

AGEING WITH HIV: EXPLORING OLDER PEOPLE'S EXPERIENCES WITH MEDICINES

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**A thesis submitted in partial fulfilment of the requirements of
the University of Kent and the University of Greenwich for the
Degree of Doctor of Philosophy**

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DECLARATION

I certify that this work has not been accepted in substance for any degree, and is not concurrently being submitted for any degree other than that of Doctor of Philosophy being studied at the Universities of Greenwich and Kent. I also declare that this work is the result of my own investigations, except where the thesis identifies work undertaken jointly with others. In these cases I have made clear exactly what was accomplished by others and what I have contributed myself, and have not plagiarised the work of others.

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Supervised by Dr Barbra Katusiime, Dr Rebecca Cassidy, and Dr Sarah Corlett

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ABSTRACT

Background: As of 2023, nearly 40 million people globally live with HIV. Antiretroviral therapy has extended life expectancy, with ageing presenting unique challenges: Older people living with HIV (PLWH) face earlier onset of comorbidities, complex polypharmacy and stigma. Currently in the UK, standard care includes specialist clinics to manage HIV and primary care to manage comorbidities. **Aim:** This thesis sought to gain a deeper understanding of the medicine-related experiences and needs of older individuals living with HIV.

Methods: A systematic review (chapter 2) was undertaken to identify interventions targeted to improve medicine optimisation outcomes in older PLWH. The findings informed a mixed-methods study design exploring the medicine related experiences and needs of older PLWH and the views of the healthcare professionals looking after them. Quantitative studies used secondary (chapter 4) and primary (chapter 5) data collected via cross-sectional surveys. Chapter 4's survey included the Living with Medicines Questionnaire version 3 (LMQ-3), and the Stigma Scale for Chronic Illnesses 8-item version (SSCI-8), chapter 5's included the mini-LMQ, and the Multidimensional Scale of Perceived Social Support (MSPSS). Qualitative studies utilised semi-structured interviews in older PLWH (chapter 6) and healthcare professionals providing care for PLWH (chapter 7). Quantitative data were analysed using IBM SPSS version 27. Qualitative data were transcribed and analysed using NVIVO (release 1.7.1).

Results: The systematic review (chapter 2) highlighted a lack of interventions targeted specifically for improving medicine experiences in older PLWH, with the majority of the nine interventions found amongst 79 articles being aimed at adherence. Although, the initial study analysing secondary-data found high medicine burden in a minority of PLWH (chapter 4), free-text comments showed an array of negative experiences with medicines and stigma. In contrast, the second study (chapter 5), found a high medicine-related burden in a majority of PLWH. Further exploration in chapter 6 highlighted two distinct groups among older PLWH: long-term survivors who have adapted over time and those diagnosed later in life who are still adjusting with their diagnosis describing higher associated medicine and treatment burden. Comorbidities often posed greater challenges than HIV itself for some. In chapter 7, staff reemphasised the complex challenges faced by older PLWH managing their healthcare. The need for improved collaboration between HIV clinics and primary care was stressed, as poor communication complicates polypharmacy and care coordination.

Conclusion: This thesis contributes to the growing understanding of the ageing HIV population, highlighting the challenges they face and strategies to enhance their medications and healthcare. It emphasises the need for a holistic, patient-centred approach that addresses their complex and interconnected needs, and better communications between healthcare professionals.

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ABBREVIATIONS AND ACRONYMS

ADR's:	Adverse Drug Reactions
AIDS:	Acquired Immunodeficiency Syndrome
ART:	Antiretroviral Therapy
ARV:	Antiretroviral
AXIS:	Appraisal tool for Cross-Sectional Studies
AZT:	Azidothymidine also known as Zidovudine
BHIVA:	British Human Immunodeficiency Virus Association
CASP:	Critical Appraisal Skills Programme
CCR5:	Chemokine receptor Type 5
CD-4:	Clusters of differentiation 4
CD-8:	Clusters of differentiation 8
CCG:	Clinical Commissioning Group
CKD:	Chronic Kidney Disease
COVID-19:	Coronavirus-19 disease
CVD:	Cardiovascular Disease
DOAC:	Direct Oral Anticoagulants
FRAX:	Fracture Risk Assessment Tool
GDPR:	General Data Protection Regulation
GCP:	Good Clinical Practice
GP:	General Practitioners
HBM:	Health Belief Model
HAART:	Highly Active Antiretroviral Therapy
HBV:	Hepatitis B Virus
HCV:	Hepatitis C Virus
HIV:	Human Immunodeficiency Virus
HIV-1:	Human Immunodeficiency Virus – 1
HIV-2:	Human Immunodeficiency Virus - 2
HRQOL:	Health-related quality of life
HRT:	Hormone Replacement Therapy
IBM™	- International Business Machines
KS:	Kaposi's Sarcoma
LESS-CHRON:	List of Evidence-Based Deprescribing for Chronic Patients criteria
LMQ:	Living with Medicines Questionnaire
LMQ-3:	Living with Medicines Questionnaire version 3
MAI:	Medication Appropriateness Index
MEMS:	Medicine Event Monitoring System
MLMQ:	Mini-Living with Medicines Questionnaire
MOR:	Medicines Management Optimisation Review
NCF:	Necessity-Concerns Framework
NHS:	National Health Service

