aggregated by age.
Kobayashi, (2019); South Africa ³³	Population survey	1048 PLWH40+; 4011 HIV uninfected older adults ≥ 40 years	63.9% on ART	Brief cognitive battery (orientation, immediate and delayed recall).	≤ 1.5 SDs below the mean composite time orientation and memory score.	Locally adapted	4.0% of PLWH40 + had cognitive impairment compared with 9.0% of uninfected older adults ≥ 40 years	Independent predictors of lower cognitive score were being older, female, unmarried, not working, having low formal education, low socioeconomic status, and having a history of cardiovascular conditions.
Ssonko, (2018); Uganda ³³	Cross-sectional	411 PLWH50+	All on ART	Folstein's MMSE	NR	NR	Mild cognitive impairment was associated with falls in the previous 12 months.	NR

Studies reporting NP test scores

Continued

Table 1 Continued

Author, publication year and country	Study design	Sample size	Treatment status of PLWH	Assessment tool used	Cut-off score or diagnosis criteria	Information on local tool validation	Prevalence estimates/ other results for PLWH50+	Correlates reported
Asilmwe, (2020); South Africa ⁶¹	Population survey	1048 PLWH40+; 3512 HIV uninfected older adults ≥40 years	68.6% on ART	A battery of conventional instruments and the Oxford Cognitive Screen-Plus (OCS-Plus)	Summarised mean cognitive scores between participants with and without HIV on the two measures.	Previously validated in the study setting	PLWH scored on average 0.06 (95% CI 0.01 to 0.12) SD units higher on the conventional cognitive function measure and 0.02 (95% CI -0.07 to 0.04) SD units lower on the OCS-Plus measure than HIV-negative participants.	ART use was non-significantly associated with better cognitive outcomes among PLWH in both instruments.
Moucheraud, (2020); Malawi ⁵¹	Cross-sectional	74 PLWH50 + and 60 young PLWH (30–49) years	All on ART	Brief cognitive battery (MMSE)	NR	NR	Mean cognitive scores: 16.0 among PLWH50 + vs 17.4 among young PLWH.	NR
Cassimjee, (2017); South Africa ²²	Cross-sectional	33 PLWH50+; 17 HIV uninfected older adults (mean age 52.2)	NR	Dementia Rating Scale-2, the Stroop Colour and Word Test, the Symbol Digits Test and the D-KEFS Trail Making Test.	N/A	NR	PLWH, in comparison to the uninfected group, had significantly poorer performance profiles in global cognitive functioning, memory, executive functioning, psychomotor functioning, and processing speed.	NR

Studies reporting dementia

Continued



Table 1 Continued

Author, publication year and country	Study design	Sample size	Treatment status of PLWH	Assessment tool used	Cut-off score or diagnosis criteria	Information on local tool validation	Prevalence estimates/ other results for PLWH50+	Correlates reported
Joska, (2019); South Africa ⁴⁰	Population survey	55 PLWH50+; 1095 HIV uninfected older adults ≥50 years	86.1% on ART	Brief Community Screening Instrument for Dementia	NR	Previously validated	18.2% of PLWH50+ had dementia compared with 10.7% of the uninfected older adults ≥50 years	Dementia status was associated with HIV infection (OR 2.2, 95% CI 1 to 4.5), older age (OR 1.0, 95% CI 1.0 to 1.1) and depressive symptoms (OR 2.7, 95% CI 1.8 to 3.9).
Atashili, (2013); Cameroon ²¹	Cross-sectional	400 HIV infected adults (20–53 years old)	All on ART	IHDS	≤10 on IHDS	Not validated	The odds of having a positive dementia screen increased progressively with increasing participants' age.	Not aggregated by age
Studies reporting HIV-associated neuropathy								
Obimakinde, (2020); Nigeria ³⁹	Cross-sectional	62 PLWH60+; 162 HIV uninfected older adults ≥60 years	All on ART	Extracted from participants' medical notes	Clinical notes	NR	19.0% in PLWH60+ had peripheral neuropathy	NR

ART, antiretroviral treatment; D-KEFS, Delis-Kaplan executive function system; HAD, HIV-associated dementia; MND, mild neurocognitive disorder; NA, not applicable; NP, neuropsychological; NR, not reported; PLWH50+, people living with HIV ≥50 years old.

impairment.^{22 33 51 53 61} The remaining study reported the proportion of HIV-associated peripheral neuropathy among PLWH50+.³⁹

Prevalence estimates of reported outcomes

The prevalence of symptomatic HAND among PLWH50 + on ART ranged from 19%³⁸ to 61%.³⁵ Two of the HAND studies documented elevated proportions of symptomatic HAND among PLWH50 + on ART compared with their younger counterparts.^{35 38} In rural South Africa, Joska *et al* examined the prevalence of dementia and its associations in a population survey of 1150 rural elderly participants. They found no significant differences in the prevalence of dementia between PLWH50+ (86% on ART) and HIV uninfected counterparts 18% vs 11%, respectively.⁶⁰ In a different study in rural South Africa, a baseline analysis of the Health and Ageing in Africa—A Longitudinal Study of an INDEPTH Community (HAALSI), HIV infected older adults (64% on ART) registered a lower prevalence of cognitive impairment (4%) than their uninfected peers (9%).⁵³ In a separate analysis of the same baseline data of the HAALSI cohort,⁶¹ HIV infected older adults scored on average 0.06 (95% CI 0.01 to 0.12) SD units higher on a conventional cognitive function measure and 0.02 (95% CI - 0.07 to 0.04) SD units lower when using the Oxford Cognitive Screen-Plus (OCS-Plus) measure than their HIV-negative counterparts.

Correlates of cognitive function/impairment

The correlates of cognitive function/impairment were reported in seven studies. The key predictors of reduced cognitive function were mainly sociodemographic: older age (≥50 years),^{21 40 53 60} living alone,²⁵ being illiterate or having low formal education level,^{25 53} being older at the time of HIV diagnosis,²⁵ being female, unmarried and having low socioeconomic status⁵³ were associated with a higher risk of impairment. However, in some studies, the effects of age, education and marital status were not significant.^{25 60} Other correlates of cognitive impairment included the presence of depressive symptoms,⁶⁰ a history of cardiovascular conditions⁵³ and a history of falls in the past 12 months.³³ HIV specific factors (such as nadir CD4 count, ART use)^{25 61} and vascular risk factors (such as smoking status, body mass index and blood pressure)²⁵ were not associated with cognitive impairment.

Frailty/grip strength

Prevalence estimates

Frailty was reported in three studies.^{33 47 62} In the first study, a hospital-based cross-sectional study of 145 PLWH50 + on ART in Tanzania, frailty assessment was completed using three measures (the Fried frailty phenotype (FFP), the Clinical Frailty Scale (CFS) and Brief Frailty Instrument for Tanzania (B-FIT 2)).⁴⁷ In this study, the authors reported low levels of frailty: 3% (when using the FFP method) and 1% (when using the CFS and BFIT-2 methods). The second study documented a similar prevalence of frailty among 292 PLWH50+ (ART status not

reported) and 322 HIV uninfected peers in rural South Africa (15% vs 18%, respectively), using a modified version of the FFP.⁶² In the third study, increasing frailty scores were significantly associated with increasing polypharmacy levels in a sample of 411 PLWH50 + on ART in Uganda.³³ Five other studies^{18 45 57 63 64} reported mean handgrip strength as an indicator of frailty, as shown in table 2.

Reported correlates of frailty

The correlates of frailty were reported in two studies. Being female, unmarried⁴⁷ and older^{47 62} were significantly associated with worse frailty scores, and there were no associations between inflammatory biomarkers with frailty.⁶² Factors associated with mean handgrip strength were reported in four of the studies. In one, HIV status was significantly associated with weaker handgrip strength.⁵⁷ In another study, being female and divorced/widowed were significantly associated with weaker handgrip strength, while having a secondary education level was significantly associated with better handgrip strength. Table 2 gives details of this outcome.

Health-related quality of life

This outcome was reported in eight studies. Three-quarters of the studies used the WHO Quality of Life measure to assess HRQOL. The overall mean quality of life scores (out of 100) ranged from 42 to 83 among PLWH50 + on ART. In two studies, PLWH50+ (partially on ART) reported better quality of life scores than their uninfected counterparts.^{63 65} In contrast, four other studies reported a lower quality of life scores^{39 41 52 66} among PLWH50 + compared with to HIV uninfected older adults or HIV infected young adults.

The correlates of quality of life were reported in only one study,⁶⁵ where having some source of income and being in the upper two wealth quintiles were significantly associated with better quality of life among PLWH50+. Additionally, being female and previously married were associated with reduced odds of good quality of life in PLWH50+. Table 3 gives more details on this outcome.

Overall, a significant number of the included studies (about 35%) had a low quality score (≤2 – indicating a high risk of bias).^{19–22 26 29 31 35–41 48 51 66} Specifically, about two-thirds of the included studies did not report participant response rates. Sixteen studies used non-probability sampling methods or did not report their sampling methods. Close to half of the included studies had substantially small samples of PLWH50+ (≤100). Furthermore, a substantial number of studies (about 40%) provided scarce information regarding their measures' reliability and validity. Details of the quality assessment of all included studies are captured in online supplemental table 2.

Table 2 Summary of prevalence estimates and correlates for frailty and handgrip strength

Author, publication year and country	Study design	Sample size	Treatment status of PLWH	Assessment tool used	Cut-off score	Tool validation	Prevalence estimates/ other results for PLWH50+	Correlates reported
Studies that assessed frailty comprehensively								
Bristow, (2021); Tanzania ⁴⁷	Cross-sectional	145 PLWH50+	99.3% on ART	Fried frailty phenotype (FFP), Clinical Frailty Scale (CFS) and B-FIT 2.	FFP: A score of 1–2 was prefrail, and a score of ≥ 3 was frail; B-FIT (A score of 8/20); CFS (a score of 5–9)	B-FIT and FFP previously validated in Tanzania.	2.8% (95% CI 0.09% to 5.4%) when using the FFP. 0.68% (95% CI –0.66% to 2.04%) when using the CFS or B-FIT 2).	FFP frailty was associated with female gender ($p=0.006$), marital status ($p=0.007$) and age ($p=0.038$). Weight loss was the most common FFP domain failure.
Edwards, (2020); South Africa ⁴²	Cross-sectional	292 PLWH50+ and 322 HIV uninfected adults (≥ 50) years.	NR	FFP	Presence of ≥ 3 of the 5 FFP phenotypes	Adapted in the local population	Frailty was similar for HIV negative and PWV (17.7% vs 14.7%, $p=0.72$) respectively as was prefrailty status (66.5% vs 63.4%).	The prevalence of frailty increased with age. There was no association between any of the inflammatory biomarkers and frailty and prefrailty.
Ssonko, (2018); Uganda ³³	Cross-sectional	411 PLWH50+	All on ART	Self-report 40-item Frailty Index Questionnaire	NR	NR	Frailty Index Scores of 5 to 6 (PR 10.6, 95% CI 1.4 to 78, $p=0.02$), and seven or more (PR 17.4, 95% CI 2.4 to 126.5, $p=0.005$) were associated with polypharmacy.	Increasing Frailty score was associated with increasing levels of polypharmacy.
Studies that assessed handgrip strength								
Bernard, (2020); Côte d'Ivoire & Senegal ⁴⁵	Cross-sectional	333 PLWH50+	All on ART	Calibrated Jamar hydraulic hand dynamometer	A performance less to the median obtained in each gender group (male/female)	NR	43.2% of women had low grip strength. 42.5% of men had low grip strength.	NR

Continued

Table 2 Continued

Author, publication year and country	Study design	Sample size	Treatment status of PLWH	Assessment tool used	Cut-off score	Tool validation	Prevalence estimates/ other results for PLWH50+	Correlates reported
Filteau, (2017); Zambia and Tanzania ¹⁸	Randomised trial	PLWH50+: 148 at baseline; 72 at 12 wks, and 50 at 2–3 years ART	ART naïve at baseline	Digital handgrip dynamometer	NA	NR	Mean grip strength change: 18.7 kgs at baseline, 20.4 kgs at 12 weeks and 23.1 kg at 2–3 years.	Reported correlates not aggregated by age.
Mugisha, (2013); Uganda ⁶³	Cross-sectional	198 PLWH50+; 311 HIV uninfected adults ≥50 years	51.0% on ART	Digital handgrip dynamometer	NA	NR	25.7 among PLWH50+; and 22.1 among the uninfected older adults ≥50 years.	NR
Negin, (2012); South Africa ⁴⁷	Cross-sectional	142 PLWH50+; 2722 HIV uninfected older adults ≥50 years	NR	Digital handgrip dynamometer	NA	Locally validated	Mean grip strength in PLWH50+ among those aged 50 years and older, HIV status was significantly associated with weaker grip strength.	When controlling for age and sex among those aged 50 years and older, HIV status was significantly associated with weaker grip strength.
Scholten, (2011); Uganda ⁶⁴	Cross-sectional	189 PLWH50+; 2017 HIV affected 50+, and 104 HIV uninfected older adults ≥50 years	51.0% on ART	Digital handgrip dynamometer	NA	Locally adapted	25.8 among PLWH50+; and 25.3 among HIV affected 50+ and 25.2 among the uninfected older adults ≥50 years.	Women scored poorly than men. Married respondents had significantly better scores than widowed and divorced respondents. Respondents with at least secondary education had significantly better scores.

ART, antiretroviral treatment; B-FIT 2, Brief Frailty Instrument of Tanzania; NA, not applicable; NR, not reported; PLWH50+, people living with HIV ≥50 years old; PR, prevalence ratio.

Author, publication year and country	Study design	Sample size	Treatment status of PLWH	Assessment tool used	Cut-off score	Information on local tool validation	Prevalence estimates/other results	Correlates reported
Studies that utilised different versions of the WHO Quality-of-Life Scale (WHOQOL)								
Obimakinde, (2020); Nigeria ³⁹	Cross-sectional	62 PLWH50+; 124 HIV uninfected older adults ≥60 years	All on ART	8-item WHOQoL	NA	NR	Mean QoL (SD): 82.7 (8.9) among PLWH50+; 86.2 (6.5) in the uninfected adults ≥50 years.	NR
Mugisha, (2013); Uganda ⁶³	Cross-sectional	198 PLWH50+; 311 HIV uninfected older adults ≥50 years	51.0% on ART	8-item WHOQoL	NA	NR	Mean QoL scores: 57.2 among PLWH50+; and 45.3 in the uninfected older adults ≥50 years	NR
Nyirenda, (2013); Uganda and South Africa ⁷⁰	Cross-sectional	400 PLWH50+; 732 HIV uninfected older adults ≥50 years	About 22% on ART	8-item WHOQoL	NA	Locally adapted and validated	Older people in South Africa were more likely to have a better quality of life (aOR 2.15, 95% CI 1.60 to 2.90) than in Uganda.	NR
Nyirenda, (2012); South Africa ⁶⁵	Cross-sectional	203 PLWH50+; 219 HIV uninfected older adults ≥50 years	23.7% on ART	8-item WHOQoL	NA	Locally adapted	Mean QoL scores: 62.5 among PLWH50+; and 59.4 in the uninfected older adults ≥50 years.	Being female and having been previously married was associated with lower odds of good QoL in PLWH50+
Yaya, (2019); Togo ⁵²	Cross-sectional	154 PLWH50+; 726 PLWH (15–49 years)	90.5% on ART	31-item WHOQOL-HIV BREF	≥77.3 was considered good quality of life.	NR	72.7% of PLWH50+ had a good global quality of life compared with 77.3% in the younger PLWH.	Correlates not aggregated by age
Maniragaba, (2018); Uganda ⁶⁶	Cross-sectional	28 PLWH50+; 884 HIV uninfected older adults ≥60 years	NR	An adapted version of the WHOQOL-OLD	An index (good, fair and poor quality of life)	NR	PLWH had poor quality of life (OR 0.45; 95% CI 0.22 to 0.93) compared with those who were HIV uninfected.	Not aggregated by HIV status

Continued

Table 3 Continued

Author, publication year and country	Study design	Sample size	Treatment status of PLWH	Assessment tool used	Cut-off score	Information on local tool validation	Prevalence estimates/other results	Correlates reported
Studies that used other measures of quality of life								
Parcesepe, (2020); Tanzania ⁴¹	Cross-sectional	82 PLWH50+; 824 PLWH (18–49 years)	ART naïve	HIV/AIDS-Targeted Quality of Life Scale	NA	Previously validated in other SSA settings	Mean QoL score: 68 among PLWH50+, and 72.4 among PLWH (18–49 years)	Reported correlates not aggregated by age.
Harding, (2014); Kenya and Uganda ²⁶	Cross-sectional	1337 adults aged 18–70 years (no of PLWH50 + NR)	49.9% on ART	Medical Outcome Scale -HIV (MOS-HIV)	NA	Previously validated in other SSA setting	Mean Mental Health score: 46.4 among PLWH50+; 46.2 in PLWH (18–49 years) Physical health score: 42.9 among PLWH50+; and 44.8 in PLWH (18–49 years)	Reported correlates not aggregated by age.

AOR, adjusted OR; ART, antiretroviral treatment; NA, not applicable; NR, not reported; PLWH50+, people living with HIV ≥50 years old; QoL, quality of life; SSA, sub-Saharan Africa.

DISCUSSION

Summary of main findings

Our review shows that the research on depression, anxiety, cognitive function, frailty and HRQoL among PLWH50 + in SSA is still scanty and largely concentrated in Uganda, South Africa and Ethiopia. Overall, PLWH50 + presented with wide-ranging prevalence of depression (6% to 59%), cognitive impairment (4% to 61%) and frailty (3%–15%). Additionally, the correlates of these outcomes were rarely investigated. Nonetheless, those reported were mainly sociodemographic variables, many of which were inconsistent. We find the current evidence inadequate to characterise the real burden and determinants of these outcomes in the region, partly because of the limited number of well-designed studies, heterogeneous findings, and substantial methodological limitations observed in many included studies. Therefore, any policies and programmes about the well-being of PLWH50 + in the region have been made on the basis of minimal evidence. The rising numbers of PLWH50 + in SSA and the potentially elevated burden of age-associated comorbidities in this population warrant more research across the region. Such data will provide the evidence needed to develop appropriate policies, programmes and interventions for the successful ageing of PLWH in SSA.

Depression and anxiety

Depression was the most frequently reported outcome in about half of the included studies. This finding is consistent with the available literature on HIV, which recognises depression as the most commonly occurring psychiatric complication in this population.⁶⁷ However, only two studies investigated anxiety, a CMD with a similar prevalence to those seen in depression.⁶⁸ The under investigation of anxiety disorders is of particular concern because accumulating research involving PLWH50 + in HICs has documented elevated anxiety levels, as high as 65%.⁶⁸ More research is needed on this outcome in the region.

Our review also noted wide-ranging prevalences of depression and anxiety. This finding corroborates previous review findings on the prevalence of CMDs in the region, although in younger HIV populations.⁶⁹ The observed variation could reflect significant contextual differences across the SSA region, for example, social environmental milieu, healthcare systems, patterns of the burden of diseases and mental health resources, which are likely to alter the risk profile of these adults.⁷⁰ It could also be attributed to potential differences in study populations, study participants and the use of diverse measurement tools (including different cut-offs for the same measures). Indeed, in the current review, depression was assessed using at least 10 different scoring systems with diverse cut-off points. Besides, the majority of the studies did not provide information on the reliability and validity of the tools they used. Hence, it is difficult to draw firm conclusions regarding the reliability, validity and applicability of many of the measures used to report this outcome. The PHQ-9, for instance, was frequently used to

report depressive symptoms among the included studies. However, most of the studies relied on previous validation of the tool, the context of which was not given. A recent review examining the validation of brief CMDs screening tools in low-income and middle-income countries did not support the use of PHQ-9 in these settings. It performed poorly in several clinic populations with lower average education but performed very well in high literate populations.⁷¹ This is especially an important consideration in SSA, where older adults are more likely to have low literacy levels. There is a need for rigorous cultural adaptation of these instruments to generate accurate epidemiological data that will inform proper intervention work among PLWH50 + in SSA.

Hiv-associated cognitive impairment

The neurological involvement in HIV disease progression remains problematic, even in well-controlled PLWH, resulting in poor quality of life. HIV associated cognitive impairment is deemed one of the most prevalent comorbidities in the era of ART. Ageing with HIV would appear to impose a synergistic impact, whereby increased comorbidities, such as hypertension, diabetes or depression, likely contribute to and maintain HIV-associated cognitive impairment. In HICs, PLWH50 + have consistently been shown to have high levels of cognitive impairments, as high as 50%. The present review found a wide-ranging prevalence of HIV-associated cognitive impairment (4%–61%). Our observation is consistent with the available literature, where the prevalence has been noted to vary widely depending on sources used and appears dependent on the populations studied, and approaches used.⁷²

Brief cognitive screening tools such as the Mini Mental State Examination and International HIV Dementia Scale (IHDS) were frequently used to document the prevalence of cognitive impairment compared with comprehensive neuropsychological batteries. While the use of the brief screeners in low-resource settings is well understood given the resource gap, researchers should exercise caution on the tools they use. Recent reviews evaluating brief screening tools for neurocognitive impairment in HIV/AIDS have indicated that some of the commonly used tools, for example, the IHDS perform poorly, especially in screening milder cognitive impairments.^{73 74} In the current review, information on tool reliability or validity was rarely reported. One of the studies reported a limited diagnostic accuracy of the IHDS. However, the OCS-Plus, one of the most recent screening tools, is promising. So far, the tool has only been used in South Africa among older adults living with HIV, and its initial evaluation yielded excellent construct and external validity.⁷⁵ This tool has the potential to address some of the unique challenges and gaps facing resource-limited settings in screening for HAND, including difficulty in performing long test batteries, limited screening tools and a shortage of clinical staff.

Frailty

Only two studies quantified the prevalence of frailty among PLWH50+, ranging from 3% to 15%. One of the studies was exclusively conducted among PLWH50+, yielding a low frequency of frailty (3%). In the other study, conducted in rural South Africa, the prevalence of frailty was similar between PLWH50 + and their uninfected counterparts (15% vs 18%, respectively). This finding supports the growing evidence in SSA, which suggest that older on effective ART have similar or better health profiles than their uninfected counterparts, contrary to what has been observed in HICs. At the global stage, the frailty prevalence in SSA appears relatively lower than that of HICs which ranges from 5% to 29%.⁷⁶ The population reaching older age in many SSA settings may be relatively fit/active, still working, which may be true of PLWH, potentially favouring better physical health in these individuals. Nonetheless, given the limited number of studies on this outcome in SSA, these findings remain preliminary and inconclusive and highlight the urgent need for more studies to shed more light on these observations.

Health-related quality of life

For some time, HRQoL has emerged as a salient indicator of HIV care and an essential target for HIV-related research, aiming to expand the service paradigm continuum.⁷⁷ This new quality of life frontier has been proposed as the 'fourth 90' to the original '90-90-90' testing and treatment target championed by UNAIDS: to ensure that 90% of people with viral load suppression have good HRQoL.⁷⁷ In the current review, research on HRQoL among PLWH50 + was scanty. Thus, little is known on the risk and protective factors of patient-reported HRQoL. Further studies should explore the independent effects of aging-related conditions such as CMDs, cognitive impairments and frailty on HRQoL among PLWH50 + in SSA to support healthy ageing even in the context of a chronic illness such as HIV infection.

Despite the observed limitations, the evidence of better mental health,^{28 44 50 51 54 58 59} as well as cognition,^{53 61} frailty/handgrip strength^{47 62 63} and quality of life,⁶⁵ among PLWH50 + on ART (mainly among the robust studies with low risk of bias) compared with uninfected older adults in the current review was striking. This observation could be part of an emerging body of evidence from SSA showing that the mental and well-being outcomes among PLWH are comparable to those without HIV. The mechanisms responsible for this observation are not well established and require further examination across many settings in SSA. However, it could be attributed to a few plausible reasons, including (1) the direct impact of ART on viral replication, inflammatory pathways and downstream disease pathophysiology, the so-called 'ART advantage',^{78 79} (2) a survivorship bias among PLWH50 + who access and remain in HIV care and (3) beneficial spillover effects of ART programmes such as enhanced access to and utilisation of primary care services resulting in early identification and management

of comorbid conditions.^{79–81} This observation could also be related to the fact that PLWH50 + on ART are more likely to use biomedical facilities due to better education and higher socioeconomic status than their HIV uninfected peers. More studies, preferably longitudinal ones, will shed more light on this observation. As it stands, however, this finding offers an interesting contrast to the commonly reported findings from HICs, which generally show that PLWH50 + present with worse physical and mental health outcomes compared with age-matched HIV uninfected people.^{5 68 82} These findings may suggest context-specific differences in the drivers of physical and mental outcomes, including the demographic and risk factor profile as well as the role of engagement in HIV care—among those with and without HIV, especially when comparing low-income and middle-income to HICs. Future studies should explore the extent to which HIV programmes could be promoting the well-being of PLWH50 + in SSA compared with HIV uninfected older adults in the general population who are likely to bear the brunt of the prevailing poor health systems and primary care systems in the region.

The correlates of mental and well-being outcomes

The correlates of CMDs, cognitive impairment, frailty and HRQoL have been scarcely investigated in SSA. In the current review, the frequently reported correlates were sociodemographic in nature, many of which (eg, age, formal education levels and wealth status) were inconsistent. However, being female was consistently associated with declining mental health, cognitive function, HRQoL and frailty status. This finding mirrors the results of a recent review of older women's physical and psychological health residing in SSA, which indicated that women were significantly more likely to report poor health compared with men.⁸³ This finding highlights the need for adequate representation of both sexes in research studies, incorporating a gender lens in their analyses to understand better the unique health challenges that each gender faces. Further studies are also urgently needed in SSA to identify potential risk and protective factors, especially those that could be modified, to suggest how to best integrate the management of these impairments in HIV care guidelines in SSA. Future studies should explore the influence of HIV-related factors, psychosocial risk (eg, loneliness, ageism, stigma, social support, living arrangements) and other comorbidities on the health and well-being of PLWH50+. To promote healthy ageing in the context of chronic conditions, such as HIV infection, the psychological and social domains are especially critical as they could be a way to compensate for physiological limitations (ie, multiple chronic conditions) and allow even in the context of disease and disability, to experience optimal quality of life.

Strengths and limitations

To our knowledge, this is the first comprehensive review of CMDs, cognitive impairment, frailty and HRQoL



among PLWH50 + living in SSA. Our expanded search of five online databases and snowballing techniques minimised the risk of missing relevant studies. However, our review should be considered in the context of important limitations. Despite a thorough search strategy, some articles may have been missed, especially in excluding non-English language studies. However, these were very few. The substantial amount of heterogeneity across the studies in terms of, for example, study design, operationalisation of age, definitions of outcomes and measures made comparisons difficult and did not allow a meta-analysis to be done. Furthermore, most of the studies recruited PLWH50 + from HIV clinics whose attendees may represent the less-healthy end of the spectrum of service users leading to overestimation of reported outcomes. Conversely, those at the filter end of the cohort may be more able to attend or be proactive concerning their well-being, leading to underestimation of outcomes. Besides, the substantial methodological limitations observed might have biased the reported findings, hence limiting their external validity.

CONCLUSIONS

Overall, the existing research on the burden and determinants of mental and well-being outcomes among PLWH50 + in SSA is scanty addressed. We also noted substantial limitations in many of the included studies, which need to be addressed in future studies. Our findings underscore the need to increase the evidence base of these outcomes in the region. Future studies should: (1) explicitly target older persons ≥ 50 years living with HIV, (2) carefully select a comparison group and have sufficient sample sizes for adequate statistical testing, (3) expand the geographical distribution of these studies in many SSA settings and use adequately standardised survey tools adapted for the region and (4) generate more data on the risk and determinants of these outcomes using a gender lens. There is also an ongoing need for well-designed longitudinal cohort studies to study the temporal patterns of these outcomes in the region.

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Navigating Life With HIV as an Older Adult on the Kenyan Coast: Perceived Health Challenges Seen Through the Biopsychosocial Model

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Objectives: This study explores the perceptions of adults living with HIV aged ≥ 50 years (recognized as older adults living with HIV—OALWH), primary caregivers and healthcare providers on the health challenges of ageing with HIV at Kilifi, a low literacy setting on the coast of Kenya.

Methods: We utilized the biopsychosocial model to explore views from 34 OALWH and 22 stakeholders on the physical, mental, and psychosocial health challenges of ageing with HIV in Kilifi in 2019. Data were drawn from semi-structured in-depth interviews, which were audio-recorded and transcribed. A framework approach was used to synthesize the data.

Results: Symptoms of common mental disorders, comorbidities, somatic symptoms, financial difficulties, stigma, and discrimination were viewed as common. There was also an overlap of perceived risk factors across the physical, mental, and psychosocial health domains, including family conflicts and poverty.

Conclusion: OALWH at the Kenyan coast are perceived to be at risk of multiple physical, mental, and psychosocial challenges. Future research should quantify the burden of these challenges and examine the resources available to these adults.

Keywords: older adults, sub-Saharan Africa, HIV, Kenya, biopsychosocial challenges

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INTRODUCTION

The last decade has witnessed a dramatic shift in the demographic profile of people living with human immunodeficiency virus (HIV) globally. Presently, many HIV clinics are caring for a growing number of adults aged ≥ 50 years (categorized as older adults) due to increased survival in people living with HIV (PLWH) and a steady rise in HIV diagnoses in this age cohort [1]. More than 30% of the PLWH in High-Income Countries (HICs) are now aged ≥ 50 years [1] compared to 15% in sub-Saharan Africa (SSA) [2]. These statistics herald a new era in the HIV epidemic response, where the needs and demands of the OALWH can no longer be ignored, especially in Eastern and Southern Africa, home to more than half the number of OALWH globally [1].

Research findings, mainly from HICs, indicate that OALWH present with an average of three comorbid conditions in addition to HIV, including medical diseases (e.g., diabetes, hypertension), mental health problems (e.g., depression, anxiety, substance use, cognitive problems) and social challenges (e.g., stigma, loneliness, and lack of social support) [3–6]. The observed mental health challenges reduce the quality of life of these adults and have important health implications, e.g., poor HIV treatment [7]. The physical health problems faced by OALWH may also be complicated by environmental and psychosocial challenges such as poverty, food insecurity and lack of support [7].

Despite the evidence of complex health challenges related to ageing and HIV, little research has qualitatively examined how OALWH understand their health and care needs. To date, most studies of ageing and HIV in SSA are cross-sectional studies focusing on biomedical processes and outcomes and rarely provide local insight into the health and wellbeing of these adults [8]. Qualitative studies are needed to better understand the experiences and needs of this diverse population, especially among low-literacy populations. This is especially important as many cohorts of OALWH are emerging for the first time across the SSA region, and the apparent variability in findings among previous studies, e.g., in the prevalence and determinants of chronic comorbidities [8]. Apart from complementing quantitative studies in accurately documenting the burden and determinants of the health challenges in these adults, qualitative studies will shed light on the contextual factors to guide the development or adaptation and subsequent implementation of culturally appropriate interventions in this population. Overall, the few qualitative studies among OALWH in SSA are mainly concentrated in Uganda [9–13] and South Africa [14–18]. Others are from Kenya, Eswatini and Malawi [19–22]. In Uganda, ageing with HIV is seen as a daily challenge financially and socially [9–13]. The key barriers to successful ageing with HIV in this setting include stigma, food insecurity, and unmet healthcare needs, particularly for associated comorbidities such as common mental disorders. In South Africa, the crucial barriers to living with HIV in old age include food insecurity, unemployment, stigma, and access to transportation and healthcare [14–18].

Emerging data suggest that OALWH in Kenya face complex challenges when seeking care, including visits to multiple providers to manage HIV and comorbidities, ageist discrimination, and inadequate social support [20, 21]. However, these data come from the Western region of Kenya. As such, the health and wellbeing experiences of OALWH from other parts of the country is not known. To bridge this research gap, we conducted in-depth interviews to explore the health challenges faced by OALWH at Kilifi, a low literacy setting at the coast of Kenya. Using the biopsychosocial framework, we explore the perceptions of 34 OALWH, 11 healthcare providers and 11 primary caregivers on the physical, mental, and psychosocial challenges of ageing with HIV in this setting.

Theoretical Framework

We utilized Engel's biopsychosocial model of health [23], which provides a logical account of the chronic, complex, and dynamic nature of HIV. This model recognizes healthy ageing as the ability to thrive in an evolving environment influenced by physical/biological,

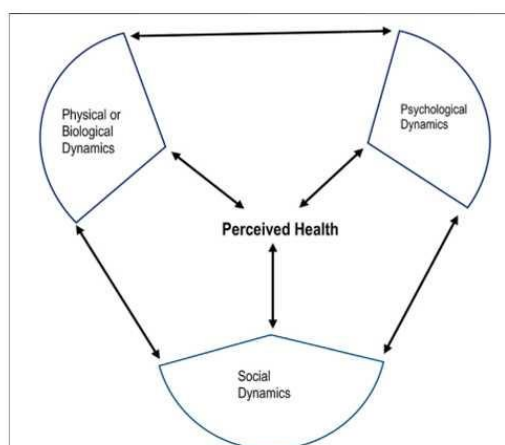


FIGURE 1 | Components of the biopsychosocial model of health (HIV-Associated Neurobehavioral Disorders Study, Kilifi County, Kenya 2019).

mental/psychological, and social factors (Figure 1). The model provides a holistic approach to understanding the health needs of older adults and is supported by calls for research that positively impact the physical, mental, and social aspects of ageing with HIV [24–26]. According to this model, the cause, manifestation and outcome of wellness and disease are determined by a dynamic interaction between physical, psychological, and social factors [23]. Each model component includes systems that reciprocally influence other dynamics in the model and also affect health.

METHODS

Study Context and Participants

This study was conducted in 2019 at the Kenya Medical Research Institute (KEMRI) located within Kilifi County on the coast of Kenya. By the end of 2019, there were roughly 1.5 million residents in Kilifi County, the majority of whom were rural dwellers (~60%), and 11% were aged ≥50 years [27]. Kilifi has an HIV prevalence of 38 per 1,000 people [28] in the general population and is currently unknown in those aged ≥50 years. People living with HIV usually receive care in specialized HIV clinics within primary care facilities.

This study involved the following three groups of participants.

- OALWH aged ≥50 years receiving HIV care and treatment at the HIV Comprehensive Care Clinic of the Kilifi County Hospital (KCH).
- Healthcare providers attending to OALWH.
- Primary caregivers of OALWH.

Recruitment and Eligibility

Study participants were selected purposively to represent diversity in the participants' characteristics, including age,

sex, and the cadre of service (for healthcare providers). Initial contact was made via a community health volunteer stationed at the KCH. Recruitment was conducted by a trained research assistant in liaison with the community health volunteer during their routine clinic visits. OALWH had to be ≥ 50 years old and on HIV treatment to be eligible. Primary caregivers were identified through the OALWH, usually during their scheduled clinic visits. These caregivers had to be directly involved in providing care and support, e.g., medical care to an OALWH. HIV providers were approached at their place of work and invited to participate. We specifically targeted providers who provided direct care to OALWH. Participants who agreed to participate were invited to a face-to-face interview at a convenient place, usually at KEMRI Kilifi.

Data Collection and Tools

The lead author (PM) conducted in-depth interviews lasting, on average 45–60 min with each participant. All the interviews were guided by a pre-tested semi-structured interview schedule developed with guidance from prior work on HIV and ageing. All interviews were conducted in Swahili, English or Giryama. We also sought permission from the participants to take notes and audio record the interviews.

Among OALWH, topic guide themes included: patient illness experiences following diagnoses. These issues were explored using general open-ended questions, followed by additional probing to highlight further the issue raised. For healthcare providers, participants were invited to share their experiences providing care to OALWH. Among caregivers, we explored different issues, including their experiences taking care of OALWH and the challenges these adults faced in their environment. We also collected respondents' demographic information such as age, sex, educational status, and employment status. For OALWH, we also collected HIV-related information. All participants were given Ksh 350 (about US\$3) as compensation for time spent in the research, with transport expenses also reimbursed.

Data Analysis

All the audio-recorded interviews were transcribed verbatim by a team of four trained research assistants. Subsequent data management was done using NVivo software (version 11). We applied the framework approach to analyze our qualitative data [29]. Initially, two authors (PM and AA) developed a preliminary coding framework inductively through in-depth reading of transcripts and deductively by considering themes from the interview schedules. These codes were discussed, and consensus reached on how they should be brought together into themes with guidance from the biopsychosocial model. The initial coding framework was progressively expanded to capture emergent themes as coding continued. When the coding was complete in NVivo, the lead author grouped all themes related to a specific concept to form categories and exported this to a word-text processor to produce charts. The generated charts were used to summarize data, look for similarities or differences and explore patterns among the three groups of participants in the analyzed data.

TABLE 1 | Sociodemographic and clinical characteristics of older adults living with HIV (HIV-Associated Neurobehavioral Disorders Study, Kilifi County, Kenya, 2019).

Characteristic	n (%) or median (IQR)
Median age	57 (54–63)
Female	18 (53%)
Educational level	
None	7 (20%)
Primary Level	21 (62%)
Secondary level	5 (15%)
Tertiary level	1 (3%)
Type of employment	
Unemployed/not working	12 (35%)
Small scale trader	15 (44%)
Casual worker	4 (12%)
Professional/skilled work	3 (9%)
Marital status	
Never married	1 (3%)
Married	19 (56%)
Separated/Divorced	7 (21%)
Widowed	7 (21%)
Living arrangements	
Alone	5 (15%)
Single generation household	4 (12%)
Multigenerational household	25 (73%)
Median household size	5 [2–9]
Residence (rural)	30 (88%)
Median duration since HIV diagnosis (years)	12 [10–15]
On ART treatment	34 (100%)
HIV status disclosure	
Non-disclosure	1 (3%)
Partial disclosure (to close family only)	18 (53%)
Full disclosure (beyond close family)	15 (44%)

Notes: ART, antiretroviral treatment; IQR, interquartile range.

Ethical Considerations

Written informed consent was obtained from all participants in the study. The study also obtained ethical clearance from the Kenya Medical Research Institute Scientific and Ethics Review Unit (KEMRI/SERU/CGMR-C/152/3804) and the Kilifi County Department of Health Services (HP/KCHS/VOL.X/171).

RESULTS

Sample Characteristics

We interviewed a total of 56 participants (34 OALWH, 11 healthcare providers and 11 primary caregivers) in this study. Among OALWH, 53% were women; most (82%) had up to a primary level of education, and their age ranged from 50 to 72 years. All the OALWH were on HIV treatment. Healthcare providers included six registered nurses, two clinical officers, two project managers of community-based organizations and one HIV counsellor. All the primary caregivers were family members, most of whom (73%) were female. Further sociodemographic information and HIV-related characteristics of the OALWH are summarized in **Table 1**.

TABLE 2 | Perceived forms of physical, mental, and psychosocial health challenges facing older adults living with HIV as discussed by study participants (HIV-Associated Neurobehavioral Disorders Study, Kilifi County, Kenya 2019).

Forms of health challenge	Number of in-depth interviews (among OALWH) where the health challenge was discussed (N = 34)	Number of in-depth interviews (among caregivers) where the health challenge was discussed (N = 11)	Number of in-depth interviews (among healthcare providers) where the health challenge was discussed (N = 11)
Physical complaints			
Comorbidities: chiefly ulcers/hyperacidity, hypertension, and diabetes	29	9	11
Wide-ranging physical symptoms, e.g., pain/ body aches, fatigue, insomnia	33	10	9
Functional impairments, e.g., difficulties walking, writing, holding things	18	3	3
Mental complaints			
Symptoms suggestive of common mental health problems, e.g., thinking too much, worry, stress, low mood, hopelessness/ giving up easily	29	9	9
Cognitive complaints chiefly memory difficulties. Others including slow mental processing/learning, attention/ concentration problems	22	7	4
Current drug and substance use, mainly "mnazi" and "ugoro," which are the local palm wine and smokeless tobacco, respectively	5	0	9
Suicide and suicidal ideations	3	0	4
Psychotic-like symptoms, e.g., disorganized behaviour, aggression, lack of restraint and unwanted thoughts	1	3	3
Psychosocial complaints			
Financial difficulties, e.g., lacking school fees for dependents, walking long distances for HIV care	31	8	9
HIV-related stigma and discrimination especially internalized and enacted stigma	29	8	11
Ageism/ageist stereotype, e.g., neglect, verbal insults, vandalism	19	5	7
Isolation and lack of support	19	5	8
Loneliness	17	1	8
Food insecurity, e.g., skipping meals or going days without food	16	5	9

Perceived Biopsychosocial Challenges Confronted by OALWH

The different forms of biopsychosocial challenges faced by OALWH are summarized in **Table 2**. Overall, most of the OALWH shared their 10-plus years of experience living with HIV, from the time of diagnosis to their current state. The majority of the OALWH described moving from a state of shock, fear, anger, denial, hopelessness, or suicidal ideation upon diagnosis to a state of acceptance and ownership. This transition was not without challenges, as many of the OALWH noted going through traumatic experiences from family members, friends, workmates, and healthcare providers. Thereafter, they narrated moving from a state of ownership to a state of constant survival characterized by an array of health problems which we have conceptualized as physical (biological),

mental (psychological) and social in the following sections according to the biopsychosocial model.

Perceived Physical Health Challenges

Physical complaints were commonly described by several participants. Key among these concerns was the onset of multiple comorbidities in these adults, which was frequently associated with pain, loss of control of one's body, emotional distress, and increased treatment burden. Hypertension, diabetes, ulcers/hyperacidity, hearing, and visual impairments were the most frequently reported comorbidities across the participants. Other conditions discussed (though to a lesser extent) included obesity, arthritis, stroke, teeth problems, cervical cancer, TB, and pneumonia. Apart from these comorbidities, somatic symptoms were also discussed in several interviews across the groups. Body

TABLE 3 | Participants' physical health challenges quotes (HIV-Associated Neurobehavioral Disorders Study, Kilifi County, Kenya 2019).

Perceived health problem	Examples
Multiple comorbidities	I am weak and constantly fatigued because I have ulcers, high blood pressure, and diabetes. My eyes are also painful and feel strained, and I sometimes experience toothache. As we are talking right now, my ears are not hearing well. So, all these diseases make me weak and significantly affect my wellbeing (<i>Female OALWH-10 years with HIV</i>)
	Ulcers is their main problem. Many of them complain of ulcers, and this is mainly because of stress. Anything small affects them. Sometimes you find one thinking too much and another telling you, "My children do not take care of me; they have forgotten about me" or "I have one child." Someone tells you about their child who died long ago but is still affected. Stress is a big problem because they pile up issues, not because of HIV but other issues. Another issue is food. The elderly must look for food for themselves and their irresponsible children, who may be drunkards. Often, you find that they deal with their stress and that of their children (<i>Nursing officer</i>)
	Last year, my hands were painful, and I could not bend. I carried out an X-ray and was told it was arthritis. I was told there was no treatment, and the only relief was by massaging myself and using painkillers. So, I bought clove oil, and it is what I have been using. There are improvements, but the problem is not resolved yet. I am also unable to work, and to make it worse, and I have difficulties sleeping whenever I am stressed. I was recently diagnosed with high blood pressure but am not taking medications yet. I also have ulcers, but I do not usually keep it in mind (<i>Female OALWH-11 years with HIV</i>)
Somatic symptoms	My knees are painful. Sometimes even squatting is a big challenge. I also cannot rise too quickly from a seated position; I have to support myself. I must also use painkillers for some relief before I can work. This has affected me because I cannot work without them. Whenever the analgesic effect wears out, it becomes very difficult to use my legs. I also experience headaches sometimes, and my relief is usually the painkiller. These painkillers have become my life now (<i>Female OALWH-2 years with HIV</i>)
	My pace has become very slow nowadays. I feel heavy, and there is nothing I am lifting or carrying. I often feel tired, and, at such times, I prefer walking around for some time. I must do this to ward off intrusive thoughts. Since being diagnosed, I have also grown weak and lost my libido. In fact, whenever I start having sex, I have this sensation of my waist being cut with a razor (<i>Male OALWH-10 years with HIV</i>)
	My husband cannot do heavy manual jobs. He used to work at the sea at night, which is usually cold and requires energy. It reached a point I had to stop him from going there anymore because he was weak and felt he was risking his life. Before this, he often used to complain of being sick. I was not at peace. I found it pointless for him to earn money that way and end up using it to medicate him. So, I told him to stay at home and do anything else. We are living by the mercies of God (caregiver)

pain, headaches, insomnia, fatigue or low energy, and limb numbness were also frequently reported. Some participants believed that the onset of the physical challenges was because of HIV-related factors (e.g., HIV infection itself, long-term ART), multimorbidity, old age, food insecurity, emotional distress, substance use, and the nature of someone's work. Participant quotes are given in **Table 3**.

Perceived Mental Health Challenges

We have discussed these issues under the following headings: symptoms suggestive of common mental health problems, cognitive symptoms, substance use problems, and others (suicidal ideation and psychotic symptoms). Participant quotes are given in **Table 4**.

Symptoms Suggestive of Common Mental Health Problems

Emotional and behavioral symptoms, suggestive of anxiety and depression, were described to be prevalent across the participant groups. Key among these symptoms included thinking too much, persistent stress, low mood, anger/irritability, worrying a lot, hopelessness, restlessness, panic attacks, and nightmares. Other prominent symptoms included insomnia, self-isolation, low self-esteem, headaches, and low libido. Overall, these symptoms were described to be on-and-off among the OALWH and were frequently associated with the exacerbation of physical conditions, chronic use of drugs, financial instability, and

overall poor quality of life. For many participants, the onset and persistence of physical body changes (e.g., peripheral neuropathy, obesity, body weakness) were considered a significant risk for mental complaints.

Cognitive/Neurological Challenges

The commonly reported complaint in this category was memory difficulty, e.g., difficulties recalling important dates or finding items. Surprisingly, most OALWH reported that they rarely forgot to take their medications. Many healthcare providers corroborated this, although they also noted that there are some OALWH at risk of poor adherence caused by cognitive impairments. Other cognitive symptoms included attention/concentration, processing/learning, movement, and multi-tasking difficulties. Peripheral neuropathy was also reported to be a common neurological problem in these adults and was associated with significant distress. Among OALWH, the cognitive symptoms were viewed as an additional disease, and many did not understand its causes. The few who sought medical attention ended up being disappointed, sometimes being advised that it will resolve on its own or there is medicine, but it is costly.

Drugs and Substance use Problems

Current drug and substance use was mainly discussed by healthcare providers. In contrast, most OALWH reported having a history of drug and substance use, especially alcohol and tobacco but stopped following HIV diagnosis. However,

TABLE 4 | Participants' mental health quotes (HIV-Associated Neurobehavioral Disorders Study, Kilifi County, Kenya 2019).

Perceived health problem	Examples
Symptoms of stress, depression, anxiety, trauma	Living with HIV is difficult, my brother because you must take medications daily without missing and must live knowing that you are sick and could die any moment. This reality makes me depressed. I also do not know who will take care of my family if I die because my relatives are useless to me! I am jobless, and this makes me very sad and depressed because I have a family that needs to be cared for! I do not have money, getting food is a big problem, and to tell you the truth, I cannot even afford to pay school fees for my children. I must borrow to survive. As we are speaking, I have a court case because am unable to repay a loan I took (<i>Male OALWH-20 years with HIV</i>)
	My eyes cannot see well and are very itchy. Today in the morning, I had to compress them with hot water. The itchiness is often accompanied by coughing. I was prescribed some medications, but they were not helpful. You see this paper am holding; I cannot read anything on it unless I view it in very bright light during the day. At night, I can hardly make out the person calling my phone! This has affected me a lot. I am worried and do not know when this problem will end. Sometimes I want to work, e.g., write something, but I cannot. At night I must also depend on someone else to guide me. Other times I cannot work at all because of my eyesight problems. Whenever I am depressed, I just run to God (<i>Female OALWH-2 years with HIV</i>)
	My mum is generally stressed and very irritable. Sometimes she can get so stressed that she falls sick, forcing us to take her to the hospital (<i>Male Caregiver</i>)
	Sometimes, she gets very preoccupied with thoughts until she cries . . . not often, but it happens. Sometimes she also has trouble sleeping, and when I inquire why she tells me, "I am always thinking, and I do not know exactly what I am thinking about, and I do not have peace." I think she would love to be free with everyone and go anywhere she wants without people talking behind her back. She is sensitive, you know. When she hears people laughing, she usually asks me, "Why are they laughing? Are they laughing at me?" Sometimes, she does not come out of her room for two or 3 days and must force her to eat something (<i>Female Caregiver</i>)
Cognitive symptoms	There is this client; her skin has spots, her jaw has dropped, and looks weak when she walks. She is often in deep thought; for instance, we could be in a seminar where many people participate, but you find her lost in her thoughts. We had to talk to her at some point, and we realized she had been abandoned by her husband, who had married another wife. We had to do a referral for this client because of these issues (<i>Project manager of a community-based organization</i>)
	You know these people are dealing with so many things which affect them. Stress, anxiety, and depression, and that is why screening is being done, and any positive case is linked with the psychiatric clinic (<i>Nursing officer</i>)
	I can plan to do one or two things but later abandon them and do something different without any reason. For instance, I could be having a meeting, perhaps with some elders, but end up not doing and instead do other things. There is also this issue of forgetting, which is like a disease to me. I usually have a problem finding my things. Like yesterday, I could not find my money. I am worried about this problem, which is like a disease nowadays. I start doing one thing, then abandon it, and do the same to another. Sometimes my food gets burnt in the kitchen because I forget I was cooking and start doing other things. One time I decided to see a clinician about this disease because it was too much. I do not know whether it is because of these medications we are taking or something else. The clinician told me it would end with time. One thing I know, though, is that I was not like this before. This problem started when I began taking these medications. I am very surprised! I am not alone in this; many of my peers also complain of the same thing. Or could it be old age (<i>Female OALWH-13 years with HIV</i>)
	I can place my things in one place and forget about them. This can be money or even fruits. If I do not tell my husband that I have bought, e.g., fruits and have placed them in the cupboard, those bananas will go bad. He (my husband) will remember, but I will not. My body also becomes numb sometimes. My hand becomes heavy and immobile, especially in the morning. This extends to the shoulders and usually makes it impossible to carry things. The hands sometimes tremble and experience prickly feeling (of pins) in addition to numbness and general weakness. One of the legs is also involved in this (<i>Female OALWH-10 years with HIV</i>)
	To speak the truth, my husband does not concentrate nowadays. Actually, the real issue is his forgetfulness. It is a real concern for me. I have tried to make him understand that he has this challenge, but he never accepts it. I have suggested we look for medications, but he does not want to. He has also become very irritable lately. I think very few people will be able to tolerate him (<i>Female Caregiver</i>)
	You might explain something to one of them (OALWH) and moments later find that they contradict that same information. We have such cases, but not very many. Some take their ARVs and septrin/co-trimoxazole the same way when it is not supposed to be. In fact, some interchange these drugs when they come for their refill appointments. Because of this, we usually emphasize how the drugs should be taken and give them shorter appointments, e.g., weekly, for those who stay nearby. We also ask them to come with their treatment support persons, but some say they do not have them (<i>Nursing officer</i>)

(Continued on following page)

TABLE 4 | (Continued) Participants' mental health quotes (HIV-Associated Neurobehavioral Disorders Study, Kilifi County, Kenya 2019).