NICE: National Institute for Health and Care Excellence
 NIHR: National Institute for Health and Care Research
 NNRTIs: Non-nucleoside reverse transcriptase inhibitors
 NRTIs: Nucleoside reverse transcriptase inhibitors
 PDDI: Potential drug-drug interaction
 PEP: Post-Exposure Prophylaxis
 PHE: Public Health England
 PICO: Population Intervention Comparison Outcome
 PI: Protease Inhibitors
 PIP: Potentially inappropriate prescribing
 PLWH: People Living with HIV
 PCP: Pneumocystis Carinii pneumonia
 PRISMA: Preferred Reporting Items for Systematic reviews and Meta-Analyses
 PROSPERO: International prospective register of systematic reviews
 PrEP: Pre-exposure prophylaxis
 PTSD: Post-traumatic stress disorder
 QRISK: QRESEARCH Cardiovascular risk algorithm
 RCT: Randomised Controlled Trials
 SARS-CoV-2: Severe Acute Respiratory Syndrome Coronavirus 2
 SPSS: Statistical Package for the Social Sciences
 SSCI-8: Stigma Scale for Chronic Illnesses Questionnaire-8
 STI: Sexually Transmitted Infections
 STOPP/START: Screening Tool of Older Persons Prescriptions/Screening Tool to alert doctors to Right Treatment criteria
 UNAIDS: Joint United Nations Programme on HIV/AIDS
 U=U: Undetectable=Untransmittable
 VAS: Visual Analogue Scale

PUBLICATIONS AND PRESENTATIONS ARISING FROM THIS RESEARCH PROGRAMME

Full papers

1. Sarma P, Cassidy R, Corlett S, Katusiime B. Ageing with HIV: Medicine Optimisation Challenges and Support Needs for Older People Living with HIV: A Systematic Review. *Drugs Aging*. 2023 Mar;40(3):179-240. doi: 10.1007/s40266-022-01003-3. Epub 2023 Jan 20. PMID: 36670321; PMCID: PMC9857901.

Oral presentations/published abstracts

1. Priya Sarma, R. Cassidy, S. Corlett, B. Katusiime. Did the COVID-19 pandemic affect medicine-related support for people living with HIV in the UK? – a cross-sectional survey. Health Services Research and Pharmacy Practice (HSRPP) Conference 2024.

Poster presentation/published abstracts

1. P Sarma, B Katusiime, S Corlett, R Cassidy. My HIV Care – Preferences of people living with HIV for medicine-related support from community pharmacists, *International Journal of Pharmacy Practice*, Volume 30, Issue Supplement_2, December 2022, Pages ii26–ii27, <https://doi.org/10.1093/ijpp/riac089.030>
2. P Sarma, B Katusiime, S Corlett, R Cassidy. Medicine-related burden in people living with HIV, British HIV association conference, Poster Abstract. P085, Wednesday 20th – Friday 22nd April 2022.

CHAPTER ONE

Introduction

1.1 Background

1.1.1 The epidemiology of HIV

Globally, an estimated 39.9 million people were living with HIV (PLWH) in 2023. (1) Despite a significant reduction in new infections since the peak of 2.9 million in 1997, the prevalence of HIV has steadily increased. The development of antiretroviral therapy (ART), a combination of antiretroviral medicines (also referred to herein as ARVs) has extended the life expectancy of PLWH, which is projected to lead to over 42 million PLWH by 2030. (2)

The decline in new HIV diagnoses in England occurring prior to the pandemic was evident up until 2021, after which HIV diagnoses increased by 22%, from 3,118 in 2021 to 3,805 in 2022 (Figure 1.1). (3) This was primarily due to a 69% rise in people previously diagnosed abroad, from 805 in 2021 to 1,361 in 2022, and delayed diagnoses attributed to the impact of COVID-19 on HIV testing among heterosexual men and women. (3) In contrast, new diagnoses of HIV in people aged 50 years or over have risen over the past decade, from 13% (829/6,565) in 2009 to 21% (936/4,453) in 2018. (4) This has particularly been observed in heterosexually transmitted cases, for example in 2018, 34% (246/724) of men and 23% (187/826) of woman were aged 50 years or older at their time of diagnosis compared to 19% (253/1,320) and 10% (184/1,916) in 2009 respectively. (4)