Perceived health problem	Examples
Substance use and suicide	My only addiction is to smokeless tobacco, but I stopped taking alcohol long ago. I have never smoked cigarettes before. I must use it (smokeless tobacco) every morning; otherwise, my heart will not be at peace; I will start feeling sad and not concentrate on any task. I only feel okay once I use it (<i>Female OALWH—2 months with HIV</i>)
	Adults of my age in this community are ill-mannered. They like taking alcohol and smoking cigarettes. They also have extra-marital affairs. Every morning, they must have a packet of cigarettes and ensure they do not miss a bottle of the local palm wine because they cannot afford beer. They have to take a bottle or two for them to sleep well (<i>Male OALWH—14 years with HIV</i>)
	I often feel like taking my own life. These thoughts come to me quite often, especially when I am stressed. Usually, a certain voice tells me that I am better off dead than alive, and another voice tells me not to do it. There is a fight between God and the devil. Sometimes I wake up in the middle of the night around midnight and start thinking about many things, which is how I lose my sleep entirely. I am just thinking, "I do not have money, my wife is unemployed, and my children are still in school. Where will I get food?" So, in the morning, I share this with my wife. At the church, we are also told that suicide is not the solution; it is adding the problems, so it is better to struggle but survive (<i>Male OALWH—14 years with HIV</i>)
	Not just suicidal ideations. Sometimes we also have cases of actual suicides. Last month, an older adult committed suicide. He was recently diagnosed with HIV, and two of his three wives also turned positive. We do not know what happened, but we received news that the old man had committed suicide 2 days later. So, it is a challenge (<i>Clinical officer</i>)

some confessed to being social drinkers. "Mnazi" and "ugoro" (smokeless tobacco or snuff) were the commonly used substances. Many providers emphasized that *mnazi* drinking is a big problem, noting that some OALWH came for their routine clinic appointments while drunk and sometimes forgot to take their ART drugs. Some providers also associated the *mnazi* drinking problem with unsuppressed viral loads, treatment default, and sexual risk-taking behaviors, e.g., multiple partners. The key underlying factors for the increased use of *mnazi* included family conflicts which often led to stress, unstable sexual partners, negative coping skills, culture, and easy access to these substances. *Ugoro*, the other commonly abused substance, was especially common among women. Beer, cigarettes, khat and marijuana were also discussed, although to a lesser extent.

Suicidal Ideation and Psychotic-like Symptoms

Three OALWH reported having intermittent suicidal ideations. This was corroborated by the healthcare providers. The commonly associated factors included persistent stress (caused mainly by financial difficulties and family conflicts), evil spirits, and HIV-related (e.g., getting tired of taking ART and not getting healed). Though limited, there were also few reports of psychotic-like symptoms (e.g., disorganized behaviour, aggression, lack of restraint and unwanted thoughts) across the three groups of participants. These cases were frequently observed around the time of HIV diagnosis.

Perceived Psychosocial Challenges

We present these issues under the following categories: a) financial challenges, b) stigma and discrimination, and c) loneliness and isolation. Participant quotes are given in Table 5.

Financial Challenges

This was discussed in virtually all the interviews we conducted. Many participants felt that financial difficulty was the most crucial issue affecting OALWH in the study setting because of its massive impact on food security, caregiving responsibilities,

emotional wellbeing, and management of HIV and other comorbidities. Many OALWH reported skipping meals or going hungry for some days, lacking school fees for their dependents, and walking long distances to access HIV care for lack of money. This was corroborated by the healthcare providers and caregivers, who further stated that many of those who slept hungry tended to skip their medications, complaining of dizziness, headaches, and stomach discomfort. To some extent, this was associated with poor treatment outcomes, including unsuppressed viral load and poor retention in care.

Stigma and Discrimination

This theme incorporates HIV-related stigma and ageism (discrimination based on age). Despite relatively high levels of disclosure, many OALWH experienced HIV-related stigma. Discriminatory behaviour (enacted stigma from malicious gossip to outright discrimination, e.g., neglect, isolation, verbal insults) was reported to be common, especially in the most rural areas of the study setting. The perpetrators were mainly family members. Stigma was also reported to be common in *mnazi* drinking dens called "mangwe," burial ceremonies, and HIV clinics. Internalized stigma emerged as an important theme, especially among the OALWH and was frequently associated with self-isolation, anxiety or high consciousness of self, fear of seeking assistance, attending very far HIV clinics, stress, and irritability.

Many participants also highlighted discrimination based on age, which was perceived in multiple settings, including the home (mainly through isolation, neglect, and lack of respect from children), HIV clinic (e.g., scolded openly and verbal insults), and the community level. It also emerged that some community members around the study setting (especially in the most rural areas) regarded older people suspiciously. Many participants narrated hearing or witnessing several older people being beaten, beheaded, or burned alive in their houses for suspected witchcraft, and the perpetrators were mainly close family members.

TABLE 5 | Participants' psychosocial challenges quotes (HIV-Associated Neurobehavioral Disorders Study, Kilifi County, Kenya 2019).

Perceived health problem	Examples
Financial challenges	I am jobless, my brother. I have also lost my hands-on skills and experience with time. I am weak and do not have money. Getting food is a problem, and to speak the truth, even raising school fees for my children is a huge problem. Nevertheless, I have a very good friend, a lawyer, who is of great help to me. Sometimes, I eat at his place, lunch and dinner, but he does not know I live with HIV. Sometimes I am depressed and anxious because I do not know how to provide for my family. My relatives are of no help to me. Like yesterday, we did not have dinner, and I had to borrow the fare to come to this place. As we speak, I am in debt and face a court case because I cannot repay a loan. Often, I sleep hungry and must borrow to survive (<i>Male OALWH-20 years with HIV</i>)
	To speak the truth, I do not receive any support from my relatives, and this is not because there are no people to help. My husband and father died. I often sleep hungry. Sometimes, I only have a cup of porridge for three consecutive days . . . and this is usually borrowed from a neighbour so that I can take my medications. Other times, I survive on a cup of tea or hot water. Fare is also a big challenge. However, whenever I lack fare, I usually walk to the clinic from Bamba to Kilifi (around 50 km). I usually start my journey 2 days ahead of my clinic appointment and have two rest points in between, first at <i>Magogoni</i> and then at Kilifi at my uncle's place. From my uncle's place, I then walk to the clinic very early in the morning before 6 am (<i>Female OALWH-5 years with HIV</i>)
	Financial challenge is a big problem for these adults because they are neglected by their children sometimes. The day I am on duty at the clinic, I usually give many of them fare. You will hear many saying, "sister, please help me with fare, I walked to the clinic, and I have to walk back." If you have a good look at them, they appear exhausted, so you end up helping them. Even food is a challenge. In our discussions, the majority say that they have one meal per day and mind you, some fail to take their medications whenever they miss a meal due to dizziness claims (<i>Nursing officer</i>)
	The other day, we visited an elderly client in the community, a woman caring for two grandchildren living with HIV. The grandmother is unemployed, and the children's mother is not around. The grandchildren are in school. They need support with their schooling in addition to food. She is largely unable to provide all these and often must borrow. Sometimes, you find that even the skills you give them, e.g., rearing chicken or fish and making baskets, are not helpful because they are old and unable to work. In such cases, we assist them with food, counselling sessions, linkages, and referrals to foster treatment adherence and the wellbeing of the children (<i>Project manager of a community-based organization</i>)
Stigma and discrimination	I usually borrow money from neighbours or friends to buy food whenever my mother does not have. I do not mind the debt because my target is to ensure that my mother has food to take her medications. However, it is a bit stressful because sometimes she sleeps hungry. And this is complicated by my father, who often quarrels my mother over small issues, increasing her stress. Every time my mum asks for money, he says he does not have it, and if we ask him how we will survive, he replies, "Can't your son look for the money?" It is frustrating because how can I take up this responsibility while in school? In fact, the one educating me is usually my grandfather (<i>Caregiver</i>)
	The elderly living with HIV undergo many challenges in the community. For instance, you find one is sick, and no one is taking care of him at home. In fact, people will avoid interacting with this person, especially where he sleeps, out of fear of contracting the virus. Some of them have called me seeking help. Sadly, when I go to their homes, I find some have not even bathed for a whole week! In such a case, I usually clean up the person and assist him in eating. It is sad because the family places the food there; the person is sick and can hardly eat alone! Some are told to stay with their HIV because they know where they took it from! As we are speaking, there is a woman I would like to talk to because she stays in Malindi but takes her ART medications from Nakuru because she does not want relatives to know that she is living with HIV. So, HIV education has come for sure, but it is far from being complete (<i>Female Peer counsellor</i>)
	She is often in a low mood. She gets offended whenever she hears people talking and laughing on the other side. I think she would really like to be free and move about without people badmouthing her. (<i>Caregiver</i>)
	For men, there is a challenge, a huge challenge. Getting them is a very big challenge. We have tried to work with male champions to convince their fellow men to join us. Stigma is a big issue. In our meetings, you mainly find the ladies coming, and when you ask them about their husband's whereabouts, they often tell you, "He has gone to work and has sent me to listen to the messages on his behalf." So, they have that fear; they do not want to be seen. The case is not different in the primary facilities because many of them are not coming. He either sends the wife or comes but is very careful not to be seen, e.g., comes in through the back. Because of this fear, you find that some of the men do not want to be tested. We have several cases where the wife is living with HIV; the husband got tested and turned positive but is still in denial. You will find the wife saying, "We went and got tested with him but has insisted that the machines were not functioning and as such, he is not infected." Others also note that their husbands have constantly refused to start ART and use condoms, and whenever these issues are brought up, they end up quarrelling (<i>Project manager of a community-based organization</i>)
	That is a big problem (stigma). Ours is a small facility, so we schedule 1 day in a week to see the clients living with HIV. Surprisingly, even the community knows Tuesday is the day for those taking ARV drugs. So, most of them come very early in the morning. Therefore, I must come in very early to serve those who have stigma. Alternatively, that person will hang around the clinic from morning till evening when everyone has left so that people will not understand what she is doing there, or you will find that they will skip their appointed clinic dates (<i>Nursing officer</i>)
	Some of them are mistreated when they come for their appointments until I get angry! Let's say you are late for your appointment; you will be shouted at, insulted, and reprimanded like a child. In fact, some end up crying and I have to calm them down. It is sad because the culprits are usually the nurses who often shout at them, saying, "Take your drugs, or you will die of AIDS alone, and you will not see us!" It is shocking because some of them are treated very badly to the point that I am also angered. Some come to my desk, shedding tears, so I have to calm them down. At some point, it was too much that some of them transferred to other clinics (<i>Adherence counsellor</i>)
	The elderly are being burned alive and cut with pangas. As a matter of fact, some of my neighbours recently cut their elderly aunt severely with a panga because of witchcraft accusations. Later, their father also passed through the same ordeal by one of his children . . . the head was completely slashed off with a very sharp panga! And the reason is always witchcraft; I have not heard of any other thing. Such cases are numerous where I am living. I have witnessed four elders being cut with pangas, and the sad part is that these people will never expose each other to the police . . . even if I know it is you who did it, I will never say it. Even when the police come, the locals will never expose the culprit (<i>Female OALWH-12 years with HIV</i>)

(Continued on following page)

TABLE 5 | (Continued) Participants' psychosocial challenges quotes (HIV-Associated Neurobehavioral Disorders Study, Kilifi County, Kenya 2019).

Perceived health problem	Examples
Loneliness and isolation	I desire to have an exclusive male companion my age to spend the rest of my life with. Having one who is already married is problematic because sometimes I am very lonely and would want to call him, but I end up avoiding it out of fear, "What if he is with the wife? And you know it is not good to break someone's marriage." Because of such challenges, I would like to have my own man who does not belong to anyone, one I can relate to freely and love fully. You know, with someone else's husband, the love is incomplete, and it feels like I must hide constantly, and it reaches a point I feel afraid. Sometimes he does not answer my calls and sends a text message saying he is at home. So, you see, with such problems, I just want to get my own man who will live with me, someone I can talk with, especially when things are difficult because it is stressful at times (<i>Female OALWH-11 years with HIV</i>)
	Sometimes, I wish I could have friends with whom I can confide and share my challenges, but I am afraid of being discriminated. You cannot trust anyone. I have many friends, but they are all fake (<i>Male OALWH-20 years with HIV</i>)
	There are times he isolates herself from other people. You might see her seated alone and in deep thought. Sometimes she wakes up and begins to shed tears. She usually feels that her life has come to an end, perhaps (<i>Caregiver</i>)
	Whom will I share my problems with? I do not have anyone. Anyone I open myself to will want to know how and why my husband is facing those challenges. What is the cause? This will mean I start discussing and revealing the issues of my husband, which is not good (caregiver)

Loneliness and Isolation

This emerged as an important theme in the conversations with OALWH and healthcare providers. Despite living in multigenerational households, many of the OALWH expressed loneliness and isolation. Some had lost their partners, some their closest relatives and others saw their circle of friends getting smaller. Still, others felt neglected by those around them.

DISCUSSION

Summary of Key Findings

We conducted this study to gain a preliminary understanding of the health challenges facing OALWH on the coast of Kenya. Our study provides insight into the complex challenges of ageing with HIV and opens up opportunities for further epidemiologic research and subsequent development of tailored interventions for OALWH. Overall, our findings reveal that OALWH in this setting are particularly vulnerable to mental health problems, especially symptoms suggestive of common mental conditions. They are also at risk of physical health challenges, including comorbidities and somatic complaints. Mental and physical health impairments are complicated by psychosocial challenges, including poverty, lack of support, stigma, and discrimination. Noteworthy, there was an overlap of perceived risk factors across the three health domains (e.g., family conflicts, poverty, food insecurity), suggesting that OALWH who experience these shared cumulative risk factors are more likely to face multiple health challenges. It also implies that the action taken to mitigate any or some of the shared enabling factors is likely to have a preventive spillover effect across multiple health domains. Most of the views of OALWH on health challenges were corroborated by views from the providers and caregivers. However, a few disparities emerged in some of the perceived health challenges. Current drug and substance use, for instance, was reported mainly by healthcare providers, while cognitive complaints were discussed by OALWH.

Physical Health Challenges

Our discussions clearly showed that physical challenges are important concerns for older adults living with HIV on the coast of Kenya, given their negative impacts on other health domains and overall health. As the number of OALWH increases in many HIV clinics, HIV care will increasingly need to draw on a wide range of medical disciplines besides evidence-based screening and monitoring protocols [30]. Unfortunately, most healthcare providers presently lack guidance and training to identify and manage declines in physical and mental capacities in this population. The siloed provision of HIV care and other comorbidities could also imply that providers are unaware of the patients' other conditions. Our findings are similar to those reported in a recent qualitative exploration of challenges seeking HIV care services for OALWH [20]. Integration of services for HIV and non-communicable diseases in primary care may enable settings like Kenya to expand healthcare coverage for PLWH.

The current findings also revealed a prominent intersection between ageing and HIV. For most participants, ageing rather than HIV was the primary concern. This is not surprising considering that among PLWH with controlled viraemia, HIV infection often stops being the overriding comorbidity but is simply a key element in the overall milieu of multiple conditions [31, 32]. In a few instances, however, participants discussed that their experiences were associated with HIV, long-term medication use, or side effects, although their providers attributed these conditions to normal ageing. They advised the OALWH to "wait," and they will improve with time. Disagreements about the cause of a symptom or health condition may contribute to doubts about the effectiveness of treatment or conceal an emerging disease and contribute to delayed diagnoses such as medication side effects and polypharmacy.

Mental Health Challenges

Our finding of substantial symptoms suggestive of common mental health conditions among OALWH is consistent with previous reports of poor mental health among PLWH in the

study setting, albeit among younger populations [33, 34]. However, our study does not establish whether the burden among OALWH is higher or lower than that observed among young PLWH. Quantitative studies are needed to confirm this comparison. Nonetheless, OALWH may be facing a higher burden of common mental problems than their younger counterparts for different reasons. Firstly, many of the longest surviving OALWH may be significantly impacted by the legacy of the early years of the epidemic, including multiple bereavements and “survivor guilt” [35]. Secondly, the higher burden may also be attributed to the numerous challenges that OALWH face, e.g., poverty, food insecurity, caregiving responsibility, double stigma, and the onset of physical body changes, as evidenced in our study.

Since the beginning of the HIV epidemic, the manifestations of cognitive and neurological problems have been ubiquitous and frequently associated with poor treatment outcomes and impairment of activities of daily living [7]. In our study, the most frequently reported cognitive problem—memory difficulty—was commonly associated with stress and shame. Strikingly, healthcare providers seldom suspected cognitive impairments among OALWH and screenings were never done. This observation is similar to what has been reported in South Africa [32, 36]. Despite the reported memory challenges in this study, OALWH rarely forgot to take their medications (from their own self-reports and that of their providers). This finding is not unique in the HIV literature [37]. It is possible that OALWH are more organized and experienced and possibly more motivated after experiencing the initial devastating outcomes of the HIV pandemic. However, it is still essential to monitor the cognitive function of these adults to prevent treatment non-adherence, considering the multiple challenges they face, which are likely to impact their cognitive function and worsen as they grow older.

Our findings also noted a section of OALWH at risk of substance use dependence, especially home-brewed alcohol, called *mnazi*. This is not surprising given that the consumption of *mnazi* is common among the inhabitants of Kilifi because it is cheap and often less regulated [38]. The need to address this problem is even more crucial since it was associated with rising cases of sexual risk-taking behaviour and poor treatment outcomes in this cohort.

Psychosocial Challenges

Psychosocial factors are well-known predictors of treatment adherence, disease progression and quality of life for PLWH [39]. Findings from our exploratory study suggest that financial difficulties, loneliness, stigma, and discrimination are prevalent among OALWH in the study setting and are associated with mental complaints and physical health problems. Similar findings have been reported in Western Kenya among OALWH [20]. These findings are not surprising, given the country's prevailing situation of older adults. According to Help Age Kenya, the majority of older people in Kenya, especially those in rural areas, live in absolute poverty [40]. A recent report, the National Gender and Equality Commission Report, dubbed “Whipping Wisdom,” also established that older adults in

Kenya faced various forms of violence, including social stigma, neglect, abandonment, and hindrance from using and disposal of property [41].

Implications

Our study highlights opportunities for interventions and further research. It is important to reiterate that the health challenges faced by OALWH at the coast of Kenya are often interconnected and require a cohesive and collaborative response to achieve maximum benefits. Such interventions should target modifiable factors such as emotional support and integrate needed social and community support, e.g., case management services, food and nutrition support, financial assistance with caregiving responsibilities, and transportation. Context-specific interventions to help OALWH develop and nurture their own coping strategies are also critical in this population. Patient-centred care and patient self-management principles (e.g., self-reliance and empowerment) are critical elements in chronic care and are advocated as universal strategies in international frameworks of chronic care [42]. Integrated care models—which focus on the holistic view of the person by considering both medical and psychosocial needs, e.g., comprehensive geriatric assessment, are likely to improve the patient situation and the treatment outcomes. While OALWH are the primary target of most of the existing interventions in this cohort [43–45], research is required on how to build the capacity of healthcare providers, family members who act as informal caregivers and friends to provide support and care to those ageing with HIV. Future research should also examine the resources and resilience among these individuals to fully understand the vital role of resilience in empowering OALWH to enact processes that buffer health from the identified stressors. Future research is also needed to quantify the existing burden of physical and mental challenges in this population in Kilifi and confirm the risk and protective factors of these challenges. Furthermore, there is an urgent need for research to pilot and test the applicability and effectiveness of interventions underlying the determinants of physical and mental impairments in this setting.

Strengths and Limitations

To our knowledge, this is the first study to richly explore the health challenges of OALWH on the coast of Kenya and among the few studies in Kenya. Unlike previous studies, a key strength of this work is that participants comprised a diverse group of stakeholders. This ensured that the views were diverse and contrasted across participant groups. Using a biopsychosocial model helped us obtain a richer insight into the complexity of the identified health challenges. However, our findings emanate from a predominantly rural setting, and circumstances may differ from those in urban areas. Only OALWH who were on long-term HIV treatment were interviewed in this study; thus, their circumstances may also differ from those who are not in care or the newly diagnosed. As is the norm for qualitative studies in general, data collection, analysis, and interpretation are subject to individual influences and researcher biases; nonetheless, we countered this effect by maintaining reflexivity and constant

discussion with the research team to provide rigour and credibility to the study.

Conclusion

Our findings provide initial insight into the biopsychosocial challenges confronted by OALWH in a low-literacy Kenyan setting. The participants' views indicate that mental complaints (especially symptoms suggestive of common mental health conditions and memory difficulties), physical problems (particularly comorbidities and somatic symptoms) and psychosocial challenges (especially poverty, stigma, and discrimination) are of concern among OALWH. Many of the perceived risk factors for these challenges often overlap across the biopsychosocial domains. Our study also highlights several opportunities for interventions and future research to tackle these issues in the study setting. Future research should quantify the burden of these challenges, examine the resources available to these adults, pilot, and test feasible interventions in this setting, and in doing so, aim to improve the lives of older adults living with HIV.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Kenya Medical Research Institute Scientific and Ethics Review Unit. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

PM, CN, and AA conceptualized the study. PM, CN, RW, and AA designed the study. PM programmed the study questions on tablets and managed project data for the entire study period. PM analysed the data. PM, RW, CN, and AA contributed to the interpretation of the data. PM wrote the first draft of the manuscript and all the authors reviewed the subsequent versions and approved the final draft for submission. All authors contributed to the article and approved the submitted version.

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CONFLICT OF INTEREST

The authors declare that they do not have any conflicts of interest.

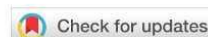
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RESEARCH ARTICLE

REVIEWED Strategies for improving mental health and wellbeing used by adults ageing with HIV from the Kenyan coast: a qualitative exploration [version 2; peer review: 2 approved]

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Abstract

Background: Physical and mental health problems are common among older adults living with HIV (OALWH). Adaptive coping strategies play a vital role in improving these adults' mental health and well-being despite the deleterious effects of HIV and ageing. However, in sub-Saharan Africa, limited evidence exists on the commonly utilized coping strategies in this population. We explore the coping strategies used by Kenyan OALWH to improve their mental health and wellbeing.

Methods: Semi-structured in-depth interviews were conducted between October and December 2019 with 56 participants: 34 OALWH (53% female), 11 healthcare providers (63% female) and 11 primary caregivers (73% female) in Kilifi County. All interviews were audio-recorded and transcribed verbatim. We used the framework approach to synthesize the qualitative data.

Results: Five major themes emerged from the analysis of participants' narratives, including self-care practices, religion and spirituality, relational living (social connectedness), generativity, identity, and mastery. Our study further revealed maladaptive coping strategies, including reliance on over-the-counter medications, self-isolation, waiting to see if symptoms would subside despite doing nothing, and HIV treatment interruptions during prolonged periods of prayer and fasting.

Conclusions: Our findings provide an initial understanding of the coping strategies used by OALWH to confront HIV and ageing challenges in a low-literacy, low socio-economic Kenyan setting. Our

Open Peer Review

Approval Status ✓ ✓

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(revision)	✓	
22 Jun 2023	view	
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version 1	?	✓
26 Aug 2022	view	view

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Any reports and responses or comments on the article can be found at the end of the article.

results suggest that interventions designed to enhance personal capacity, social support, positive religiosity and spirituality, and intergenerational connections may be beneficial in improving the mental health and well-being of OALWH.

Keywords

HIV; ageing; Kenya; coping; mental health and well-being



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REVISED Amendments from Version 1

We have revised the title of the manuscript to reflect the study setting – the Kenyan coast. Besides, we have also clarified the type of qualitative interviews conducted in the study – key-informant interviews. We have also completed the COREQ form to guide peer review. Additionally, we have made it clear that the translation of data took place during the analysis stage. Moreover, we have added a table highlighting the sociodemographic and clinical characteristics of OALWH. We have also strengthened the implications of the study findings to policymakers and healthcare providers.

Any further responses from the reviewers can be found at the end of the article

Introduction

Population ageing is now a reality worldwide, and sub-Saharan Africa (SSA) has the most rapidly ageing population¹. Thus, ageing and health are important priorities^{2,3}. Investing in healthy ageing and long-term healthcare systems is more important than ever as the world grapples with this demographic shift. One subpopulation of older adults that deserves special attention is that of adults ageing with HIV, aged ≥ 50 years. With improved access to combination antiretroviral therapy (cART) and a rising trend of HIV infection among the elderly, the number of older adults living with HIV (OALWH) in the world is expected to rise rapidly⁴. This puts more pressure on HIV health services to develop and implement appropriate programs that address these adults' unique needs. The research on HIV and ageing in SSA is limited⁵. However, most of the global evidence suggests that apart from physical health challenges, OALWH face unique mental health burdens and challenges to their social well-being that may differ from their uninfected peers and younger counterparts, e.g. elevated comorbidity and early-onset geriatric conditions^{6–11}. Despite the observed challenges, intervention research designed to address the unique needs of OALWH is currently insufficient¹², and it is unclear how these adults cope and age with HIV, especially in SSA, where the health system is largely unprepared to meet their complex healthcare needs.

Based on one perspective in the existing literature on HIV and ageing^{6,10}, it would appear that the outlook for OALWH is bleak despite the gains conferred by cART. Nonetheless, there is another approach to understanding the life experiences of OALWH – an approach focusing on strength and not on deficit^{13–15}. The deficit or challenges approach, which focuses on monitoring the presence of chronic comorbidities in OALWH, has important limitations. It is disease-centred and measures a person's health deficits at a stage in life where little can be done to prevent the decline in function. Moreover, the approach overlooks the fact that the process of ageing with HIV is multidimensional where, in addition to the impact of the virus on biological systems, other factors shape the ageing process, often well before an individual gets to middle age. The strengths approach encourages policymakers and health professionals to look beyond disease states and approach ageing with HIV as a process to maximize a person's well-being by strengthening positive factors, e.g. adaptive coping skills.

As an intermediate mechanism of psychological stress and health outcomes, coping strategies are vital in maintaining physical and mental health^{16,17}. The research on coping originates and is largely influenced by the work of Lazarus and Folkman¹⁸. They define coping as the cognitive and behavioural efforts undertaken by an individual to alter or manage a problem caused by a specific stressful situation. According to Lazarus and colleagues, stress emanates from an imbalance between demands and resources or when pressure surpasses one's perceived ability to cope¹⁸.

While several studies have examined how people living with HIV (PLWH) cope with a chronic illness, few have addressed this issue among OALWH, especially in SSA^{17,19}. Drawing on semi-structured interviews with 76 OALWH in the United Kingdom, Rosenfeld and colleagues identified a few coping strategies, including volunteering, accentuating the positive, minimizing the role of HIV medications, and accessing support from mental health workers and HIV organizations²⁰. In America, the frequently reported coping strategies for healthy ageing among OALWH include self-care, spirituality, social support (from family, friends, professionals, and pets), and generativity (e.g. mentoring, volunteerism)^{21–25}. In SSA, little research has focused on how older adults cope with HIV and illness-related stressors. In one of the few studies on coping in this population in the region, OALWH in South Africa adopted HIV status acceptance, ART adherence, abstinence from sexual relations, and accessing social support as key coping strategies in dealing with HIV diagnosis, stigma, disclosure and the healthcare system²⁶.

As the HIV and ageing agenda gain momentum in SSA, there is a crucial need for a greater understanding of how the OALWH cope and live with HIV. In this paper, we explore the perceptions of 34 OALWH, 11 primary caregivers and 11 healthcare providers on the coping strategies and support available to OALWH in a low-resource Kenyan setting.

Methods**Ethics**

Written informed consent was obtained from all respondents before participation. Ethical clearance was granted by the local institutional review board, the Kenya Medical Research Institute Scientific and Ethics Review Unit (KEMRI/SERU/CGMR-C/152/3804), on March 6 2019. Permission to conduct the study in Kilifi County was granted by the research office, Department of Health (HP/KCHS/VOL.X/171) on April 3 2019.

Study design, setting and sample

This study is part of a larger qualitative study conducted in 2019 at the Kenya Medical Research Institute-Wellcome Trust Research Programme (KWTRP) in Kilifi County on the Kenyan coast. The original study focused on understanding the health challenges and coping strategies of older adults living with HIV among 56 participants (34 OALWH, 11 caregivers and 11 healthcare providers). Arising from the primary dataset are two manuscripts; the first (a preprint published in medRxiv) reports the health challenges facing the OALWH²⁷. Briefly, the participants' narratives indicated that mental and psychosocial

complaints, e.g., common mental health problems, poverty, stigma, and discrimination) were common among the OALWH in addition to physical health challenges, e.g., comorbidities and somatic symptoms). The current manuscript is the second paper, where we explore the same participants' perceptions to understand the coping strategies and support available to the OALWH in this low-resource setting.

Kilifi is mainly rural, and the majority of the inhabitants belong to the Mijikenda tribe, whose primary source of livelihood is small scale trading and subsistence farming. More than half of Kilifi residents live below the poverty line, and a significant proportion (about 40%) do not have formal education²⁸. The HIV prevalence is higher among females (54 per 1000 people) than males (23 per 1000 people)²⁹.

Our sample included: a) older adults living with HIV aged ≥ 50 years receiving HIV care and treatment at the Kilifi County Referral Hospital (KCH) HIV clinic; b) primary caregivers of older adults living with HIV and c) healthcare providers attending to the older adults living with HIV including nurses, clinical officers, counsellors, and project coordinators of community-based organizations.

Sampling strategy and recruitment

We recruited our sample using a purposive sampling technique to maximize diversity in respondents' characteristics, e.g. age and sex. Participants were recruited by trained study staff in liaison with a community health volunteer stationed at the KCH specialized HIV clinic. After introducing the study at the clinic, OALWH were approached (during their routine clinic visits), and those expressing interest were given more information regarding the project e.g. study objectives and how to participate. We had no specific target sample size. We recruited and assessed participants until we reached data saturation. The older adults living with HIV had to be at least 50 years old and on cART for them to take part. Caregivers were identified through the OALWH during their routine clinic visits. To participate, they had to be directly involved in the care of an OALWH. We approached healthcare providers at their places of work and invited them to participate. We targeted providers who were directly involved in the care of OALWH. Participants who agreed to take part were interviewed once, immediately after enrolment, if available, or at an appointment made for a future date. Apart from a few health providers who were interviewed at their place of work, the majority (over 80%) were interviewed at the KEMRI Wellcome Trust Research Programme. Only the interviewing researcher and participant were present during the interview. The researcher and participants had no prior contact/relationship in this study.

Data collection and instruments

We used key-informant interviews to collect data from all the participant groups. The lead author (PNM) conducted all the qualitative interviews, which lasted approximately 45 – 60 minutes each. At the time of conducting this study, PNM was a PhD Fellow at the KEMRI-Wellcome Trust

Research Programme, Kilifi, Kenya, with extensive training in mixed methods. A pre-tested, semi-structured interview was used to guide the interviews. The interview guide was created new for this study. Over three-quarters of the interviews were conducted in Swahili – the national language in Kenya. The rest of the interviews were conducted in either Giriama (the local language) or English. All interviews were digitally recorded with permission from the participants.

General information about coping/living strategies and social support was elicited among participants, leading to specific explorations of coping with long-term HIV, ageing, and health changes, e.g. mental difficulties. Interview questions focused on what challenges participants were experiencing (for OALWH) or presented with (for the other key informants) regarding ageing with HIV, what helped the OALWH through difficult periods, and how they coped daily and long-term basis. The interviewing researcher took down some notes during and after the interview, which helped plan subsequent interviews.

Data analysis

The audio-recorded interviews were transcribed verbatim by four research assistants. Translation of data took place during the analysis stage. Participants' original language (Swahili) was used to develop codes, categories and themes, which were then translated into English. QSR Nvivo software version 11.0 was used for data management and analysis. The analysis of our qualitative data followed the Framework approach as described by Ritchie and Spice³⁰. A preliminary coding framework was developed inductively (through in-depth reading of transcripts) and deductively (considering themes in the interview guide) by two authors (PNM and AA). This was done independently by the two authors. The arising codes were then discussed, and a consensus was reached on how they should be brought together into themes. The initial coding framework was subsequently expanded to capture any emerging theme as coding progressed. After coding, themes related to specific concepts were grouped to form categories and later exported to a word document to produce charts. The charts were then used to summarize the data, looking for similarities or differences.

Results

Summary of participant characteristics

We included 56 participants in this study (34 OALWH, 11 healthcare providers and 11 primary caregivers) after reaching data saturation. All approached participants agreed to participate. Among OALWH, slightly more than half were women (53%); most (82%) had up to a primary level of education, most (73%) lived in multigenerational households, and had a median age of 57 years (54 – 63 years). All the OALWH were on HIV treatment and had lived with HIV for a median duration of 12 years (10 – 15 years). Healthcare providers comprised six registered nurses, two clinical officers, two project managers of community-based organizations and one HIV counsellor. On the other hand, all the primary caregivers were family members, the majority (73%) of whom were female. [Table 1](#) gives more sociodemographic and clinical details of OALWH.

Table 1. Sociodemographic and clinical characteristics of older adults living with HIV.

Characteristic	n (%) or median (IQR)
Median age	57 (54 – 63)
Female	18 (53%)
Educational level	
None	7 (20%)
Primary Level	21 (62%)
Secondary level	5 (15%)
Tertiary level	1 (3%)
Type of employment	
Unemployed/not working	12 (35%)
Small scale trader	15 (44%)
Casual worker	4 (12%)
Professional/skilled work	3 (9%)
Marital status	
Never married	1 (3%)
Married	19 (56%)
Separated/Divorced	7 (21%)
Widowed	7 (21%)
Living arrangements	
Alone	5 (15%)
Single generation household	4 (12%)
Multigenerational household	25 (73%)
Median household size	5 (2 – 9)
Residence (rural)	30 (88%)
Median duration since HIV diagnosis (years)	12 (10 – 15)
On ART treatment	34 (100%)
HIV status disclosure	
Non-disclosure	1 (3%)
Partial disclosure (to close family only)	18 (53%)
Full disclosure (beyond close family)	15 (44%)

Notes: ART –Antiretroviral treatment; IQR –Interquartile Range

Perceived coping strategies for mental and well-being challenges

Participants utilized multiple strategies to maintain or improve their mental health and well-being in the face of various biopsychosocial challenges. Analysis of the respondents' narrative accounts revealed five major themes: self-care, religion and

spirituality, generativity, social connectedness, identity, and mastery.

Self-care

Within the respondents' narratives, this was either a change in behaviour or a pattern that developed over time to cope and live with HIV. The frequently discussed self-care strategies included abandoning/abstaining from risky behaviours (e.g. multiple sex partners, unprotected sex, tobacco smoking, and hazardous alcohol use), strict treatment adherence (e.g. cART and routine HIV clinic appointments), acceptance and disclosure of one's HIV status, shifting focus (from negative to positive things), and practising self-control (e.g. managing thoughts or attitudes). To a lesser extent, some OALWH reported monitoring their diet (as a form of weight loss strategy), seeking information (e.g. from seminars and HIV clinics), and using traditional forms of treatment to stay healthy. Similarly, some OALWH engaged in physical exercise, including walking, jogging, running, swimming, skipping rope, traditional dances, and makeshift weightlifting. However, many of these activities were unstructured and irregular, while some of the OALWH (especially women) felt embarrassed doing some of the activities, e.g. swimming and weightlifting. Still, a few of the OALWH acknowledged that their nature of work (e.g. walking long distances to work; heavy manual work - such as pulling carts, casual labourer at construction sites; farming, grazing livestock, and house chores) was as good as physical exercise. Common sources of information for these strategies were trial and error and sometimes healthcare providers, family, and friends. Some self-care strategies were regarded as helpful, e.g. in reducing distress and improving physical health outcomes.

Other self-care strategies included relying on over-the-counter medications (especially for symptoms like pain and sleeping difficulties) and skipping HIV medications when one lacks food. *Waiting* to see if the symptoms would lessen despite doing nothing was also practised by a few OALWH. Some of the participants' quotes on this theme are provided in Table 2.

Religion and spirituality

Most respondents described religion or spiritual practices as an important strategy through which OALWH drew their strength, besides giving them hope to live. Prayers, belief in God, attending religious meetings, singing, or listening to worship music, reading the scriptures or listening to uplifting messages of hope, fellowship with other believers, membership to church groups and other expressions of spirituality were regarded as instrumental in providing OALWH with emotional, social and sometimes financial support. For instance, several OALWH reported using prayer when faced with persistent emotional challenges, e.g. thinking too much, sleeping problems, and having nightmares. Others sought emotional support (counselling) and material support (with basic needs) from pastors.

However, a few healthcare providers felt that some of the religious activities or beliefs among OALWH had negative

Table 2. Participants' quotes on perceived coping strategies for mental and well-being challenges.

Main coping strategy	Participant's quote
Selfcare	"Letting go of certain behaviours has helped me a lot. I wasted much money on drinking spree, multiple sexual partners who, of course, needed upkeep, and other pleasures. However, I abandoned all these things following my diagnosis, and I can see some improvements in my health and life". (Male OALWH)
	"I maintain a very active life! I usually wake up early in the morning, make my bed, mop my house, prepare breakfast, take a shower, and leave for work. I have a niece staying with me, but I do most of the work myself. I wash my clothes after every two days. I also do farming. I tend my greenhouse and chicken. I wash the dishes in the morning. I am very happy". (Female OALWH)
	"I usually wake up very tired and having muscular pains! I have to take <i>arcton</i> (a common analgesic) to work and be productive. It is frustrating because I have to buy medications every day. My well-being is dependent on these medications". (Female OALWH)
Religion and spirituality	"Some of the clients stop taking their ART medications. Some usually say, 'I found a herbal doctor who said my disease will go away if I use their herbal medication.' So they will stop the ART medication until they realize that the herbal medicine is not helping and then come back to the clinic, usually in worse off conditions". (Clinical officer)
	"When I find myself crowded with thoughts, as I shared with you initially, I usually run to God because he is the one who knows why I am undergoing those issues. And when I pray, I usually feel comforted, relieved and at peace even if I still do not have anything ...but I feel much better when I put God first". (Female OALWH)
	"Sometimes I am worried, stressed, anxious and experience nightmares, but I encourage myself in God. I usually kneel and pray to God. I wake up my wife, we pray together and go back to sleep, and we usually feel much better in the morning". (Male OALWH)
Generativity	"Sometimes back, one of my kidneys had problems...it was quite painful. Later, as I was studying the bible, I was instructed (<i>by God</i>) to go for prayers for 18 days. I left home and camped in a nearby bush for 18 days, and that was the end of that problem. I have never had that issue again; I never went to a hospital. You know God does not need help to do his work...he is perfect!" (Male OALWH)
	"In our community, most of them go to traditional doctors or <i>waambezi</i> (seers or prophets) in addition to their routine clinics. And some of them stop taking their ART medications. For instance, one may be instructed to leave their ART medications and pray for three months or sometimes drink some traditional drugs for a certain duration. So it becomes complicated; they usually come back in worse conditions." (Clinical officer)
	"I usually volunteer at the clinic as a peer counsellor. I have had a few clients come to me looking for marriage partners. I usually go ahead and connect them. As a matter of fact, I have succeeded in joining five people who are now happily married". (Female OALWH)
Nursing officer	"On several occasions, the clinicians have called upon me to talk to my peers on different issues, e.g. stigma and non-suppressed HIV". (Female OALWH)
	"My role as a counsellor or an elder happens on different platforms...at the clinic; I may advise people on various issues, including adherence to ART. I also like discussing and sharing things with community members, my children...e.g. on different issues such as developments, health, and well-being. I love it very much". (Male OALWH)
	"I have one person who is their...like their head...So in case, I find a client with stigma ...I call him, And he talks with the client...I find him very helpful". (Nursing officer)
Caregiver	"She (OALWH) helps me a lot. For instance, she educates women in church on various issues relating to HIV...she also teaches children and girls... let us say she has the qualities of a leader". (Caregiver)

Main coping strategy	Participant's quote
Social connectedness/ support systems	"It affects me a lot (<i>living with HIV</i>)...for instance, we slept without taking supper yesterday. I had to borrow the fare to come here today. However, it is not every day that we sleep hungry because I have a good friend who owns a hotel nearby...he usually gives us food. Sometimes I just take the children to eat there and pay later. He encourages me not to be worried". (Male OALWH)
	I usually encourage, advise and motivate him so that he can bounce back to his normal well-being. I always try to understand him...be empathetic so that he can recover completely. I also help him with food, and even other people support him with food...however, most of the time, we counsel him". (Caregiver)
	"I did not see the importance (of going to support groups)...why spend hours listening to people...it was even depressing...every time people are saying the same things. People were complaining a lot...there were no benefits...you know sometimes you want to see tangible benefits; e.g. we get registered, look for support such as financial support, but there was nothing like that. I like a positive outlook". (Female OALWH)
	"Financial problem is a big issue among these adults...there is one I had to give some little income (<i>about \$10</i>) to start selling fish...because I had to ask her what she could do...then she told me that she used to sell fish. So I gave her 1000 Ksh (<i>about \$10</i>) to start her small business. Since that day, I have never had a problem with her routine clinic appointments. I thank God. Even her overall health has improved". (Nursing officer)
Identity and mastery	"We have five areas of empowerment, including spiritual, economic, emotional, social and physical aspects. We support them in all these areas...our primary goal is to help them stand on their own". (Project Manager CBO)
	"To be honest, my brother...I do not despair easily...I have trained myself that way...I know I was born one day, and there is an appointed time for me to die! I have made up my mind to do everything I can to live today, and when my time to die comes, I will say goodbye! As long as I am alive, I will take my medications. I am the last person to surrender! I am like a soldier". (Male OALWH)
	"I did not plan on getting this disease...so I have chosen to take each day at a time...I have not aged because of HIV...as a matter of fact, I am least concerned about the HIV infection...I have forgotten about it! I believe that as long as I take my medications well, I will continue living like anyone else...if I follow the clinician's advice. That is my philosophy, and I am not worried at all!" (Female OALWH)
	"The cohort I have is very informed about their medications and health. They even carry their medications everywhere. They tell you that 'this medication is my life". (Nursing officer)
	"I have not received help or support from people, and I do not bother to ask! I like taking care of myself...I do not want to make this disease a source of income by depending on others...I do my own business...not big, but I can live off my sweat...I have learnt to go out of my way and be active, and hardworking. I have realized this is important for my health and well-being as well. I also eat well and do some exercises...mostly walking". (Female OALWH)

implications on health, e.g. poor retention in care and virologic non-suppression. For instance, some of the OALWH (especially women) sought the services of religious people popularly known as “*waombezi*”, believed to be seers or prophets with special healing powers. Subsequently, they stopped taking their ART drugs, believing they have been cured of HIV infection after receiving prayers from these seers, only for them to come back later to the HIV clinic with severe HIV disease. Others occasionally go into prolonged periods of prayer and fasting where they change their ART medication schedule or stop taking them altogether. Still, others mixed biomedical and traditional forms of treatment, which sometimes led to poor health outcomes in the OALWH.

Generativity

Generativity is the willingness to engage in acts that promote the well-being of other people besides self and family, especially younger generations, to ensure their survival. Our analysis of participants’ narratives revealed three main categories of generativity. In the first category, many OALWH took leadership roles in the family and community, e.g. as family heads, village elders, religious leaders, and HIV support group coordinators. Through sharing stories of the years of the HIV epidemic, serving on different committees, and being involved with HIV advocacy, these respondents utilized their status, time and experience to lead others and, in the process, derived personal satisfaction and fulfilment. The second form of generativity discussed was volunteerism, where some of the OALWH offered their skills and services to benefit other individuals. Participants volunteered in different ways, including serving as community health volunteers. They offered various services such as health education to families of people living with HIV and caregiving to some people living with HIV. For many of these respondents, volunteering provided a focus, purpose, and opportunities to make a social contribution and reciprocate the support they had experienced. Given their extended duration of living with HIV, some participants acknowledged the need to serve as mentors to nurture and guide those recently diagnosed with HIV and young people living with HIV. This came out as the third form of generativity.

Social connectedness/support systems

Respondents’ narratives also uncovered various formal and informal support systems regarded as positive contributors to mental health and well-being. Support was received from diverse sources, including family members, friends, healthcare providers within the HIV clinics, HIV community organizations, and informal support groups. Family was an important source of comfort and support in managing the challenges of ageing with HIV for some of the OALWH. Specific support included occasional financial support (for fare and basic needs), companionship, medication and routine clinic appointment reminders, and emotional support. However, some of the OALWH felt more comfortable seeking help from other sources (e.g. friends and healthcare providers) other than the family partly because of dysfunctional families, fear of disclosing their HIV status, or simply because they lacked the means.

Several participants also portrayed existing mental health services (within HIV clinics) as especially important settings for formal and informal therapeutic conversations with people who would listen and support them, as well as providing specialist knowledge vital in the management of HIV and ageing challenges. Some of the mental health support services offered by HIV clinics included occasional psychoeducation on HIV, occasional screening of depressive symptoms, psychopharmacology (e.g. provision of antidepressants), peer counselling, referral services (with community organizations or other higher-level hospitals) and HIV support groups (e.g. for discordant couples). However, many of such services tended to vary from one HIV clinic to another, according to some participants (those who had experience receiving care or attending to clients from other HIV clinics). Specialist services, e.g., psychologists, psychiatrists, and geriatricians, were unavailable.

Community-based organizations dedicated to the health and well-being of OALWH did not come up in our discussions with the participants. The few existing organizations supported different groups of people living with HIV, including OALWH. Some of the support services they offered included occasional assistance with basic needs (e.g. food and tuition fees for orphans), supporting community health volunteers (e.g. fare), employing healthcare providers (e.g. counsellors), community HIV testing, empowering people living with HIV (spiritually, economically – e.g. through skills training including making soaps, tailoring, weaving, psychosocial counselling, referral services), and legal services (mainly for women).

Although the HIV support groups were perceived as instrumental in giving a sense of belonging, membership and camaraderie, which buffered or moderated many of the stresses of ageing with HIV, some of the OALWH avoided these groups or scaled back their involvement. To some of these adults, attending the groups undermined their goal of lessening HIV’s role in their current and imagined future, which they regarded vital for their mental health and well-being. Thus, they avoided the groups to limit a persistent focus on that issue. Other OALWH cited monotony, time-wasting, gossip, lack of support, poor leadership and no apparent benefits with such groups hence their collapse.

Identity and mastery

Identity refers to how individuals perceive themselves in relation to HIV, while mastery is the ability to accomplish what needs to be done to live a good life. Identity can also be understood as HIV centrality, how much of oneself is defined by the HIV diagnosis. Many of the OALWH described themselves as much more than their diagnosis. The concepts of self-reliance, self-supporting, depending on oneself as a resource and managing one’s care incorporated behaviours and self-perceptions of mastery and control in ageing with HIV. According to several OALWH, identity and mastery developed over time. In the process, respondents utilized their background and personal strengths to identify tools to achieve mastery over the challenges of ageing with HIV. Several participants noted

that they no longer had problems with their HIV status as they used to be in the early years of HIV diagnosis. As a matter of fact, they could disclose to anyone, including public gatherings. Others later came to the point of viewing their HIV status as a blessing in disguise or a wake-up call in their lives, making them gain control of their lives, e.g. through investments, personal development, abandoning risky behaviours such as multiple sexual partners and substance use. Some considered themselves better off than their uninfected peers who still engage in such behaviours. Attaining mastery also gave OALWH opportunities to engage in mentorship and psychoeducation, especially for newly diagnosed HIV individuals.

Discussion

Summary of key findings

Given the demographic imperative of a rapidly ageing society and the growing number of older adults ageing with multiple chronic conditions such as HIV, there has been rising attention in recent years on understanding ways to promote resilience among older adults and on designing interventions that can strengthen their ability to cope, improve quality of life, prevent, or delay functional decline, and decrease healthcare costs. This study provides a preliminary understanding of coping among OALWH residing in a low-resource setting in Kenya. Overall, our findings portray a picture of OALWH who integrate various living strategies into their lifestyle to address their mental health and well-being challenges. Five main strategies emerged: self-care practices, religion and spirituality activities, relational living (social connectedness), generativity, identity, and mastery. Many of these strategies were developed by the OALWH themselves, sometimes collaborating with other peers, providers, and caregivers, thus representing respondents' deep engagement with their mental health and well-being and a culture of survival. This highlights the importance of working with OALWH to understand their values and aspirations and reinforces calls to include their subjective experiences in care and management. Our study also revealed maladaptive coping strategies among these adults highlighting the crucial need to identify such patterns and look for ways to address them, given their impact on health.

Self-care

Although a well-established approach for several chronic conditions^{31,32}, self-care programmes for OALWH are still emerging, especially in SSA. Self-care is regarded as a critical element in chronic care; thus, a major focus of many interventions and patients who engage in self-care have been shown to have significantly improved clinical outcomes, a better quality of life, fewer hospitalizations, and longer survival^{31,33}. Participants in the current study discussed several self-care strategies to promote their mental health and well-being. Reported self-care practices ranged from those with beneficial health impacts to those potentially deleterious to their overall health. Most of the selfcare strategies discussed in the present study, e.g., positive lifestyle behaviours, were perceived to be beneficial and effective in promoting the mental health and wellbeing of OALWH. However, existing research provides only modest evidence

on the effectiveness of selfcare strategies in this population³⁴. Intervention research will be able to establish which self-care strategies yield positive effects in this setting. Many of the OALWH relied upon their internal strengths for continued adherence to HIV treatment and avoidance/abandoning of previously harmful lifestyle elements, including drug use. With time, several OALWH reported reduced family conflicts, improved self-efficacy, and better financial decisions (investments and planning for one's old age). Although male and female OALWH acknowledged the importance of others, many observed that they were responsible for their self-preservation. Our findings of OALWH embracing their responsibility for self-preservation are consistent with those reported by Emlet and colleagues in the United States of America among 25 OALWH²¹ and Solomon and colleagues in Canada among 14 older men living with HIV²⁴.

Religion and spirituality

Consistent with previous work, this study found that religion and spirituality played an essential role in coping among OALWH²⁵. In literature, involvement in religious and spiritual practices has been noted to correspond to better health-related outcomes²⁵. Such association may provide one with social support, norms for healthy behaviours, and a sense of hope and well-being, ultimately promoting their mental health³⁵. These strategies may also act as buffers to life stress by allowing them to interpret their life experiences in the context of their beliefs, which provide purpose and meaning in life and promote transcendence over circumstances. Nevertheless, certain religious practices may hinder positive biopsychosocial outcomes. In the current study, some of the healthcare providers noted that some of the OALWH abandoned their ART medications after receiving prayers from their pastors or after taking part in an extended duration of prayer and fasting. There is a need to re-examine the role that "traditional healers" and other "influencers" play in the identification and care of OALWH and how to work together to ensure that OALWH maintain their treatment routines.