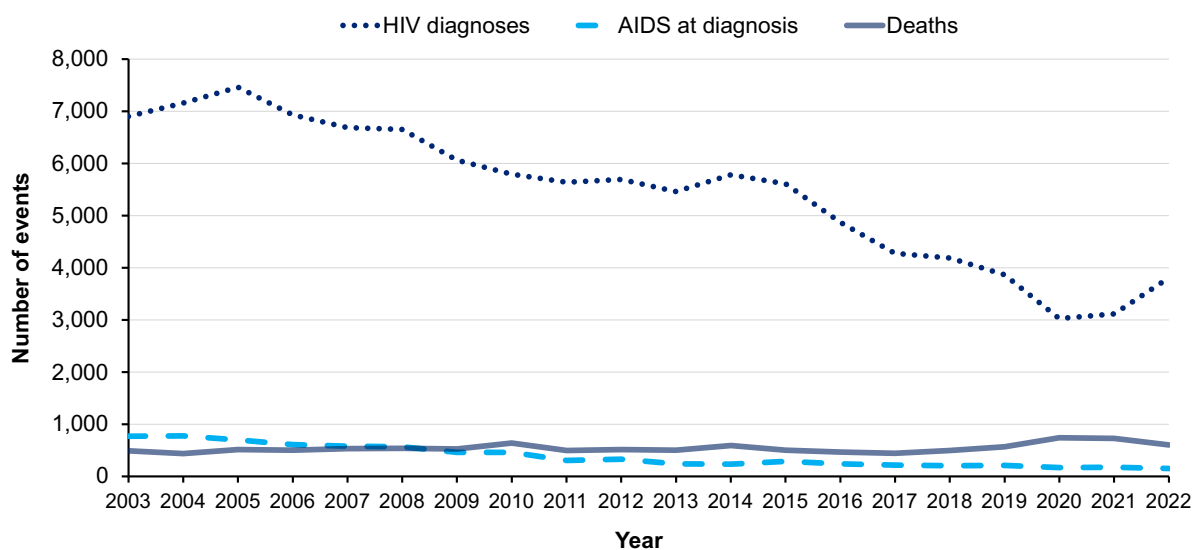


Figure 1.1 HIV diagnoses, AIDS at diagnosis, and all cause deaths in PLWH, England, 2003 to 2022. Source: UK Health Security Agency, London. (3)

The Global AIDS Strategy (2021-2026) aims to address the inequalities fuelling the AIDS epidemic and to place individuals at the centre of efforts to eliminate AIDS as a public health threat by 2030. (5) Decades of evidence from the HIV response indicate that intersecting inequalities hinder the progress towards this goal. The strategy provides a framework for transformative action, focusing on reducing these inequalities by 2025 and aligning with the broader Sustainable Development Goals. (5) By keeping people at the core, the strategy

seeks to unite global, regional, and local partners to achieve zero new HIV infections, zero discrimination, and zero AIDS-related deaths.

There were 105,200 PLWH in the UK in 2019 and in 2021, 95% of PLWH were diagnosed and knew their serostatus, 99% on antiretrovirals, and 98% of those on treatment were virally suppressed. (6-7) Steep declines in new diagnoses in gay and bisexual men, the group with the highest HIV transmission rate, for the third consecutive year, shows that combination prevention (i.e. increased HIV testing, condom use, swift ART initiation, and the availability of pre-exposure prophylaxis (PrEP)) has been effective in the UK. (4) However, an estimated 94,800 people were living with HIV in England at the end of 2018 and there were twice as many people unaware of their positive HIV status in England outside of London compared to within London. (8) Therefore, in order to eliminate transmission in the UK, persistent prevention efforts and targeting of specific groups (e.g. PLWH outside of London and PLWH 50 years and older) will be needed.

Due to the availability of effective HIV treatment prolonging the lives of PLWH and the occurrence of new diagnoses in the UK, there were 96,142 PLWH receiving HIV care in 2018. (4) This is a 47% increase from 65,249 people receiving care in 2009. (4) Furthermore, 40% (38,193/96,142) of people receiving HIV care were 50 years old or over. (4)

1.1.2 The course of HIV infection

HIV is a pathogen that belongs to a subgroup of retroviruses called lentivirus, and as with all viruses, it must invade and use the host's cells in order to replicate. (9) HIV works by attacking CD4 T-lymphocytes of the human immune system. There are two types of the virus, HIV-1 and HIV-2; HIV-1 being more predominant worldwide.