Social connectedness

While several studies of PLWH have identified the value of receiving social support^{36,37}, few have examined this subject among OALWH. Understanding the influence of perceived social support on the mental health and well-being of OALWH is crucial because it is likely to play a major role in managing their multiple negative life stressors. Greater social connectedness may address the negative mental and physical impacts of ageing with HIV through enhanced cognitive efficiency, better social competency, productivity, personal control, and life satisfaction. Our results attest that OALWH are aware of the significance of others in their lives. Family members, sexual partners, friends, religious groups, and the HIV clinics were regarded as important sources of support by many OALWH. Similarly, Rosenfeld and colleagues attest to the importance of social support in improving the mental health and well-being of OALWH residing in the United Kingdom³⁰. Our findings also echo previous observations by Emlet and colleagues in the US²¹. Interestingly, avoidance of HIV support

groups was noted as a strategy to support mental health and well-being by a few OALWH by shifting the constant focus on HIV. This finding is consistent with previous findings in other places^{20,24}. This underscores the need for HIV support groups to understand clients' needs and fine-tune their support services accordingly. Although having others to rely upon for help and support, many OALWH maintained an aspect of independence to avoid overreliance on others who, according to them, had responsibilities and problems of their own.

Generativity

Another important element of coping for OALWH revealed in this study was generativity. This concept has its origin in the psychoanalyst Erik Erikson emphasizing a concern for establishing, caring, nurturing, guiding, and maintaining the next generations³⁸. Taking up leadership roles, volunteerism and mentorship were identified as important elements of generativity among OALWH. They were often associated with personal satisfaction and happiness and reduced the focus on their health challenges. Our findings reinforce the importance of social connectedness among OALWH but, more importantly, add a new element to previous research. Instead of viewing OALWH as the passive recipients of social support and care, it places the individuals in a contributory role of giving back to the community through these acts of generativity. Our findings align with those of Emler and colleagues among 30 OALWH in Canada²². Programmes that enhance intergenerational connections, community involvement and generative acts within the HIV community could potentially promote the mental health and well-being of OALWH.

Identity and mastery

Mastery has previously been examined in the HIV literature, and results show that acquiring mastery is essential in improving mental health and reducing symptoms of common mental disorders^{39,40}. Our participants discussed how they achieved identity and mastery in their lives, and this was important in ageing with HIV. Many of them described their HIV diagnosis as a turning point in their lives and expressed relief (from the persistent unknown suffering before HIV diagnosis). After the initial shock was over, many of them drew on their backgrounds and strengths to identify tools to achieve mastery over the challenges of ageing with HIV. This ushered in a period of lifestyle adjustments, e.g. diet, risky behaviours, taking personal control of one's life, and thinking of one's future (e.g. investments). For some of these clients, the awareness of the complexities of ageing with HIV increases their urgency for mastery of self-care. Our findings mirror those of earlier research conducted among OALWH in high-income countries (HICs)⁴¹.

Apart from the positive highlights on living strategies, our study also reveals important concerns in the coping of OALWH in this setting which may threaten their mental health and well-being. Though not many, some of the OALWH reported over-reliance on over-the-counter medications. Overreliance on OTC drugs could be due to medications being the only option offered to these clients by their healthcare providers, health

illiteracy on the part of caregivers, or financial difficulties in seeking other therapies. Still, some of the OALWH isolated themselves from sources of support, afraid of what people will say about them. Others tended to wait for symptoms to run their course or do 'nothing'. Many of such symptoms were part of the symptom profile for common mental disorders suggesting undiagnosed or inadequately treated common mental disorders. The OALWH may not know how to relieve such symptoms or maybe lack the motivation to find a solution. This emphasizes the need for healthcare providers to adequately screen for such symptoms and have knowledge of the overlapping presentation of these disorders experienced by OALWH. The providers noted that they rarely screened for common mental disorders in these clients mainly because of competing interests (e.g. the treatment emphasis is predominantly on physical health outcomes such as HIV viral load suppression) and inadequate treatment modalities for common mental disorders (CMDs). Others mixed biomedical care with traditional therapies, many of which were deemed ineffective, leading to health deterioration among those affected. Still, other OALWH skipped their medications whenever they missed food. These observations highlight some of the well-known patient-related challenges (e.g. health illiteracy, culture, financial difficulties) as well as health system challenges (e.g. inadequately trained providers to screen for CMDs and inadequate resources such as essential medicines)^{42,43} which have been pointed out as some of the barriers in the delivery of chronic care and promotion of coping strategies in this population.

Implications

Policymakers and service providers need to recognize OALWH as a unique client population in need of targeted HIV care. Through in-service training or continuing medical education, healthcare providers can build their skills, knowledge and attitudes on HIV and ageing to respond to the dynamic needs of OALWH adequately. In the long term, however, policymakers need to build a pool of HIV experts, e.g., geriatricians, to respond to the current gaps in human resources in HIV clinics. Shared decision-making models will empower and actively engage OALWH to manage their unique healthcare and social needs effectively. Of key importance is also the integration of other health services, e.g., mental health and chronic care, into HIV care services. There is also a crucial need to strengthen the financial and nutritional support of OALWH as many of them are affected by poverty which sometimes affects their HIV care, e.g., by skipping medicines when missing food. Our paper has highlighted the importance of self-care, the different forms it takes and potential opportunities to embrace some of these modalities further. From our present findings and the available evidence on some of these strategies, ignoring them could lead to poorer health outcomes and poorer care in this population¹⁷. To attain more favourable mental health and well-being, OALWH require training and support to effectively cope with HIV and ageing challenges, communicate their potential needs to access services and participate in shared decision making with their providers. Given that the challenges of OALWH can be diverse-including medical, physical and social - and that individual preferences will often dictate uptake of and access

to different models (e.g. new technologies, group work, individual therapy), theoretically, sound models of intervention should be considered to meet the preferences of various population groups. Additional qualitative studies could further examine how characteristics of resilience and strengths are utilized in HIV and ageing outcomes. Quantitative studies could shed some light on which subgroups of OALWH are more likely or less likely to cope effectively. These findings could lead to identifying at-risk individuals and developing targeted interventions.

Strengths and limitations

Our study is among the few reports in SSA and the first in Kenya to comprehensively explore the coping strategies for OALWH with mental health and well-being challenges. Unlike previous reports, an important strength of this work is that respondents included a diverse group of stakeholders, including clinicians, community-based organizations, primary caregivers, and the OALWH themselves. This helped us gain a comprehensive understanding of the research question through triangulation. Nonetheless, our participants were predominantly from a rural setting and in routine HIV care; thus, their circumstances may differ from those in urban areas and those who may not be in routine HIV care. We used reflexivity to minimize individual biases (e.g., researchers' personal beliefs on the research methods and previous knowledge of the subject) by maintaining research diaries and fieldnotes of observations, interactions, incidents, emotions, and conversations and holding frequent discussions with fellow researchers how this may have affected the research process.

Conclusions

Our findings provide an initial understanding of the coping strategies utilized by OALWH to confront HIV and ageing challenges in a low-literacy Kenyan setting. This study underscores the importance of coping in this vulnerable population and suggests that interventions designed to enhance personal capacity, social support, positive religiosity and spirituality, intergenerational connections, self-identify, and mastery may be beneficial in the improvement of mental health and well-being in this growing population. Our study also highlights a few potential obstacles that may impede successful

coping in this population, including over-reliance on over-the-counter medication, waiting for symptoms to run their course or doing 'nothing', self-isolation, seeking support in the wrong places, and skipping meals. Traditional healers and biomedical practitioners need to deliberate on how they can collaborate to promote the health and wellbeing of OALWH. These findings will assist providers, caregivers, and other stakeholders to best address the specific health and well-being needs of OALWH in this setting.

Data availability

Underlying data

The underlying data transcripts are not publicly available due to confidentiality reasons. However, individual applications can be made through the data governance committee of the KEMRI Wellcome Trust Research Programme, which will review the application and advise as appropriate. Requests can be sent to the coordinator of the Data Governance Committee using the following email dgc@kemri-wellcome.org. Successful applicants will be provided with de-identified transcripts (in the Swahili language). In the event that one requires translation services for the transcripts, this will be agreed upon with the applicants for it to be done within the programme.

Extended data

figshare: Additional file 1: Interview guide for in-depth interviews among adults living with HIV, healthcare providers and primary caregivers. <https://doi.org/10.6084/m9.figshare.20489208.v1>⁴⁴

Data are available under the terms of the [Creative Commons Attribution 4.0 International license](#) (CC-BY 4.0).

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Jepchirchir Kiplagat 

Academic Model Providing Access to Healthcare (AMPATH), College of Health Sciences, Moi University, Eldoret, Kenya

The authors have responded to the comments to my satisfaction and would recommend indexing of the manuscript.

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: HIV and ageing

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Version 1

Reviewer Report 22 May 2023

<https://doi.org/10.21956/wellcomeopenres.20191.r56999>

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Marie-Josée Brouillette 

McGill University, Montreal, Québec, Canada

This qualitative study explores the coping strategies used by Kenyan older adults living with HIV (OALWH) to improve their mental health and wellbeing. Semi-structured in-depth interviews were

conducted with 56 participants that included OALWH, healthcare providers and primary caregivers in Kilifi County, a rural area. The needs of OALWH are of increasing interest and this paper is very pertinent, It is well written and clear.

A few comments for consideration by the authors:

1. In the intro, the authors state: *'The strengths approach encourages policymakers and health professionals to look beyond disease states and approach ageing with HIV as a process to maximize a person's well-being by strengthening positive factors, e.g. adaptive coping skills.'*; could the authors expand on the implication of their findings for policy makers and specific implications for HC professionals, beyond general statements? For example, the fact the patients did not take their medication when they went without food, was it on response to instruction from the HC professionals and do these instructions have to be changed?
2. It is unclear why the sample included healthcare providers: can you please justify?
3. Recruitment. The sample was recruited using a purposive sampling technique to maximize diversity in respondents' characteristics, e.g. age and sex., and participants were recruited by trained study staff in liaison with a community health volunteer specialized HIV clinic. All those approached agreed to participate. About 40% of Kilifi residents do not have formal education yet the sample for this study, most (82%) had up to a primary level of education. Is it possible that, while participants were of diverse age and sex, they overwhelmingly represent the more educated, more vocal and open members of the HIV community? The leaders? The narratives are in general quite positive, sometimes surprisingly so. This is the kind of language often heard from leaders in AIDS service organizations, and the section on generativity suggests this as many were in fact leaders. Could the authors comment on how representative of their sample might be?
4. The paper mentions that community-based organizations dedicated to the health and well-being of OALWH did not come up in their discussions. Although the services provided seem pertinent, they were not mentioned. This is an area that may have implications for those groups: what is to be understood from this lack of mention? Is this related to concerns about confidentiality? Lack of pertinence?

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Yes

If applicable, is the statistical analysis and its interpretation appropriate?

Yes

Are all the source data underlying the results available to ensure full reproducibility?

Yes

Are the conclusions drawn adequately supported by the results?

Yes

Competing Interests: No competing interests were disclosed.**Reviewer Expertise:** HIV, cognition and quality of life of older adults with HIV**I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.**

Reviewer Report 06 October 2022

<https://doi.org/10.21956/wellcomeopenres.20191.r52185>

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**Jepchirchir Kiplagat**

Academic Model Providing Access to Healthcare (AMPATH), College of Health Sciences, Moi University, Eldoret, Kenya

This is a very interesting paper addressing some of the concern care providers and policy makers should be aware on aging population. This qualitative exploratory study provides relevant information for understanding coping mechanisms used by aging population with HIV to improve their mental health and wellbeing. While this is timely and uncovers ways of improving care for the aging HIV population, the manuscript requires improvement in some areas before its final publication.

Title:

The title is clear. May want to include the setting of the study as this is key.

Abstract:

The abstract is detailed and provides a clear and concise.

Introduction:

The introduction covers relevant information to the study. Sentence 2 in the first paragraph is too long and needs rephrasing. Reference 6 within the first paragraph does not speak to SSA's limited research. There are two sentences following each other starting with the word 'Despite' and need rephrasing too. The last paragraph in the introduction section should be moved to methods.

Methods:

The method section is relatively well done. However, it needs to be clear what type of qualitative interviews were done for each group – in depth interviews? Key informant interviews? Focus group discussions? The methods including the reporting should follow COREQ guidelines. May need to complete the COREQ form to guide the review.

The authors mention that over three-quarters of the interviews were conducted in Swahili and

others in the local language or English. During the analysis recorded interviews were transcribed verbatim. We are not informed at what point the information was translated. At transcription or after?

Results:

The results including the quotes are well presented. It might be helpful to a reader when a table summarizing participants' characteristics is included. Remove the quantifying word under section on self-care first paragraph where it starts with...a good number of the... you may want to reword to read ... some self-care strategies were

Under generativity, the second sentence begins to discuss the results. Would leave that sentence out and provide it under discussion. There is also a sentence under 'Social connectedness/support systems', second paragraph, the second to last sentence that read.... "However, such services tended to vary from one HIV clinic to another....." This sentence denotes that data was collected from multiple clinics, when in the methods, the authors are clear that the data was collected from Kilifi County Hospital HIV clinic.

Discussion:

This section looks ok as is written. Demonstrate a clear engagement with literature in the field. However, there is a moderate amount of repetitions in the discussion that is not necessary/does not provide any meaning...For example sentence under self-care "...Although existing evidence provides only modest evidence of effectiveness of these strategies, most of these strategies were reported to be effective in promoting mental health and wellbeing among OALWH" First, this sentence needs to be qualified by referencing, and two, 'these' strategies need to be clarified. Strengths and limitation allude to minimizing potential bias by maintaining reflexivity. How was this done? What potential beliefs/biases did the researcher have in data collection?

Conclusion:

The conclusion is focused to the study findings. However, some statements sound accusative, for example -"Further engagement with traditional healers/prophets may be warranted to mitigate the present obstacles and dangers some of these individuals present to the OALWH". This statement could be toned down while maintaining what needs to be communicated.

Data availability:

Indicate that the transcripts are in Kiswahili. It is unclear how this study was able to complete the analysis and present the data in English if the information was not translated.

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Partly

If applicable, is the statistical analysis and its interpretation appropriate?

Not applicable

Are all the source data underlying the results available to ensure full reproducibility?

Partly

Are the conclusions drawn adequately supported by the results?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: HIV and ageing

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

RESEARCH ARTICLE

Prevalence and factors associated with mild depressive and anxiety symptoms in older adults living with HIV from the Kenyan coast

Patrick N. Mwangala^{1,2,3,§} , Carophine Nasambu¹, Ryan G. Wagner⁴, Charles R. Newton^{1,3,5,6} and Amina Abubakar^{1,3,5,6}

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Abstract

Introduction: Empirical research on the burden and determinants of common mental disorders (CMDs), especially depression and anxiety, among older adults living with HIV (OALWH) in sub-Saharan Africa is inadequate. To bridge the gap in Kenya we: (1) determined the prevalence of CMDs among OALWH on routine HIV care compared to HIV-negative peers; (2) investigated HIV status as an independent predictor of CMDs in older adults; and (3) investigated CMD determinants.

Methods: In a cross-sectional study conducted between 2020 and 2021, the prevalence of CMDs and associated determinants were investigated at the Kenyan coast among 440 adults aged ≥ 50 years (257 OALWH). The Patient Health Questionnaire and Generalized Anxiety Disorder scale were administered alongside measures capturing biopsychosocial information. Logistic regression was used to examine the correlates of CMDs.

Results: No significant differences were found in the prevalence of mild depressive symptoms, 23.8% versus 18.2% ($p = 0.16$) and mild anxiety symptoms, 11.7% versus 7.2% ($p = 0.12$) among OALWH compared to HIV-negative peers, respectively. HIV status was not independently predictive of CMDs. Among OALWH, higher perceived HIV-related stigma, ageism, increasing household HIV burden, loneliness, increasing functional disability, sleeping difficulties, chronic fatigue and advanced age (>70 years) were associated with elevated CMDs. Among HIV-negative older adults, loneliness, increased medication burden and sleeping difficulties were associated with elevated depressive symptoms. Easier access to HIV care was the only factor associated with lower CMDs among OALWH.

Conclusions: On the Kenyan coast, the burden of moderate and severe CMDs among older adults is low; however, both OALWH and their HIV-negative peers have a similar relatively high burden of mild depressive and anxiety symptoms. Our results also suggest that determinants of CMDs among OALWH in this setting are predominantly psychosocial factors. These results highlight the need for psychosocial interventions (at the family, community and clinical levels) to mitigate the risks of mild CMDs as they are known to be potentially debilitating.

Keywords: common mental disorders; HIV infection; older adults; prevalence; correlates; Kenya

Additional information may be found under the Supporting Information tab of this article.

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1 | INTRODUCTION

Common mental disorders (CMDs), especially depression and anxiety, are among the leading causes of disability worldwide [1, 2] and cost the global economy about US\$1.2 trillion a year [3]. Notably, the global burden of both disorders has not reduced since 1990, despite compelling evidence of cost-effective interventions [4]. Efforts to address this substantial burden of CMDs should be directed at the most vulnerable in

society, including older adults living with HIV (OALWH) residing in sub-Saharan Africa (SSA). In Kenya, the increasing population of OALWH [5] is experiencing an elevated incidence of chronic age-related conditions [6], all potentially resulting in an increase of CMDs.

The prevalence of depression among OALWH in SSA ranges from 6% to 59% [7] compared to 26% among their HIV-negative peers [8]. Outside SSA, estimates of depression among OALWH range from 19% to 45% in Asia [9, 10], 39%

to 90% in the United States [11, 12], 16% to 35% in Latin America and the Caribbean [13], and 28% in Europe [14]. Anxiety, on the other hand, ranges from 3% to 21% among OALWH in SSA [7] and 35% to 56% in high-income countries (HICs) [14, 15].

Understanding the determinants of CMDs among older adults is critical in designing and implementing contextually relevant mental health interventions. A recent review indicated that frequently reported determinants of depression among OALWH were mainly socio-demographic in nature [7]. Among psychosocial factors, HIV-related stigma [16], HIV status disclosure [16] and increasing disability scores have been associated with higher odds of depressive symptoms, while social support [17], resilience [16] and spirituality [17] have been shown to be protective factors. Biomedical and lifestyle factors, including alcohol use [17], current/former tobacco smoking [18] and back pain [19], have been associated with elevated levels of depression among OALWH. Among HIV-negative older adults in SSA, rural residence [20, 21], poor social network [20], living alone [22], being female [8, 20] and a lifetime of unskilled occupation [21] have been associated with elevated odds of depression. No study in SSA has examined the determinants of anxiety among OALWH.

Several reasons call for investigating depression and anxiety among older adults. Firstly, known risk factors for CMD, such as poverty, are more prevalent in older ages [23, 24]. Secondly, CMDs in late life are severely under-researched and underdiagnosed in primary care [7, 25]. Besides, the prognosis of CMDs among old adults appears to be worse than for young people [26]. Late-life CMDs may also elevate the risk of developing dementia [27]. Among people living with HIV (PLWH), depression and anxiety have been associated with non-adherence to combination antiretroviral therapy (cART), risky sexual behaviours, reduced quality of life and higher suicide rates [28–30]. Given that CMDs are rarely detected but can have serious health impacts on older people, it is increasingly important to assess for mild, moderate and severe levels to determine the scale of the problem [31].

To bridge the gap in Kenya, our study seeks to: (1) determine the prevalence of depressive and anxiety symptoms among OALWH compared to their HIV-negative peers; (2) investigate HIV status as an independent predictor of depressive and anxiety symptoms in the older adults; and (3) investigate the determinants of CMDs among older adults at the coast of Kenya.

2 | METHODS

2.1 | Study design and setting

This cross-sectional study was conducted at the Kenyan coast in Kilifi and Mombasa Counties between February 2020 and October 2021. The majority of Kilifi residents are rural dwellers whose main form of livelihood is subsistence farming and small-scale trading [32]. Kilifi has an adult HIV prevalence of 4.5% [33]. Mombasa County borders Kilifi County to the north and is considered urban. The common sources of income in Mombasa county include tourism, wholesale and retail trade. The Mombasa adult HIV prevalence is 7.5% [33].

2.2 | Study participants and recruitment

2.2.1 | Older adults living with HIV

OALWH were recruited from two public HIV specialized clinics in Kilifi and Mombasa Counties. As inclusion criteria, participants had to be aged ≥ 50 years of age, with a confirmed HIV seropositivity status, and on cART.

In both facilities, we were assisted by community health volunteers or healthcare providers in reviewing existing records to identify all potential participants. We used systematic sampling to identify potential clients for the study.

2.2.2 | Older adults without HIV

All HIV-negative older adults were recruited in Kilifi County. The Kilifi Health and Demographic Surveillance System was used to identify families with eligible older adults. Potential participants aged ≥ 50 were randomly identified from the existing database and followed up at their homes using GPS coordinates. To be included in the study, individuals had to be ≥ 50 years, and residents of Kilifi county, and provide consent for participation, including willingness to be tested for HIV using a rapid HIV testing kit (OraQuick) for a confirmation of HIV-negative status. We chose HIV-negative adults aged ≥ 50 years as our comparison group to the OALWH based on previous research [34, 35].

2.3 | Sample size calculations

Our sample size was calculated using previous studies from Uganda [36] and South Africa [35]. An overall sample size of at least 372 individuals was needed to detect a difference in CMDs between OALWH and HIV-negative community controls at 80% power and a 5% level of statistical significance. A sample of 450 participants was considered sufficient, allowing for missing data.

2.4 | Measures

The research instruments were programmed on android tablets using the Research Electronic Data Capture (REDCap) platform [37] for face-to-face interviewer administration. All research assistants were trained for 2 weeks by the first author prior to data collection.

2.4.1 | Socio-demographic and asset index form

Socio-demographic information was captured in REDCap. We also collected information on individual and family ownership of disposable assets for asset index computation. Participants were also asked to provide information on their access to social support, food security in the past week, the number of PLWH within the household and whether they were caring for a sick family member.

2.4.2 | General health form

We captured the participant's anthropometric details. Other information included hours spent on sedentary activities in a day, sexual activity, household HIV burden, number of medications one used and common somatic complaints.

Among OALWH, HIV-specific information questions were asked relating to the disclosure of HIV status and access to HIV care. Information regarding their current cART regimen and overall duration on cART was extracted from medical records. Blood samples were also collected from OALWH for viral load testing.

2.4.3 | Psychosocial measures

The brief 12-item HIV stigma scale [38] was utilized to assess participants' perceived HIV-related stigma. Higher scores indicate a greater level of perceived stigma. In the current study, this scale yielded good internal consistency alpha, 0.78 (95% CI 0.73, 0.83).

The 12-item World Health Organization Disability Assessment Schedule 2 (WHODAS 2) [39] was used to assess for functional disability among participants. Higher scores indicate a greater level of disability. In this study, the tool demonstrated good internal consistency alpha, 0.77 (95% CI 0.70, 0.84).

The UCLA 8-item loneliness scale [40] was used to assess participants' perceived loneliness. Higher scores equate to a greater level of loneliness. In the present study, this scale had acceptable internal consistency alpha, 0.61 (95% CI 0.56, 0.64).

The 20-item Ageism survey [41] was used to assess participants' experiences of ageism. Higher scores indicate more frequent experiences of ageism. In the current study, the internal reliability (Cronbach's alpha) was 0.89 (95% CI 0.87, 0.92).

2.4.4 | Measures of common mental disorders

The 7-item Generalized Anxiety Disorder scale (GAD-7) [42] and the 9-item Patient Health Questionnaire (PHQ-9) [43] were utilized to measure anxiety and depressive symptoms in the previous 2-week period, respectively. The total scores range from 0 to 21 for GAD-7 and 0 to 27 for PHQ-9. For GAD-7, total scores of 5–9, 10–14 and 15–21 represent mild, moderate and severe anxiety symptoms, respectively [44]. Total scores of 5–9, 10–14 and 15–27 indicate mild, moderate and severe depressive symptoms [45], respectively. A cut-off score of ≥ 5 for both PHQ-9 and GAD-7 was used to define a positive screen for depressive and anxiety symptoms in the current study, similar to previous studies in Ethiopia [46] and Tanzania [47]. In the present study, the internal consistency alphas for PHQ-9 and GAD-7 were good, 0.75 (95% CI 0.70, 0.79) and 0.74 (95% CI 0.70, 0.79), respectively.

2.4.5 | Translation of new study measures

All study questionnaires not previously adapted to the local language of Swahili underwent the recommended adaptation procedure in line with international guidelines [48].

2.5 | Statistical analysis

All analyses were carried out in STATA version 15.0 (StataCorp LP, College Station, TX, USA). Independent Student's *t*-test and Chi-square test were used to compare differences in continuous and categorical independent variables, respectively. We used proportions as percentages to estimate the

prevalence of CMDs among OALWH and their HIV-negative counterparts. The Chi-square test was utilized to compare group differences on binary outcome variables. To investigate HIV status as an independent predictor of CMDs, we utilized logistic regression analyses adjusting for exposure variables that accounted for differences in CMDs. To examine the correlates of CMDs, we used logistic regression models to explore univariate relationships between the binary outcome variables and the different exposure variables. Exposure variables with a *p*-value < 0.15 in the univariate analysis were subsequently entered into the multivariable models using forward selection (data for OALWH and HIV-negative older adults were analysed separately for this set of analyses). In all models, collinearity was checked and for all tests of the hypothesis, a two-tailed *p*-value < 0.05 was regarded as statistically significant. The overall fit of the final models was examined by Hosmer and Lemeshow (HL) goodness of fit test where a *p*-value of > 0.05 was considered a good fit. The HL test results were cross-checked using McFadden's pseudo-R squared statistic.

2.6 | Ethics approval and consent to participate

The study was approved by the Kenya Medical Research Institute Scientific and Ethics Review Unit (Ref: KEMRI/SERU/CGMR-C/152/3804). Permission to conduct the study was granted by the research office Kilifi (Ref: HP/KCHS/VOLX/171) and Mombasa (Ref: COH/Msa/RSC/04). All respondents provided written informed consent for their participation.

3 | RESULTS

3.1 | Sample characteristics

A total of 440 participants were included in this study, with a mean age of 60.1 (SD = 6.9) years. The participant response rate was 90%. This included 72 (16%) OALWH in Mombasa and 368 (84%) in Kilifi. Most participants had formal education (63.2%), were unemployed (65.5%), lived in multigenerational households (81.6%) and cared for a sick family member (66.4%). OALWH were likely to be younger, unmarried, more educated, have lower monthly household income, live alone, with a smaller number of dependents and more food insecure (Table 1).

3.2 | HIV-related characteristics of OALWH

The majority of the OALWH had disclosed their HIV status (95.3%) and were on first-line cART treatment (90%). The mean (SD) duration of HIV treatment was 11.4 (4.3) years. Nearly, all (98.1%) of the OALWH had a viral load of ≤ 1000 copies/ml (Table 2).

3.3 | Prevalence estimates for CMDs

The prevalence of mild depressive symptoms was 23.8% among OALWH compared to 18.2% in the comparison group ($p = 0.16$). The prevalence of mild anxiety symptoms was 11.7% among OALWH compared to 7.2% in the comparison group ($p = 0.12$). The prevalence of comorbid mild depressive

Table 1. Characteristics of the study population by HIV status, N = 440

Characteristic	Total sample N = 440	HIV status		p-value
		Older adults without HIV, n = 183	Older adults living with HIV, n = 257	
Socio-demographic				
Age (years)				
50–59	227 (51.6)	84 (45.9)	143 (55.6)	0.02
60–69	171 (38.9)	74 (40.4)	97 (37.7)	
≥70	42 (9.5)	25 (13.7)	17 (6.6)	
Sex				
Female	258 (58.6)	98 (53.6)	160 (62.3)	0.07
Male	182 (41.4)	85 (46.4)	97 (37.7)	
Marital status				
Never married	12 (2.8)	4 (2.2)	8 (3.1)	<0.001†
Separated/Divorced/Widowed	181 (41.1)	45 (24.6)	136 (52.9)	
Married/cohabiting	247 (56.1)	134 (73.2)	113 (44.0)	
Education level				
None	162 (36.8)	90 (49.2)	72 (28.0)	<0.001†
Primary	182 (41.4)	65 (35.5)	117 (45.5)	
Secondary	73 (16.6)	22 (12.0)	51 (19.9)	
Tertiary	23 (5.2)	6 (3.3)	17 (6.6)	
Employment				
Unemployed	288 (65.5)	126 (68.9)	162 (63.0)	0.1
Employed	116 (26.3)	39 (21.3)	77 (30.0)	
Retired	36 (8.2)	18 (9.8)	18 (7.0)	
Monthly household income (Ksh)				
≤10,000	279 (63.4)	69 (37.7)	210 (81.7)	<0.001
Above 10,000	161 (36.6)	114 (62.3)	47 (18.3)	
Living arrangements				
Multiple generational families	359 (81.6)	169 (92.3)	190 (73.9)	<0.001†
Single generational families	41 (9.3)	6 (3.3)	35 (13.6)	
Alone	40 (9.1)	8 (4.4)	32 (12.5)	
Number of dependents, mean (SD)	3.2 (2.6)	3.6 (2.5)	2.9 (2.7)	0.01
Caring for a sick family member, OM = 2				
Yes	291 (66.4)	104 (57.1)	187 (73.1)	0.001
No	147 (33.6)	78 (42.9)	69 (26.9)	
Access to instrumental/social support				
None	199 (45.2)	93 (50.8)	106 (41.2)	0.07
Sometimes	215 (48.9)	83 (45.4)	132 (51.4)	
Most of the time	26 (5.9)	7 (3.8)	19 (7.4)	
Food insecurity (lack of food in the past week), OM = 3				
Never	293 (67.1)	134 (73.6)	159 (62.4)	0.002†
Sometimes	119 (27.2)	45 (24.7)	74 (29.0)	
Most of the times/always	25 (5.7)	3 (1.7)	22 (8.6)	
Asset index score ^a —mean (SD)	2.3 (1.5)	1.9 (1.2)	2.5 (1.6)	<0.001
Body mass index—mean (SD), OM = 11	24.9 (6.0)	24.7 (6.1)	25.0 (5.9)	0.7
Loneliness score ^b —mean (SD), OM = 3	13.9 (3.7)	13.0 (3.4)	14.6 (3.7)	<0.001
Functional disability score ^c —mean (SD), OM = 2	2.5 (4.3)	1.5 (3.0)	3.1 (4.9)	<0.001
Ageism score ^d —mean (SD)	4.2 (5.9)	3.0 (4.4)	5.0 (6.6)	<0.001
Hours spent in sedentary activities in a day, mean (SD), OM = 12	4.5 (2.6)	4.3 (2.1)	4.6 (2.9)	0.3

(Continued)

Table 1. (Continued)

Characteristic	Total sample N = 440	HIV status		p-value
		Older adults without HIV, n = 183	Older adults living with HIV, n = 257	
Sexually active, OM = 4				
Yes	206 (47.3)	105 (57.4)	101 (39.9)	<0.001
No	230 (52.7)	78 (42.6)	152 (60.1)	
Sleeping difficulties in the past month, OM = 4				
None	276 (63.3)	125 (68.3)	151 (59.7)	0.01 [†]
Sometimes	131 (30.1)	53 (29.0)	78 (30.8)	
Most of the times/always	29 (6.6)	5 (2.7)	24 (9.5)	
Chronic fatigue				
Yes	56 (12.7)	21 (11.5)	35 (13.6)	0.5
No	384 (87.3)	162 (88.5)	222 (86.4)	
Number of medications participants are currently using, mean (SD), OM = 8	1.6 (1.6)	0.4 (1.2)	2.4 (1.2)	<0.001

Note: All numbers are reported as frequencies with percentages unless otherwise stated. *p*-values are for the difference between OALWH and their HIV-negative peers by sample characteristic. *p*-values have been derived from Chi-square test (or Fisher's exact test) and independent Student's *t*-test for categorical and continuous independent variables, respectively.

Abbreviations: Ksh, Kenya shillings; OM, observation with missing value; SD, standard deviation.

^aScore range = 0–8, higher scores indicate better socio-economic status.

^bScore range = 8–27, higher scores indicate greater loneliness.

^cScore range = 0–33, higher scores indicate increasing disability.

^dScore range = 0–34, higher scores indicate increasing ageism.

[†]Based on Fisher's exact test.

and anxiety symptoms among OALWH was 10.1% compared to 4.4% in the comparison group (*p* = 0.03) (Table 3).

3.4 | Association between HIV status and CMDs

In univariate and multivariate logistic regression analyses, HIV seropositivity was not significantly associated with depressive or anxiety symptoms (Table 4). However, HIV seropositivity was significantly associated with higher odds of a positive screen for depressive and anxiety symptoms co-occurrence in univariate but not in the multivariate model.

3.5 | Determinants of CMDs in OALWH

Table 5 presents results from logistic regression analyses exploring the determinants of CMDs among OALWH.

3.5.1 | Depressive symptoms

In the multivariable logistic regression model, factors significantly associated with higher odds of depressive symptoms among OALWH were functional disability, ageism, sleeping difficulties, chronic fatigue, increasing household HIV burden and perceived HIV-related stigma. Easier access to HIV care was significantly associated with lower odds of depressive symptoms.

3.5.2 | Anxiety symptoms

In the multivariable analyses, age ≥70, perceived loneliness, functional disability, ageism and sleeping difficulties were sig-

nificantly associated with higher odds of anxiety symptoms among OALWH.

3.5.3 | Comorbid depressive and anxiety symptoms

In the multivariable analyses, perceived functional disability and ageism were significantly associated with higher odds of comorbid depressive and anxiety symptoms. Easier access to HIV care was significantly associated with lower odds of comorbid depressive and anxiety symptoms.

3.6 | Determinants of CMDs in HIV-negative older adults

The current work largely focused on OALWH. As such, we only provide a summary of the factors associated with CMDs among the HIV-negative older adults using the available data, particularly focusing on mild depressive symptoms whose prevalence was relatively high in the current sample, that is >10%. In multivariable analyses (Table S1), sleeping difficulties, perceived loneliness and increasing medication burden were significantly associated with higher odds of a positive screen for depressive symptoms among HIV-negative older adults. Greater sedentary behaviour and higher monthly household income were significantly associated with lower odds of depressive symptoms.

Table 2. HIV-related clinical and psychosocial characteristics of OALWH, n = 257

Characteristic	Mean (SD) or frequency (%)
HIV status disclosure	
Yes	245 (95.3%)
No	12 (4.7%)
Household HIV burden, mean (SD); OM = 5	1.4 (1.6)
cART regimen	
First line	233 (90.7%)
Second line	23 (8.9%)
Third line	1 (0.4%)
cART regimen change/interruption since HIV diagnosis	
Yes	110 (42.8%)
No	147 (57.2%)
Duration on cART (years), mean (SD), OM = 10	11.4 (4.3)
Viral suppression, OM = 45	
Yes	208 (98.1%)
No	4 (1.9%)
Access to HIV care, OM = 4	
Easily accessible	169 (66.8%)
Not easily accessible	84 (33.2%)
Perceived HIV-stigma score, OM = 1	
Personalized stigma ^a —mean (SD)	5.0 (1.9)
Disclosure concerns ^b —mean (SD)	8.6 (2.0)
Concerns about public attitudes ^c —mean (SD)	7.6 (2.2)
Negative self-image ^d —mean (SD)	6.4 (2.1)
Overall stigma ^e —mean (SD)	27.5 (5.4)

Abbreviations: cART, combination antiretroviral therapy; OM, observation with missing value; OALWH, older adults living with HIV.

^aScore range = 3–12, higher scores indicate greater stigma.

^bScore range = 3–12, higher scores indicate greater stigma.

^cScore range = 3–12, higher scores indicate greater stigma.

^dScore range = 3–12, higher scores indicate greater stigma.

^eScore range = 12–44, higher scores indicate greater stigma.

4 | DISCUSSION

To our knowledge, this is the first study in Kenya and among the first reports from SSA investigating CMDs among OALWH compared to their HIV-negative peers. Our study found a relatively high burden of mild depressive and anxiety symptoms; however, HIV status was not independently associated with these symptoms. The correlates of CMDs in our study were predominantly psychosocial factors, many of which are potentially modifiable, thus highlighting the need to address the psychosocial needs of these adults alongside their biomedical needs.

Our finding of no significant differences in the prevalence of CMDs between OALWH and their HIV-negative peers is dissimilar to other emerging reports in SSA. In rural Uganda, OALWH on cART had a significantly lower prevalence of probable depression than their HIV-negative peers [36], similar to what was reported in rural South Africa [35]. Our

finding also offers an interesting contrast to the predominant findings in HICs showing that OALWH present with worse CMDs than their HIV-negative peers [24]. The observed variation could reflect contextual differences across settings, for example healthcare systems, informal support systems and mental health resources that are likely to alter the risk profile of these adults. HIV status was not found to be an independent predictor of CMDs in our study. This observation is consistent with previous findings from South Africa [49] and Uganda [19] but contrasts with common research findings in HICs [24]. Our study may be part of an emerging body of evidence in SSA showing that the psychological health of OALWH is not worse than among those without HIV.

HIV-related stigma was significantly associated with higher odds of depressive symptoms among OALWH in our study. These findings are consistent with previous findings in the literature [12, 16, 50] and provide additional evidence of the critical role of addressing intersecting stigma in improving the mental wellbeing of OALWH. Relatedly, ageism was also significantly associated with higher odds of depressive symptoms, anxiety symptoms and their co-occurrence among OALWH. This finding is consistent with previous research conducted outside SSA [51]. Ageism could have an adverse impact on the mental health of OALWH through psychological, behavioural and physiological pathways [52]. Interventions addressing both ageist and HIV-stigmatizing attitudes at the community level will potentially improve the mental health of OALWH.

Increasing household HIV burden was significantly associated with higher odds of depressive symptoms among OALWH in our study. This may be related to the high caregiving burden often experienced by OALWH caring for HIV-positive children. This observation concurs with previous findings in the study setting [53].

Loneliness is common among older adults in general [54]. In this study, higher perceived loneliness was significantly associated with elevated odds of anxiety symptoms among OALWH and depressive symptoms among HIV-negative older adults. Our finding is consistent with previous studies from HICs [12, 55]. Theoretical models suggest that loneliness has cognitive, biological and social consequences that could potentially heighten the risk of subsequent CMDs [56]. Higher perceived functional disability was also strongly associated with higher odds of depressive symptoms, anxiety symptoms and their co-occurrence among OALWH in the current study, consistent with previous findings [19, 57, 58]. Since functional disability occurs frequently among OALWH, there is a need for early identification to help preserve functional independence.

Sleep disturbance is a prominent symptom in people with CMDs, especially depression, and was formerly regarded as a main secondary indicator of depression [59]. Nonetheless, multiple prospective studies have identified insomnia as an independent risk indicator for emerging or recurrent depression, suggesting that sleep problems are not necessarily secondary effects of CMDs but a predictive prodromal symptom [60, 61]. In this study, persistent sleep problems were significantly associated with higher odds of depressive symptoms, anxiety symptoms and their co-occurrence among OALWH and higher odds of depressive symptoms among HIV-negative

Table 3. Prevalence of common mental disorders in OALWH versus their HIV-negative peers

	Older adults without HIV, n = 181		Older adults living with HIV, n = 256		p-value
	Number	Prevalence (95% CI)	Number	Prevalence (95% CI)	
Severity of depressive symptoms					
Mild	28	15.5 (10.5, 21.6)	49	19.1 (14.5, 24.5)	0.3 [†]
Moderate	5	2.8 (0.9, 6.3)	8	3.1 (1.4, 6.1)	
Severe	–	–	4	1.6 (0.4, 4.0)	
Positive depressive symptoms screen (cut-off ≥5)					
Yes	33	18.2 (12.9, 24.6)	61	23.8 (18.7, 29.5)	0.2
Severity of anxiety symptoms					
Mild	13	7.2 (3.9, 12.0)	26	10.2 (6.7, 14.5)	0.1 [†]
Moderate	–	–	4	1.6 (0.4, 4.0)	
Positive anxiety symptoms screen (cut-off ≥5)					
Yes	13	7.2 (3.9, 12.0)	30	11.7 (8.0, 16.3)	0.1
Positive screen for comorbid depressive and anxiety symptoms					
Yes	8	4.4 (1.9, 8.4)	26	10.1 (6.7, 14.5)	0.03

Abbreviation: 95% CI, 95% confidence interval; OALWH, older adults living with HIV.

[†]Based on Fisher's exact test.

older adults. This finding is consistent with previous findings [59, 62, 63]. A combination of pharmacological and non-pharmacological interventions for sleep disturbances may effectively reduce and possibly prevent CMDs [64].

Chronic fatigue was also significantly associated with increased odds of depressive symptoms among OALWH in our study, similar to what has been reported elsewhere [65, 66]. Fatigue is a vital indicator of ageing-related declines in health and functioning [67]. Fatigue management strategies, such as adequate rest and sleep, are likely to improve the mental health of OALWH. Among HIV-negative older adults, an increased medication burden was also significantly associated with higher odds of depressive symptoms, consistent with previous findings [68]. While the exact mechanism for this association is unknown, we know that the use of medication increases as the number of medical conditions rises. Multiple medications, which are easily detected by clinicians, can provide an important clue to healthcare providers to further investigate depression in their clients.

Among socio-demographic factors, old age (≥70 years) was significantly associated with higher odds of anxiety symptoms in OALWH, while higher monthly household income was significantly associated with lower depressive symptoms among HIV-negative older adults. Mixed findings have been reported on these factors previously [69].

Easier access to HIV care was the only protective indicator for CMDs in OALWH in the current study. Given that many OALWH in Kenya face unique challenges with seeking HIV care services [70], programmes aimed at strengthening HIV care access or financial support have the potential to improve OALWHs' mental wellbeing. Further decentralizing HIV care into the community possibly utilizing community health workers may also be beneficial.

Among HIV-negative older adults, an increasing number of hours on sedentary activities was significantly associated with lower odds of depressive symptoms. More studies are needed

to better understand the mechanism involved. Emerging data suggest that passive sedentary behaviours, for example television watching, increase the risk of depression, while mentally active sedentary behaviours, for example reading, may be protective against depression [71].

Most of our data (about 84%) were collected after the onset of the COVID-19 pandemic. Some studies have reported elevated levels of loneliness, depression, anxiety and insomnia among older adults following the outbreak of COVID-19 [72–74], while others have reported no changes before and during the pandemic despite increased loneliness during the pandemic [75]. Other studies have shown that younger populations have had higher rates of CMDs compared to older adults [76–79]. While it is possible that the emergence of the pandemic may have created an environment where the determinants of poor mental health could have been exacerbated, our study found low prevalences of CMDs, similar to previous research, suggesting higher resilience to the mental health effects of COVID-19 [80]. The long-term impacts of the pandemic remain unclear, especially in SSA where data on older adults' mental health are very scarce. More studies are needed to elucidate these findings.

The strengths of the current study include the focus on a neglected but rapidly growing population of OALWH, the use of a comparison group and sufficient sample size. Nonetheless, the cross-sectional nature of the study precludes any conclusion on causality. We recruited our OALWH from public HIV clinics, as such, our findings may not be readily generalizable to OALWH who may be out of care or attending private or urban HIV clinics or recruited from the community. We also utilized self-report screening measures which could be subject to reporting bias. Relatedly, the mental health screening measures do not give a clinical diagnosis of the studied CMDs, hence, we only report the symptomatology of these conditions.

Table 4. Association between HIV status and common mental disorders across the whole sample of older adults

Covariate	Positive screen for depressive symptoms		Positive screen for anxiety symptoms		Comorbid depressive and anxiety symptoms	
	Crude analysis OR (95% CI)	Adjusted analysis aOR (95% CI)	Crude analysis OR (95% CI)	Adjusted analysis aOR (95% CI)	Crude analysis OR (95% CI)	Adjusted analysis aOR (95% CI)
HIV status						
Seronegative	Ref	Ref	Ref	Ref	Ref	Ref
Seropositive	1.40 (0.87, 2.25)	0.54 (0.27, 1.07)	1.72 (0.87, 3.39)	0.46 (0.18, 1.19)	2.46* (1.09, 5.57)	0.74 (0.25, 2.22)
Sex						
Male		Ref		Ref		Ref
Female		1.68 (0.84, 3.38)		2.49 (0.95, 6.54)		1.93 (0.67, 5.56)
Age (years)						
50–59		Ref		Ref		Ref
60–69		0.89 (0.46, 1.70)		1.78 (0.71, 4.47)		1.72 (0.59, 4.98)
Above 70		0.56 (0.19, 1.69)		3.99* (1.08, 14.71)		3.94 (0.92, 16.94)
Marital status						
Never married		Ref		Ref		Ref
Separated/Divorced/Widowed		0.14* (0.03, 0.69)		0.40 (0.06, 2.75)		0.83 (0.06, 11.27)
Married/cohabiting		0.12* (0.02, 0.62)		0.48 (0.07, 3.53)		1.26 (0.09, 18.17)
Asset Index score		0.77* (0.60, 0.98)		1.06 (0.77, 1.46)		0.91 (0.63, 1.32)
Sexually active						
No		Ref		Ref		Ref
Yes		2.61* (1.24, 5.47)		0.96 (0.38, 2.43)		0.81 (0.28, 2.29)
Functional disability score		1.18** (1.09, 1.28)		1.14* (1.05, 1.24)		1.14* (1.04, 1.24)
Loneliness score		1.12* (1.03, 1.22)		1.16* (1.04, 1.30)		1.12 (0.99, 1.27)
Ageism score		1.10** (1.04, 1.16)		1.16** (1.08, 1.24)		1.16** (1.08, 1.25)
Caring for a sick family member		2.08* (1.08, 4.02)		3.50* (1.32, 9.28)		3.07* (1.03, 9.20)
Chronic fatigue		3.14** (1.46, 6.72)		1.80 (0.69, 4.67)		1.86 (0.66, 5.24)
Sleeping difficulties for the past month						
None		Ref		Ref		Ref
Sometimes		4.62** (2.38, 8.98)		3.64* (1.47, 9.03)		4.69* (1.59, 13.88)
Most of the time/always		10.89** (3.57, 33.24)		4.89* (1.35, 17.63)		7.30* (1.76, 30.27)
Number of the final model		431		431		431
Hosmer–Lemeshow test		$\chi^2 = 433.90$; $p = 0.25$		$\chi^2 = 307.20$; $p = 0.99$		$\chi^2 = 338.67$; $p = 0.99$
Variance explained		35.0%		36.4%		38.8%

Abbreviations: aOR, adjusted odds ratio; CMD, common mental disorder; GAD, generalized anxiety disorder; OR, odds ratio; Ref, reference group.

* p -value < 0.05, ** p -value < 0.001.

Despite the outlined limitations, this study has important implications for the care of older adults in our setting. We observed substantial levels of mild depressive and anxiety symptoms in both OALWH and their HIV-negative peers, highlighting the need for culturally appropriate mental health interventions in these older adults, regardless of their HIV status. Routine screening for CMDs should be strengthened to identify those at risk. Risk indicators for depressive

symptoms, anxiety symptoms and their co-occurrence in this study were predominantly psychosocial factors. Unfortunately, there is a paucity of research on psychosocial interventions among OALWH [81] and those in the general population [82], especially in SSA. Our findings highlight the need to strengthen the evidence base for interventions for CMDs among older adults in low-resource settings like Kenya.

Table 5. Univariate and multivariable analysis of correlates of common mental disorders among OALWH

Covariate	Positive screen for depressive symptoms		Positive screen for anxiety symptoms		Comorbid depressive and anxiety symptoms	
	Univariate analysis OR (95% CI)	Multivariable analysis aOR (95% CI)	Univariate analysis OR (95% CI)	Multivariable analysis aOR (95% CI)	Univariate analysis OR (95% CI)	Multivariable analysis aOR (95% CI)
Age (years)						
50–59	Ref	Ref	Ref	Ref	Ref	Ref
60–69	0.77 (0.41, 1.44)	0.55 (0.23, 1.32)	1.18 (0.51, 2.72)	2.03 (0.66, 6.20)	1.12 (0.45, 2.76)	0.73 (0.19, 2.84)
≥70	1.35 (0.44, 4.15)	1.00 (0.19, 5.24)	4.19** (1.27, 13.80)	7.43** (1.25, 44.36)	4.55** (1.37, 15.09)	4.76 (0.70, 32.55)
Sex						
Male	Ref	Ref	Ref	Ref	Ref	Ref
Female	1.34 (0.73, 2.45)	1.36 (0.58, 3.19)	1.79 (0.76, 4.19)	2.17 (0.58, 8.08)	1.73 (0.70, 4.29)	2.59 (0.64, 10.45)
Marital status						
Never married	Ref	–	–	–	–	–
Separated/Divorced/Widowed	0.19** (0.04, 0.82)	–	–	–	–	–
Married/cohabiting	0.16** (0.04, 0.73)	–	–	–	–	–
Education level						
None	Ref	–	Ref	–	Ref	–
Primary	0.80 (0.41, 1.57)	–	0.51* (0.22, 1.19)	–	0.52* (0.22, 1.25)	–
Secondary	0.78 (0.34, 1.80)	–	0.38* (0.11, 1.24)	–	0.20** (0.04, 0.96)	–
Tertiary	0.16* (0.02, 1.28)	–	0.28 (0.03, 2.30)	–	0.31 (0.04, 2.59)	–
Monthly household income (Ksh)						
≤10,000	Ref	–	Ref	–		
Above 10,000	0.33*** (0.12, 0.86)	–	0.13* (0.02, 1.02)	–	0.16* (0.02, 1.22)	–
Living arrangements						
Multiple generational families	–	–	–	–	Ref	–
Single generational families	–	–	–	–	2.11* (0.77, 5.78)	–
Alone	–	–	–	–	1.05 (0.29, 3.82)	–
Number of dependents, mean (SD)	–	–	0.87* (0.74, 1.04)	–	–	–
Caring for a sick family member						
No	Ref	–	–	–	–	–
Yes	0.63* (0.33, 1.16)	–	–	–	–	–
Food insecurity (lack of food in the past week)						
Never	Ref	–	Ref	–	Ref	–
Sometimes	2.92*** (1.55, 5.49)	–	4.21*** (1.75, 10.14)	–	5.95*** (2.18, 16.20)	–

(Continued)

Table 5. (Continued)

Covariate	Positive screen for depressive symptoms		Positive screen for anxiety symptoms		Comorbid depressive and anxiety symptoms	
	Univariate analysis OR (95% CI)	Multivariable analysis aOR (95% CI)	Univariate analysis OR (95% CI)	Multivariable analysis aOR (95% CI)	Univariate analysis OR (95% CI)	Multivariable analysis aOR (95% CI)
Most of the times/always	2.9** (1.11, 7.62)	–	6.21** (1.96, 19.70)	–	9.56*** (2.76, 33.15)	–
Loneliness score, mean (SD)	1.21*** (1.12, 1.32)	–	1.29*** (1.16, 1.43)	1.16** (1.01, 1.34)	1.28*** (1.15, 1.42)	–
Functional disability score, mean (SD)	1.25*** (1.15, 1.35)	1.15** (1.04, 1.28)	1.19*** (1.10, 1.28)	1.10** (1.01, 1.20)	1.18*** (1.10, 1.27)	1.12** (1.03, 1.22)
Ageism score, mean (SD)	1.14*** (1.08, 1.19)	1.10** (1.04, 1.17)	1.17*** (1.10, 1.24)	1.14*** (1.06, 1.23)	1.17*** (1.11, 1.24)	1.23*** (1.13, 1.33)
Hours spent in sedentary behaviours in a day, mean (SD)	–	–	–	–	1.13* (1.00, 1.28)	–
Sexually active	–	–	Ref	–	Ref	–
No	–	–	0.44* (0.18, 1.06)	–	0.44* (0.17, 1.15)	–
Yes	–	–	–	–	–	–
Sleeping difficulties in the past month	–	–	–	–	–	–
None	Ref	Ref	Ref	Ref	Ref	–
Sometimes	6.59*** (3.18, 13.66)	3.51** (1.38, 8.89)	10.17*** (3.29, 31.47)	6.41** (1.73, 23.83)	11.75*** (3.28, 42.0)	–
Most of the times/always	25.60*** (9.00, 72.99)	8.82*** (2.33, 33.37)	18.25*** (4.94, 67.40)	6.18** (1.26, 30.22)	20.31*** (4.80, 85.96)	–
Chronic fatigue	–	–	–	–	–	–
No	Ref	Ref	Ref	–	Ref	–
Yes	7.90*** (3.66, 17.02)	5.41** (1.78, 16.38)	2.68** (1.09, 6.62)	–	3.36** (1.33, 8.46)	–
Number of medications participants are currently using, mean (SD)	–	–	–	–	1.24* (0.94, 1.64)	–
HIV status disclosure	–	–	–	–	–	–
Yes	Ref	–	–	–	–	–
No	2.40* (0.73, 7.85)	–	–	–	–	–
Household HIV burden, mean (SD)	1.30** (1.09, 1.55)	1.37** (1.08, 1.74)	1.20* (0.98, 1.47)	–	1.21* (0.98, 1.49)	–
cART regimen change/interruption since HIV diagnosis	–	–	–	–	–	–
No	–	–	Ref	–	Ref	–
Yes	–	–	2.13* (0.97, 4.68)	–	1.88* (0.82, 4.34)	–
Access to HIV care	–	–	–	–	–	–
Not easily accessible	Ref	Ref	Ref	–	Ref	Ref
Easily accessible	0.47** (0.26, 0.85)	0.35** (0.15, 0.83)	0.36** (0.16, 0.78)	–	0.29** (0.12, 0.68)	0.16** (0.04, 0.60)

(Continued)

Table 5. (Continued)

Covariate	Positive screen for depressive symptoms		Positive screen for anxiety symptoms		Comorbid depressive and anxiety symptoms	
	Univariate analysis OR (95% CI)	Multivariable analysis aOR (95% CI)	Univariate analysis OR (95% CI)	Multivariable analysis aOR (95% CI)	Univariate analysis OR (95% CI)	Multivariable analysis aOR (95% CI)
Perceived HIV-stigma score, mean (SD)						
Personalized stigma	1.21** (1.04, 1.41)	1.27** (1.02, 1.59)	1.16* (0.96, 1.42)	–	1.25** (1.02, 1.54)	–
Disclosure concerns	–	–	–	–	–	–
Concerns about public attitudes	1.23** (1.06, 1.42)	–	1.29** (1.06, 1.57)	–	1.23** (1.00, 1.51)	–
Negative self-image	1.22** (1.06, 1.40)	–	1.20** (1.00, 1.44)	–	1.36** (1.12, 1.66)	–
Overall stigma	1.11*** (1.05, 1.18)	–	1.10** (1.02, 1.20)	–	1.13** (1.04, 1.23)	–
<i>n</i> for the final model		251		252		245
Variance explained		41.7%		41.0%		42.0%
Hosmer–Lemeshow test		$\chi^2 = 241.96$; <i>p</i> -value = 0.35		$\chi^2 = 210.85$; <i>p</i> -value = 0.79		$\chi^2 = 176.09$; <i>p</i> -value = 0.99
cvMean AUC (95% CI)		0.91 (0.87, 0.96)		0.88 (0.82, 0.95)		0.92 (0.89, 0.96)

Note: Only a priori variables (age and sex), as well as those with *p*-value < 0.15 in the univariate analysis or multivariable *p* < 0.05, are presented here. Ten independent variables were fitted for the multivariable model on depressive symptoms, seven variables for both the anxiety symptoms and CMD comorbidity.

Abbreviations: aOR, adjusted odds ratio; cvMean AUC, cross-validated mean area under the curve for the final multivariable model; OR, odds ratio; Ref, reference group; OALWH, older adults living with HIV.

p* value < 0.15, *p* value < 0.05, ****p* value < 0.01.

5 | CONCLUSIONS

Ambulatory, out-patient OALWH and their HIV-negative peers from the community have similar levels of mild depressive and anxiety symptoms. Additionally, living with HIV is not predictive of CMDs in this setting. Our study provides an initial understanding of the determinants of CMDs from a low-resource setting. Modifiable risk factors, such as ageism, HIV-related stigma, loneliness, functional disability and sleeping difficulties, represent a target for preventive interventions through psychosocial interventions at the family, community and clinical levels.

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COMPETING INTERESTS

The authors have no competing interests to disclose.

AUTHORS' CONTRIBUTIONS

PNM, CRN and AA conceptualized the study. PNM, CRN, RGW and AA designed the study. PNM and CN programmed the study questions on tablets and managed project data for the entire study period. PNM analysed the data. PNM, CN, RGW, CRN and AA contributed to the interpretation of the data. PNM wrote the first draft of the manuscript and all the authors reviewed the subsequent versions and approved the final draft for submission.

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DISCLAIMER

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DATA AVAILABILITY STATEMENT

Application for data access can be made through the Data Governance Committee of the KEMRI Wellcome Trust Research Programme who will review the application and advise as appropriate ensuring that uses are compatible with the consent obtained from participants for data collection. Requests can be sent to the coordinator of the Data Governance Committee using the following email dgc@kemri-wellcome.org.

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SUPPORTING INFORMATION

Additional information may be found under the Supporting Information tab for this article:

Table S1. Univariate and multivariable analysis of the correlates of depressive symptoms among HIV-negative older adults.



Prevalence and Factors Associated With Frailty Among Older Adults Living With HIV Compared to Their Uninfected Peers From the Kenyan Coast

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Objectives: a) To document the prevalence and correlates of frailty among older adults living with HIV (OALWH) and their uninfected peers, and b) Investigate HIV status as an independent predictor of frailty.

Methods: This cross-sectional study was conducted between 2020 and 2021 at the Kenyan coast among 440 older adults aged ≥ 50 years (257 OALWH). Frailty was assessed using the Reported Edmonton Frail Scale. Logistic regression was used to examine the correlates of frailty.

Results: The prevalence of frailty was significantly higher among OALWH (24%) than their uninfected peers (13%). HIV seropositivity was not independently associated with frailty. Sleeping difficulties, ageism, higher waist/hip ratio, visiting traditional healers, HIV treatment change/interruption, prolonged illness following HIV diagnosis, and self-reported diabetes were significantly associated with higher odds of frailty. Residing in larger households, having higher income, having friends, being male and light physical activities were significantly associated with reduced odds of frailty.

Conclusion: The prevalence of frailty is elevated among OALWH; however, factors other than HIV are predominant, particularly psychosocial factors. Multicomponent interventions are needed to prevent/delay and manage frailty in this setting.

Keywords: HIV, aging, frailty, correlates, sub-Saharan Africa

INTRODUCTION

Recent years have witnessed a remarkable rise in the population of older adults in developing countries, including Kenya, making caring for the elderly a public health priority [1]. A better understanding of the factors that influence healthy ageing is crucial for designing appropriate therapies to prevent functional decline, maintain independence, and preserve the quality of life of

these adults. In this context, increasing attention has been paid to geriatric syndromes, especially frailty, as a potential explanation of the health diversity among older adults [2]. Although a universal definition is still lacking, frailty is commonly conceptualized as the increased vulnerability to external and internal stressors resulting from a significant loss of physiologic reserve [3]. Several pathophysiological pathways, including cellular senescence, mitochondrial dysfunction, oxidative stress, and dysregulation of inflammatory processes, underlie the frailty syndrome [4]. Growing evidence from systematic reviews also links frailty with adverse health outcomes, including emergency hospital admissions [5], disability [6], poor quality of life [7], dementia [8], and premature mortality [9]. Given the high burden, negative impacts on older adults, and the dynamic nature of frailty, identifying the determinants of frailty is imperative, especially among vulnerable older adults such as those ageing with HIV.

Frailty has been examined extensively in recent years; however, most work has been conducted in older populations in high-income countries (HICs). Some work has been conducted in LMICs, but this has been confined to Brazil, Mexico, China [10] and South Africa [11–14]. So far, results indicate that the prevalence of frailty is highly variable, both between countries and between populations within a country, due to differences in the populations studied and the measurement of frailty. A recent meta-analysis of European studies showed a frailty prevalence of 12% among community-based studies and 45% in non-community-based studies [15]. In Latin America, the prevalence of frailty among community-dwelling older adults was 20%, with a range of 8%–43% in the studies reviewed [16]. Among OALWH, the global prevalence of frailty ranges from 5% to 29% [17]. In SSA, there has been growing attention to the risks of frailty in the ageing population, both in the general population and among people living with HIV (PLWH). To our knowledge, about a dozen studies on frailty have been conducted among older adults in the general population in SSA: South Africa [11–14], Tanzania [18–20], Ghana [13, 14], Nigeria [21], and Burkina Faso [22] with prevalence estimates ranging from 5.4% [11] to 63.3% [21]. Only two studies have focused on OALWH [23], with prevalence estimates ranging from 2.8% to 14.7%.

Identifying the risk and protective factors of frailty may be useful for developing interventions designed to prevent and/or lower the burden that frailty places on a person and provide future directions for public health policy. Indeed, numerous studies have focused on identifying the factors associated with frailty, including the role of biological, lifestyle, and psychological factors [18]. Among older adults in the general population, sociodemographic factors (e.g., being female, older age, low education levels, low income, living alone), physical factors (e.g., obesity, malnourishment, hearing loss, visual impairment, persistent pain), lifestyle factors (e.g., smoking, alcohol consumption, sedentary behaviours) and psychological factors (e.g., depressive symptoms, and sleeping problems) have been identified as risk factors for frailty [24–33]. Most of these studies have focused on sociodemographic factors. However, recently published studies have focused more on lifestyle-related, psychological, and biological factors associated with frailty,

which may reflect a growing interest in potentially modifiable factors for frailty. Among OALWH, less research on risk and protective factors has been conducted. In a past systematic review [17], the predictors of frailty included older age, comorbidities, diagnosis of acquired immunodeficiency syndrome (AIDS) and low current CD4⁺ cell count.

Like many parts of SSA, Kenya's population of older adults is increasing rapidly. In the most recent population census of 2019, the proportion of older adults aged ≥ 50 years was about 11%, representing approximately 5.2 million individuals [34]. Kenya is also witnessing an increase in chronic age-related conditions [35], which coincides with a high prevalence of HIV among those aged ≥ 50 years [36]. Hence, establishing the current burden and determinants of frailty is essential if health and social care services are to meet the needs of Kenya's ageing population. The present study aims to: a) determine the prevalence of frailty among OALWH compared to their uninfected peers; b) investigate HIV status as an independent predictor of frailty in the older adults; and c) investigate the determinants of frailty among the older adults at the coast of Kenya.

METHODS

Study Design and Setting

This was a cross-sectional study carried out at the Kenyan coast in Mombasa and Kilifi counties between 2020 and 2021. With an estimated population of about 1.5 million people [37], most Kilifi residents are rural inhabitants of the Mijikenda tribe, whose primary source of livelihood is subsistence farming and small-scale trading. In Kilifi, the prevalence of HIV in adults is 4.5% [38]. Mombasa County borders Kilifi to the north and hosts Mombasa City, the second-largest city and chief port of Kenya. It has a population of about 1.2 million residents [37]. Given its urban nature, the county is made up of the local (Mijikenda and Swahili) and immigrant communities from other parts of Kenya. At about 60%, the formal sector provides the majority of employment in Mombasa County [39]. The prevalence of HIV in adults in Mombasa is about 7.5% [38].

Study Participants and Recruitment Older Adults Living With HIV (OALWH)

We recruited the OALWH from two public HIV-specialized clinics in Mombasa and Kilifi counties (one in each). We specifically selected the two clinics because of their wide client catchment area and their large volume of potential participants. To be included, clients had to be aged ≥ 50 years of age, have a confirmed HIV seropositivity status, be on HIV treatment, and be willing and able to provide informed consent for their involvement.

In both HIV clinics, two community health volunteers or healthcare providers assisted us in reviewing existing records to identify potential clients. Efforts were made to contact all potential clients who had contact details (in alphabetical order) to invite them to participate in our study. Study introductions were conducted in person by a research assistant before any enrolment. Participant recruitment began in

Mombasa County; however, it was interrupted by the onset of the COVID-19 pandemic after recruiting and assessing only 72 OALWH. Upon resumption of project activities, the recruitment and assessment of remaining clients ($n = 368$) took place in Kilifi County.

HIV Uninfected Older Adults

All the older adults without HIV were recruited from Kilifi County. The Kilifi Health and Demographic Surveillance System (KHDSS) was used to identify families with eligible older adults. Subsequently, potential participants aged ≥ 50 years were randomly identified from the existing database and followed up at their homes using Global Positioning System (GPS) coordinates by our trained research assistants. Project information was shared with all individuals who expressed interest in participation. As inclusion criteria, individuals had to be ≥ 50 years old, inhabitants of Kilifi county, and provide consent to their involvement, including willingness to be tested for HIV using a rapid HIV testing kit (OraQuick) for a confirmation of their HIV seronegative status.

Sample Size Calculations

We calculated our sample size using a previous study [40], which reported significant differences in the prevalence estimate of frailty between OALWH and their uninfected counterparts. Power analyses in Stata (using effect estimates and comparison of two group proportions) were conducted to estimate the required sample size. An overall sample of 310 was required to detect a difference in frailty between OALWH and uninfected peers at 80% power and a 5% level of statistical significance. A sample of 450 participants was deemed sufficient, allowing for missing data.

Measures

We programmed all our research instruments on Android tablets using the Research Electronic Data Capture (REDCap) platform [41] for face-to-face interviewer administration. The first author (the study coordinator) trained the research assistants for 2 weeks to facilitate the proper administration of the study tools. All study tools not previously adapted to the local language of Swahili underwent recommended adaptation procedures, that is, forward translation, forward translation review, back translation, harmonization by a panel of experts, pilot testing, pilot testing review, and proofreading [42].

Sociodemographic and Asset Index Form

Sociodemographic characteristics, including participants' age, sex, marital status, educational level, occupational status, household size, income, living arrangements and number of dependents, were captured in REDCap. We also collected information on individual and family ownership of disposable assets for asset index computation as a proxy for socioeconomic status. The participants also provided information on their food security in the past week, access to social support, social network of close friends, the number of people living with HIV in the household, and whether they were taking care of sick family members at the time and visiting traditional healers.

General Health Information

We also gathered the participants' anthropometric details (such as height, weight, blood pressure, waist, and hip circumference), hours spent on sedentary activities in a day, sexual activity, number of medications one was using, self-reported comorbidities, past medical history, and common complaints, e.g., fatigue, pain, sleeping difficulties, visual and hearing problems.

For OALWH, we also asked HIV-specific questions relating to the disclosure of HIV status, access to the HIV clinic, and past medical history, e.g., cART regimen change/interruption and prolonged illness after HIV diagnosis. Information pertaining to their current ART regimen and overall duration on ART were extracted from their medical records. We also collected 10 mL of venous blood samples from the OALWH for viral load measurement.

Psychosocial Measures

Psychosocial variables included HIV-related stigma, functional disability, loneliness, and age-related discrimination (ageism). All these constructs were assessed using interviewer-administered Likert scales, the brief 12-item HIV stigma scale [43], the 12-item World Health Organization Disability Assessment Schedule 2 [44], UCLA 8-item loneliness scale [45], and the 20-item ageism survey [46]. In each scale, a higher score translates into a greater level of impairment.

Measures of Frailty

We assessed frailty using the modified Reported Edmonton Frail Scale [47]. It assesses nine domains of frailty: cognition, general health status, functional independence, social support, medication use, nutrition, mood, continence, and self-reported functional performance. Each domain comprises a set of questions examining the construct. Test scores range from 0–18, and participants are classified conventionally into 5 categories, with a higher score representing a higher degree of frailty: 0–5 (not frail), 6–7 (apparently vulnerable), 8–9 (mild frailty), 10–11 (moderate frailty) and 12–18 (severe frailty). In the current study, we collapsed these categories into three: 0–5 (non-frail), 6–7 (pre-frail) and 8–18 (frail) to enable meaningful analysis of the correlates of frailty [48, 49].

Data Analysis

We conducted all our analyses in STATA version 15.0 (StataCorp LP, College Station, TX, United States). We utilized descriptive statistics to summarize sample characteristics. Specifically, independent Student's *t*-test and Chi-square test were used to compare differences in independent variables. Proportions were used to estimate the prevalence of frailty among OALWH and their uninfected peers. To examine HIV status as an independent predictor of frailty, we used logistic regression analyses adjusting for relevant exposure variables that accounted for differences in frailty. Examination of the correlates of frailty applied logistic regression models to explore univariate associations between the binary outcome variables (frailty) and the various exposure variables. Exposure variables with a *p*-value < 0.15 in the univariate analysis were then entered into the multivariable models using forward selection. In all models, collinearity was

TABLE 1 | Characteristics of the study population by HIV status, $n = 440$ (The HIV-associated Neurocognitive Disorders study, Kenya, 2020 and 2021).

Characteristic	Total sample $n = 440$	HIV status		p -value
		HIV uninfected older adults, $n = 183$	HIV-infected older adults, $n = 257$	
Age (years)				
50–59	227 (51.6)	84 (45.9)	143 (55.6)	0.02
60–69	171 (38.9)	74 (40.4)	97 (37.7)	
≥70	42 (9.5)	25 (13.7)	17 (6.6)	
Sex				
Female	258 (58.6)	98 (53.6)	160 (62.3)	0.07
Male	182 (41.4)	85 (46.4)	97 (37.7)	
Marital status				
Never married	12 (2.8)	4 (2.2)	8 (3.1)	<0.001 ^a
Separated/Divorced/Widowed	181 (41.1)	45 (24.6)	136 (52.9)	
Married/cohabiting	247 (56.1)	134 (73.2)	113 (44.0)	
Education level				
None	162 (36.8)	90 (49.2)	72 (28.0)	<0.001 ^a
Primary	182 (41.4)	65 (35.5)	117 (45.5)	
Secondary	73 (16.6)	22 (12.0)	51 (19.9)	
Tertiary	23 (5.2)	6 (3.3)	17 (6.6)	
Employment				
Unemployed	288 (65.5)	126 (68.9)	162 (63.0)	0.1
Employed	116 (26.3)	39 (21.3)	77 (30.0)	
Retired	36 (8.2)	18 (9.8)	18 (7.0)	
Household size				
One to two people	69 (15.7)	15 (8.2)	54 (21.0)	0.001
Three to six people	297 (67.5)	131 (71.6)	166 (64.6)	
Above seven people	74 (16.8)	37 (20.2)	37 (14.4)	
Monthly household income (Ksh)				
≤10,000	279 (63.4)	69 (37.7)	210 (81.7)	<0.001
Above 10,000	161 (36.6)	114 (62.3)	47 (18.3)	
Living arrangements				
Multiple generational families	359 (81.6)	169 (92.3)	190 (73.9)	<0.001 ^a
Single generational families	41 (9.3)	6 (3.3)	35 (13.6)	
Alone	40 (9.1)	8 (4.4)	32 (12.5)	
Number of dependents, mean (SD)	3.2 (2.6)	3.6 (2.5)	2.9 (2.7)	0.01
Caring for a sick family member, OM = 2				
Yes	291 (66.4)	104 (57.1)	187 (73.1)	0.001
No	147 (33.6)	78 (42.9)	69 (26.9)	
Social network of close friends (yes or no question) OM = 1				
None	19 (4.3)	4 (2.2)	15 (5.9)	0.1 ^a
Yes	420 (95.7)	179 (97.8)	241 (91.4)	
Access to instrumental/social support				
None	199 (45.2)	93 (50.8)	106 (41.2)	0.07
Sometimes	215 (48.9)	83 (45.4)	132 (51.4)	
Most of the time	26 (5.9)	7 (3.8)	19 (7.4)	
Seeking the services of traditional healers OM = 4				
No	399 (91.5)	166 (90.7)	233 (92.1)	0.6
Yes	37 (8.5)	17 (9.3)	20 (7.9)	
History of cerebrovascular accident OM = 4				
No	427 (97.9)	178 (97.3)	249 (98.4)	0.5 ^a
Yes	9 (2.1)	5 (2.7)	4 (1.6)	
Food insecurity (lack of food in the past week), OM = 3				
Never	293 (67.1)	134 (73.6)	159 (62.4)	0.002 ^a
Sometimes	119 (27.2)	45 (24.7)	74 (29.0)	
Most of the time/always	25 (5.7)	3 (1.7)	22 (8.6)	
Asset index score ^a —mean (SD)	2.3 (1.5)	1.9 (1.2)	2.5 (1.6)	<0.001

(Continued on following page)

TABLE 1 | (Continued) Characteristics of the study population by HIV status, $n = 440$ (The HIV-associated Neurocognitive Disorders study, Kenya, 2020 and 2021).

Characteristic	Total sample $n = 440$	HIV status		p -value
		HIV uninfected older adults, $n = 183$	HIV-infected older adults, $n = 257$	
Body mass index—mean (SD), OM = 11	24.9 (6.0)	24.7 (6.1)	25.0 (5.9)	0.7
High waist-hip ratio				
No	202 (46.3)	77 (42.1)	125 (49.4)	0.1
Yes	234 (53.7)	106 (57.9)	128 (50.6)	
Loneliness score ^b —mean (SD), OM = 3	13.9 (3.7)	13.0 (3.4)	14.6 (3.7)	<0.001
Functional disability score ^c —mean (SD), OM = 2	2.5 (4.3)	1.5 (3.0)	3.1 (4.9)	<0.001
Ageism score ^d —mean (SD)	4.2 (5.9)	3.0 (4.4)	5.0 (6.6)	<0.001
Hours spent in sedentary activities in a day, mean (SD), OM = 12	4.5 (2.6)	4.3 (2.1)	4.6 (2.9)	0.3
Days spent doing light activities in the past week, mean (SD), OM = 5	5.6 (2.4)	4.6 (3.0)	6.4 (1.6)	<0.001
Sexually active, OM = 4				
Yes	206 (47.3)	105 (57.4)	101 (39.9)	<0.001
No	230 (52.7)	78 (42.6)	152 (60.1)	
Sleeping difficulties in the past month, OM = 4				
None	276 (63.3)	125 (68.3)	151 (59.7)	0.01*
Sometimes	131 (30.1)	53 (29.0)	78 (30.8)	
Most of the time/always	29 (6.6)	5 (2.7)	24 (9.5)	
Frequent bodily pain				
No	334 (75.9)	134 (73.2)	200 (77.8)	0.3
Yes	106 (24.1)	49 (26.8)	57 (22.2)	
Self-reported hearing ability OM = 4				
Very good	360 (82.6)	151 (82.5)	209 (82.6)	0.90
Averagely/very bad	76 (17.4)	32 (17.5)	44 (17.4)	
Self-reported Hypertension, OM = 4				
No	322 (73.9)	138 (75.4)	184 (72.7)	0.5
Yes	114 (26.1)	45 (24.6)	69 (27.3)	
Self-reported diabetes, OM = 4				
No	412 (94.5)	175 (95.6)	237 (93.7)	0.4*
Yes	24 (5.5)	8 (4.4)	16 (6.3)	
Number of medications participants are currently using, mean (SD), OM = 8	1.6 (1.6)	0.4 (1.2)	2.4 (1.2)	<0.001

All numbers are reported as frequencies with percentages unless otherwise stated p -values are for the difference between OALWH and their uninfected peers by sample characteristic. SD, standard deviation; OM, observation with missing value; Ksh Kenya shillings.

^aScore range = 0 to 8, higher scores indicate better socioeconomic status.

^bScore range = 8 to 27, higher scores indicate greater loneliness.

^cScore range = 0 to 33, higher scores indicate increasing disability.

^dScore range = 0 to 34, higher scores indicate increasing agism.

*based on Fisher's exact test.

checked, and for all hypothesis tests, a two-tailed p -value <0.05 was deemed statistically significant. We checked the overall fit of the final models using Hosmer and Lemeshow's goodness of fit, where a p -value of >0.05 was considered a good fit.

RESULTS

Sample Characteristics

Our sample comprised 440 participants, 257 (58%) of whom were OALWH. An overall response rate of 90% was achieved at recruitment. Among the respondents, 6 (1.4%) did not

complete the outcome measure. **Table 1** gives the details of the demographic and biopsychosocial information of these participants. In brief, the mean age of the respondents was 60.1 (SD = 6.9) years and 58.6% were female. The majority of the participants were unemployed (65.5%), had a monthly household income of less than 10,000 Kenyan shillings—about \$90 (63.4%), lived in multigenerational households (81.6%), and had caregiving responsibilities (66.4%). Moreover, close to half of them reported being sexually active, and a similar proportion reported that they were not accessing/receiving adequate social support. Adults living with HIV were likely to be younger, unmarried, more educated, have lower monthly household income, live alone, and have fewer dependents.

TABLE 2 | HIV-related, clinical, and psychosocial characteristics of OALWH, $n = 257$ (The HIV-associated Neurocognitive Disorders study, Kenya, 2020 and 2021).

Characteristic	Mean (SD) or frequency (%)
HIV status disclosure	
Yes	245 (95.3%)
No	12 (4.7%)
Household HIV burden, mean (SD); OM = 5	1.4 (1.6)
cART regimen	
First line	233 (90.7%)
Second line	23 (8.9%)
Third line	1 (0.4%)
cART regimen change/interruption since HIV diagnosis	
Yes	110 (42.8%)
No	147 (57.2%)
Duration on cART (years), mean (SD), OM = 10	11.4 (4.3)
Viral suppression, OM = 45	
Yes	208 (98.1%)
No	4 (1.9%)
Access to HIV clinic, OM = 4	
Easily accessible	169 (66.8%)
Not easily accessible	84 (33.2%)
History of a neurological condition, OM = 4	
No	236 (93.3%)
Yes	17 (6.7%)
History of prolonged illness following HIV diagnosis, OM = 6	
No	223 (88.8%)
Yes	28 (11.2%)
Perceived HIV-stigma score, OM = 1	
Personalized stigma ^a —mean (SD)	5.0 (1.9)
Disclosure concerns ^b —mean (SD)	8.6 (2.0)
Concerns about public attitudes ^c —mean (SD)	7.6 (2.2)
Negative self-image ^d —mean (SD)	6.4 (2.1)
Overall stigma ^e —mean (SD)	27.5 (5.4)

^aScore range = 3 to 12, higher scores indicate greater stigma.^bScore range = 3 to 12, higher scores indicate greater stigma.^cScore range = 3 to 12, higher scores indicate greater stigma.^dScore range = 3 to 12, higher scores indicate greater stigma.^eScore range = 12 to 44, higher scores indicate greater stigma; OM, observation with missing value; cART, combination antiretroviral therapy.

HIV-Related Characteristics of Older Adults Living With HIV

All the OALWH were receiving HIV treatment, most (90%) of whom were on a first-line cART regimen. Most (95.3%) of them

had disclosed their HIV status. The mean (SD) duration of HIV treatment was 11.4 (4.3) years. Additionally, nearly all of them (98.1%) had suppressed viral load ($\leq 1,000$ copies/mL). Further details are highlighted in Table 2.

Frailty Prevalence Estimates

The overall prevalence of frailty across the sample was 19.4% (95% CI: 15.7–23.4). Groupwise, older adults living with HIV presented with a significantly higher prevalence of frailty (23.9%) than their uninfected peers (12.8%), $p < 0.01$ (Table 3).

Association Between HIV Status and Frailty

In univariate logistic regression analyses (Table 4), HIV seropositivity was significantly associated with higher odds of frailty (OR 2.13; 95% CI 1.26, 3.60). However, in the multivariable logistic regression model (Table 4), HIV seropositivity was not significantly associated with frailty (aOR 1.26; 95% CI 0.60, 2.63).

Determinants of Frailty in Older Adults Living With HIV

Table 5 presents results from univariate and multivariate logistic regression analyses exploring the determinants of frailty among older adults living with HIV.

In the multivariable logistic regression model, factors significantly associated with higher odds of frailty among OALWH were sleeping difficulties in the past month, increasing ageism scores, visiting traditional healers, high waist-to-hip ratio, a history of cART regimen change/interruption, and a history of prolonged illness after HIV diagnosis. On the other hand, having a social network of close friends, a larger household, a higher household income ($\geq 10,000$ Ksh; about \$86) and taking part in light physical activities such as walking in the past week were significantly associated with lower odds of frailty.

Determinants of Frailty in Older Adults Without HIV

In multivariable analyses (Table 6), sleeping difficulties in the past month, self-reported diabetes, and light physical activities in the past week were significantly associated with higher odds of

TABLE 3 | Prevalence of frailty in OALWH versus their uninfected peers (The HIV-associated Neurocognitive Disorders study, Kenya, 2020 and 2021).

	Older adults without HIV, $n = 179$		Older adults living with HIV, $n = 255$		Total sample, $n = 434$		p-value (between groups)
	Number	Prevalence (95% CI)	Number	Prevalence (95% CI)	Number	Prevalence (95% CI)	
Not frail	119	66.5 (59.1–73.3)	140	54.9 (48.6–61.1)	259	59.7 (54.9–64.3)	0.02
Pre-frail	37	20.7 (15.0–27.3)	54	21.2 (16.3–26.7)	91	21.0 (17.2–25.1)	0.9
Frail	23	12.8 (8.3–18.7)	61	23.9 (18.8–29.6)	84	19.4 (15.7–23.4)	<0.01

95% CI, 95% confidence interval.

Note: The number of respondents reported in this table (434) is slightly lower than the overall sample size (440) because six participants were dropped from the analysis due to incomplete data on the frailty tool.

TABLE 4 | Association between HIV status and frailty among older adults (The HIV-associated Neurocognitive Disorders study, Kenya, 2020 and 2021).

Covariate	Positive screen for frailty	
	Crude analysis OR (95% CI)	Adjusted analysis aOR (95% CI)
HIV status		
Seronegative	Ref	Ref
Seropositive	2.13** (1.26, 3.60)	1.26 (0.60, 2.63)
Sex		
Female		Ref
Male		1.29 (0.62, 2.70)
Age (years)		
50–59		Ref
60–69		1.26 (0.64, 2.50)
Above 70		1.20 (0.40, 3.61)
Abnormal waist-hip ratio		
No		Ref
Yes		2.75** (1.41, 5.37)
Household size		
One to two people		Ref
Three to six people		0.37* (0.17, 0.82)
Seven and above		0.36 (0.12, 1.04)
Monthly household income (Ksh)		
≤10,000		Ref
Above 10,000		0.49 (0.22, 1.08)
Social network of close friends		
No		Ref
Yes		0.34 (0.10, 1.17)
Caring for a sick family member		
No		Ref
Yes		0.51* (0.27, 0.97)
Functional disability score		1.05 (0.98, 1.12)
Ageism score		1.08** (1.03, 1.13)
Sleeping difficulties for the past month		
None		Ref
Sometimes		3.70** (1.93, 7.10)
Most of the time/always		2.94 (0.99, 8.76)
Sexually active		
No		Ref
Yes		0.54 (0.26, 1.10)
Seeking the services of traditional healers		
No		Ref
Yes		2.95* (1.24, 7.05)
Self-reported hearing		
Very good		Ref
Averagely/very bad		1.58 (0.78, 3.22)
History of cerebrovascular accident		
No		Ref
Yes		5.87 (0.85, 40.68)
Number of individuals in the final model		427
Hosmer-Lemeshow Test		$\chi^2 = 402.62$; $p = 0.36$
Variance explained		30.81%

CI, confidence interval; OR, odds ratio; aOR, adjusted odds ratio; Ref, reference group.

* – p-value < 0.05, ** – p-value < 0.01.

Note: The number of individuals in the final model (427) is slightly lower than the actual sample size (440) because some of the observations had missing values.

TABLE 5 | Univariate and multivariable analysis of correlates of frailty among OALWH (The HIV-associated Neurocognitive Disorders study, Kenya, 2020 and 2021).

Covariate	Positive screen for frailty by mod-REFS	
	Univariate analysis OR (95% CI)	Multivariable analysis aOR (95% CI)
Age (years)		
50–59	Ref	Ref
60–69	0.96 (0.53, 1.76)	1.58 (0.63, 3.96)
≥70	0.66 (0.18, 2.41)	0.33 (0.05, 2.05)
Sex		
Female	Ref	Ref
Male	1.09 (0.60, 1.99)	1.32 (0.52, 3.39)
Monthly household income (Ksh)		
≤10,000	Ref	Ref
Above 10,000	0.26*** (0.09, 0.76)	0.13** (0.03, 0.60)
Household size		
One to two	Ref	Ref
Three to six	0.33*** (0.17, 0.63)	0.35** (0.12, 0.99)
Above seven	0.26*** (0.09, 0.73)	0.26 (0.06, 1.15)
Caring for a sick family member		
No	Ref	—
Yes	0.13*** (0.07, 0.24)	—
Having close friends (<i>social network</i>)		
No	Ref	Ref
Yes	0.09*** (0.03, 0.31)	0.13*** (0.03, 0.56)
Access to instrumental/social support		
Not accessing	Ref	—
Sometimes	2.53*** (1.33, 4.84)	—
Most of the time/always	1.48 (0.44, 5.05)	—
Food insecurity (lack of food in the past week)		
Never	Ref	—
Sometimes	2.36*** (1.27, 4.40)	—
Most of the time/always	1.25 (0.43, 3.67)	—
A+sset index, mean (SD)	1.16* (0.97, 1.38)	—
Waist hip ratio		
Normal	Ref	Ref
Abnormal	2.23*** (1.22, 4.06)	3.67*** (1.48, 9.10)
Self-reported Hypertension		
No	Ref	—
Yes	0.37*** (0.19, 0.74)	—
Loneliness score, mean (SD)	1.15*** (1.06, 1.24)	—
Functional disability score, mean (SD)	1.13*** (1.06, 1.20)	—
Ageism score, mean (SD)	1.14*** (1.08, 1.19)	1.11*** (1.04, 1.18)
Days spent doing light activities in the past week, mean (SD)	0.69*** (0.58, 0.82)	0.77*** (0.61, 0.98)
Hours spent in sedentary behaviours in a day, mean (SD)	0.79*** (0.70, 0.90)	—
Sexually active		
No	Ref	—
Yes	0.60* (0.33, 1.11)	—
Sleeping difficulties in the past month		
None	Ref	Ref
Sometimes	5.44*** (2.77, 10.71)	2.80** (1.14, 6.87)
Most of the time/always	7.82*** (3.04, 20.15)	1.92 (0.49, 7.43)
Seeking the services of traditional healers		
No	Ref	Ref
Yes	5.60*** (2.17, 14.46)	9.86*** (2.45, 39.68)
HIV status disclosure (<i>family/relatives</i>)		
No	Ref	—
Yes	3.55*** (1.91, 6.61)	—

(Continued on following page)

TABLE 5 | (Continued) Univariate and multivariable analysis of correlates of frailty among OALWH (The HIV-associated Neurocognitive Disorders study, Kenya, 2020 and 2021).

Covariate	Positive screen for frailty by mod-REFS	
	Univariate analysis OR (95% CI)	Multivariable analysis aOR (95% CI)
History of a neurological condition		
No	Ref	—
Yes	5.15*** (1.87, 14.21)	—
Prolonged period of illness following HIV diagnosis		
No	Ref	Ref
Yes	3.72*** (1.66, 8.35)	6.58*** (2.13, 20.33)
ART Regimen		
1st line	Ref	—
2nd line	3.07*** (1.27, 7.38)	—
Mean HIV duration (SD)	1.05* (0.98, 1.13)	—
Viral suppression		
Yes	Ref	—
No	8.56* (0.87, 84.01)	—
cART regimen change/interruption since HIV diagnosis		
No	Ref	Ref
Yes	6.86*** (3.55, 13.26)	3.36*** (1.43, 7.91)
Access to HIV clinic		
Not easily accessible	Ref	—
Easily accessible	1.77* (0.90, 3.52)	—
Perceived HIV-stigma score, mean (SD)		
Personalized stigma	0.85* (0.72, 1.00)	—
Disclosure concerns	1.37*** (1.16, 1.62)	—
Concerns about public attitudes	1.18** (1.02, 1.36)	—
Overall stigma	1.05** (0.99, 1.11)	—
n for the final model		248
Variance explained		43.35%
Hosmer-Lemeshow test		$\chi^2 = 235.00$; p -value = 0.07
cvMean AUC (95% CI)		0.90 (0.86, 0.95)

Only a priori variables (age, sex) and those with p -value < 0.15 in the univariate analysis or multivariable p < 0.05 are presented here. OR, odds ratio; aOR, adjusted odds ratio; Ref, reference group; cvMean AUC, cross-validated mean area under the curve for the final multivariable model.

* – p -value < 0.15, ** – p -value < 0.05, *** – p -value < 0.01.

Note: The number of individuals in the final model (248) is slightly lower than the actual sample size for older adults living with HIV (257) because some of the observations had missing values.

frailty among the HIV uninfected older adults. Conversely, being male was significantly associated with reduced odds of frailty in these adults.

DISCUSSION

Our study adds to the growing number of reports on the burden and determinants of frailty in low- and middle-income countries. In this study, the prevalence of frailty was significantly higher in OALWH (23.9%; 95% CI 18.8–29.6) compared to their uninfected peers (12.8%; 95% CI 8.3–18.7); however, HIV seropositivity was not significantly associated with frailty after adjusting for biopsychosocial factors. To our knowledge, there have been only two previous studies of frailty among OALWH in SSA. The first one, a cross-sectional sample of 145 OALWH (67% female) on ART and a median age of 57 years in Tanzania, reported a low prevalence of frailty (2.8%) [50]. The other

one, a population-based cohort of 614 older adults (292 OALWH) in South Africa, reported a frailty prevalence of 17.7% in OALWH compared to 14.7% in their uninfected peers [51]. The variations in frailty prevalence could partly be attributed to differences in frailty measurement and the fact that older adults are a highly heterogeneous group, having different genetic backgrounds, medical profiles, and biological, as well as social-environmental factors at different stages of life, thus highlighting the need for country-specific frailty data using tools validated within the country or region of interest. Our finding of a higher prevalence of frailty in OALWH than their uninfected peers is consistent with previous evidence, which has demonstrated both higher frequency of frailty in OALWH and the development of frailty at earlier ages for OALWH than for individuals without HIV [17]. Many factors may predispose OALWH to elevated rates of frailty, including the effects of persistent inflammation from HIV (even in well-controlled viraemia),

TABLE 6 | Univariate and multivariable analysis of correlates of frailty among HIV-uninfected older adults (The HIV-associated Neurocognitive Disorders study, Kenya, 2020 and 2021).

Covariate	Positive screen for frailty by mod-REFS	
	Univariate analysis OR (95% CI)	Multivariable analysis aOR (95% CI)
Age (years)		
50–59	Ref	Ref
60–69	1.73 (0.62, 4.81)	0.91 (0.26, 3.22)
≥70	3.38** (1.02, 11.24)	4.61 (0.95, 22.29)
Sex		
Female	Ref	Ref
Male	2.29* (0.89, 5.86)	0.26** (0.07, 0.94)
Monthly household income (Ksh)		
≤10,000	Ref	—
Above 10,000	0.51* (0.21, 1.24)	—
Number of close family members/friends one interacted with at least once in the past month, mean (SD)	0.90* (0.81, 1.01)	—
Loneliness score, mean (SD)	1.11* (0.97, 1.26)	—
Functional disability score, mean (SD)	1.13** (1.00, 1.27)	—
Ageism score, mean (SD)	1.08* (0.99, 1.17)	—
Days spent doing light activities in the past week, mean (SD)	1.25** (1.03, 1.52)	1.29** (1.01, 1.66)
Sexually active		
No	Ref	—
Yes	0.27**** (0.11, 0.70)	—
Sleeping difficulties in the past month		
None	Ref	Ref
Sometimes	6.27*** (2.35, 16.70)	4.30** (1.41, 13.07)
Most of the time/always	11.05** (1.58, 77.26)	14.72** (1.11, 194.78)
Self-reported hearing		
Very good	Ref	—
Averagely/very bad	4.69*** (1.83, 11.99)	—
Frequent bodily pain		
No	Ref	—
Yes	2.39* (0.97, 5.89)	—
Self-reported diabetes		
No	Ref	Ref
Yes	8.00*** (1.85, 34.64)	8.35** (1.23, 56.92)
Self-reported hypertension		
No	Ref	—
Yes	3.29** (1.33, 8.11)	—
Number of medications participants are currently using, mean (SD)	1.38* (0.98, 1.93)	—
<i>n</i> for the final model		177
Variance explained		30.33%
Hosmer-Lemeshow test		$\chi^2 = 110.02$; <i>p</i> -value = 0.97
cvMean AUC (95% CI)		0.87 (0.79, 0.94)

Only a priori variables (age, sex) and those with *p*-value < 0.15 in the univariate analysis or multivariable *p* < 0.05 are presented here. OR, odds ratio; aOR, adjusted odds ratio; Ref, reference group; cvMean AUC, cross-validated mean area under the curve for the final multivariable model. * – *p*-value < 0.15, ** – *p*-value < 0.05, *** – *p*-value < 0.01.

Note: The number of individuals in the final model is slightly lower than the actual sample size of older adults without HIV because some of the observations had missing values.

toxic effects of earlier cART regimens, delayed initiation of ART, and higher rates of multimorbidity [52].

Literature suggests that it is a constellation of environmental, disease-specific, and biological factors that contribute to frailty [17, 24–33], though most of the evidence is concentrated in HICs. In the present study, the factors significantly associated with frailty were predominantly psychosocial, many of which are

potentially modifiable with appropriate programs and interventions. Consistent with previous studies [33, 53], our study showed that sleeping difficulties were associated with higher odds of frailty in OALWH and their uninfected peers. Sleep problems may impact frailty in numerous ways, including decreased energy expenditure, elevated inflammatory response, disturbed hormonal pathways, tissue growth and repair [53].

These mechanisms may explain the associations observed. Interventions targeting sleeping problems—such as exercise and mindfulness-based stress reduction, may have potential clinical implications for OALWH and their uninfected peers.

Increasing ageism scores were also significantly associated with elevated odds of frailty in OALWH in our study. Ageism, commonly conceptualized as the stereotyping, prejudice and discrimination against people based on age, is becoming increasingly important in older adults [54]. Very few studies have examined the possible association between frailty and ageism. Our finding is consistent with the limited previous research [55]. Persistent exposure to ageism could lead to the internalization of the ageist messages by the OALWH, thus becoming part of their unconscious beliefs. In some cases, the adults may act subconsciously to fulfil the ageist stereotypes, even if detrimental to their health and wellbeing, e.g., physiologic stress response, and physical functioning performance, which may influence frailty. The observed association could also be explained by the health status and higher educational levels among OALWH.

A higher waist/hip ratio was also significantly associated with elevated odds of frailty among OALWH in our study, consistent with previous findings of a positive association between central/abdominal obesity and frailty [56, 57]. As HIV infection has become a manageable chronic illness, it has been progressively accompanied by a growing prevalence of overweight and obesity [58]. Moreover, long-term treatment with cART may contribute to lipodystrophy, often characterized by fat redistribution with a relative increase in abdominal fat [59]. Lipid depositions and infiltration in muscle fibre may bring about frailty by decreasing mobility and increasing loss of muscle strength. Interventions to minimize obesity and sedentary behaviour could potentially be beneficial in addressing frailty.

Visiting traditional healers was significantly associated with elevated odds of frailty among OALWH in our study. We are not aware of previous research that has examined this relationship. Plausibly, frail individuals visit the healers to have their frailty symptoms addressed, especially when the primary care services fail to address these concerns. A previous qualitative exploration of the health and wellbeing of OALWH in the study setting has linked seeking help or treatment from traditional and certain faith healers with poor health outcomes, including defaulting HIV treatment and unsuppressed viral load [60]. Healthcare providers have a reason to be concerned, given the observed impacts of untreated or improperly treated HIV on the development of frailty among OALWH.

Only two HIV-related factors were associated with elevated odds of frailty in our sample: a history of cART regimen change/interruption and prolonged illness following HIV diagnosis. These factors may be indicators of virological failure, ART toxicity or late HIV diagnosis, commonly associated with poorer health outcomes and risk of severe disease. Indeed, previous research has revealed an independent positive association between AIDS diagnosis, viral-load non-suppression, low CD4 count and frailty [17, 61]. Many of the OALWH who have lived with HIV for several years may be significantly impacted by the legacy of the early years of the epidemic, thus predisposing them to a heightened risk of frailty.

These adults will more likely require additional support to manage the challenges of ageing with HIV successfully.

Several social factors, e.g., social isolation, social networks, socioeconomic status, social support, social engagement, and social capital, have the potential to influence the health of older adults [62]. In our study, higher monthly household income, residence in a larger household, and having a social network of close friends were all associated with reduced odds of frailty among OALWH, thus confirming previous research [17, 31] and highlighting the importance of promoting positive social factors to aid healthy ageing in older adults living with HIV. These factors may, directly and indirectly, affect frailty, e.g., food security, energy expenditure, and better health-seeking behaviours.

Physical activities have the potential to promote physical function, prevent falls and improve general health, hence delaying the onset and progression of frailty. In our study, participating in light physical activities such as walking was associated with reduced odds of frailty among OALWH, confirming previous research [63]. Exercise may also have positive effects on obesity, stress, loneliness in the case of group activities and muscular strength, which have been identified as potential risk factors for the incidence of frailty. However, light physical activities were associated with elevated odds of frailty among the HIV uninfected older adults in our study. This was a surprise finding, inconsistent with previous investigations [64–66]. This warrants more exploration in the study setting.

Self-reported diabetes was also associated with higher odds of frailty among HIV uninfected older adults in our study, consistent with previous reports [67]. Prospective evidence suggests that unhealthy behaviours and obesity may partly explain the association, and to a larger extent, by poor glucose control and altered serum lipid profile among individuals with diabetes, suggesting that diabetes nutritional therapy may reduce the risk of frailty [67]. Individuals with diabetic neuropathy are particularly at an increased risk of early-onset frailty [68]. Prevention programmes in the pre-frail states through appropriate exercise, nutrition and glycemic control may delay the development of frailty in these adults.

Similar to previous studies, this study showed that males are less likely to be frail than females, suggesting that being male is a protective factor against frailty [24]. Differences in physical activity, muscle mass and higher fat percentages may explain gender discrepancies in frailty. This may also be a question of selection—a classical observation in gerontological research where women live longer but in poorer health [69]. In this respect, men experience more life-threatening chronic conditions compared to women who experience more “non-life-threatening” conditions associated with more morbidity—as such the men who survive are those who tend to have better health status. Still, our observation may be related to social stigma of males appearing/acting/reporting weakness, that is, social preference bias, given the self-reported nature of the construct.

Implications

The prevalence of frailty in this study was relatively high for both OALWH and their uninfected peers. Preventing, delaying, or treating frailty is more critical in this

setting, given its high burden and the fact that frailty is a known predictor of future disability and dependency. Within the clinical practice, an easy-to-use frailty score will allow the easy identification of those at risk, thus allowing planning of future health and social care needs of these adults. Our study also highlighted some of the correlates of frailty in this setting. Many of the factors identified, such as sleeping difficulties, social engagement, ageism, and visiting traditional healers, are potentially modifiable with appropriate programs. Our findings provide the foundation for developing culturally appropriate interventions and healthcare strategies to prevent, delay and manage frailty and its consequences to improve the health and functional status of older adults at risk of frailty. Individual, community-based, or clinic-based interventions such as comprehensive geriatric assessment, physical activity, promoting social engagement, addressing discrimination, and proper management of comorbidities, e.g., diabetes, may benefit older adults. Wider public health approaches, including proactive testing of older adults to avoid late diagnosis and advanced immunosuppression, will benefit OALWH. Our results also highlight the need for well-designed prospective studies to establish the incidence, pathophysiology, predictors of transition and outcomes of frailty in this population and assess potential interventions.

Strengths and Limitations

Our study is among the very few reports on frailty in SSA and the first one in Kenya. It extends the existing evidence base regarding the prevalence and correlates of frailty in low-resource settings like Kenya. A further strength is the use of a relatively large sample size of people ≥ 50 years living with HIV and the inclusion of a community-based comparison group which enabled us to give a detailed profile of frailty in this population. We also collected detailed information on sociodemographic, physical, lifestyle and psychological factors, which helped us examine the correlates of frailty in this population. The primary limitation, nonetheless, was the use of a cross-sectional design, which precludes any conclusions on causality. Besides, our sample was predominantly from a rural setting; thus, our participants' experiences may differ from those in urban places. Also, the OALWH were invited to participate from a health facility (i.e., not a population-based sample) and may not be entirely representative of all OALWH in this area. For instance, the sample of OALWH in the study had very high levels of cART treatment and viral suppression, and our observations would probably be different in individuals not seeking care (either because they are unaware of their status or do not believe they need treatment).

Conclusion

In this cross-sectional study, we found a significantly higher prevalence of frailty among OALWH (24%) compared to their uninfected peers (13%). However, HIV seropositivity was not significantly associated with frailty after adjustment for demographic, psychosocial and physical factors, underscoring the importance of these factors. Specifically, OALWH who experience sleeping difficulties, ageism, have a high waist/hip ratio, visit traditional healers, have a history of cART regimen

change/interruption and prolonged illness after HIV diagnosis have higher odds of frailty. In contrast, those who reside in larger households, have higher household income, have a social network of friends, and engage in light physical activity have reduced odds of frailty. On the other hand, HIV-uninfected older adults with sleeping difficulties, self-reported diabetes and taking part in light physical activities have elevated odds of frailty, while being male is associated with reduced odds of frailty. These factors should be considered in designing and implementing programs to prevent, delay, or treat frailty in this setting. Further prospective work is required to investigate the directionality and potential mediators of the association between frailty and the observed correlates.

DATA AVAILABILITY STATEMENT

Application for data access can be made through the Data Governance Committee of the KEMRI Wellcome Trust Research Programme who will review the application and advise as appropriate, ensuring that uses are compatible with the consent obtained from participants for data collection. Requests can be sent to the coordinator of the Data Governance Committee using the following email, dgc@kemri-wellcome.org.

ETHICS STATEMENT

The studies involving humans were approved by the Kenya Medical Research Institute Scientific and Ethics Review Unit (Ref: KEMRI/SERU/CGMR-C/152/3804). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

PM, CRN, and AA conceptualized the study. PM, CRN, RW, and AA designed the study. PM and CN programmed the study questions on tablets and managed project data for the entire study period. PM analysed the data. PM, CN, RW, CRN, and AA contributed to the interpretation of the data. PM wrote the first draft of the manuscript, and all the authors reviewed the subsequent versions and approved the final draft for submission.

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CONFLICT OF INTEREST

The authors declare that they do not have any conflicts of interest.

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