Without treatment, HIV will continue to replicate and infect specific white blood cells (CD4 cells), weakening the immune system. HIV infection can be categorised into three phases: the first few weeks of infection known as the acute phase; an asymptomatic period or latent phase; and the late stage, where the host's immunity is depleted and unable to function efficiently (Figure 1). During the acute phase, there is an elevated risk of transmission as flu-like symptoms experienced by the individual are non-specific (e.g. fever, malaise, diarrhoea, rash) and sometimes associated with abnormal laboratory results where plasma HIV RNA levels are high. (10) HIV continues to multiply at low levels during the latent phase, and without ART the infection could take up to 10 years or longer to advance to the late stage. When in the late stage (AIDS) people living with HIV (PLWH) are unable to recognise or fight life-threatening opportunistic infections and cancers, eventually leading to death. (9,11-12)

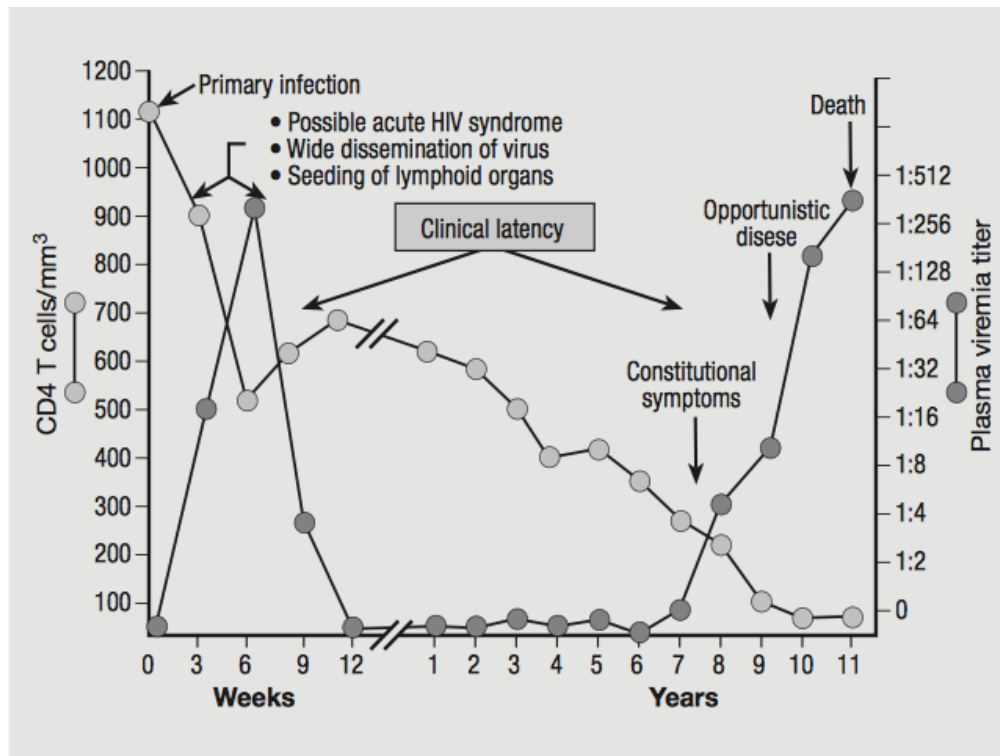


Figure 1.2 The progression of HIV disease in the absence of therapy.

Source: A brief history of antiretroviral therapy of HIV infection: success and challenges, 2011. (10)

Historically, without treatment HIV could worsen an individual's immune system, leading to the emergence of Kaposi's Sarcoma (KS), a rare type of cancer, and Pneumocystis Carinii pneumonia (PCP) cases in groups of previously healthy, homosexual males. (2-3) In addition, other infections that are also associated with immunosuppression, such as thrush and cytomegalovirus, were also seen in these individuals. (2)

1.1.3 HIV transmission in older adults/ prevalence of HIV in older adults

Transmission of HIV occurs through mucosal exposure to infected blood or bodily fluids (13,14) , although with lower quantities in saliva, sweat, and tears, compared to semen, blood, and vaginal/cervical secretions. Transmission risk increases with the amount of virus present; therefore, transmission via casual contact (e.g. kissing or handshaking) is very unlikely. (15) HIV can be transmitted between humans through needle-stick injuries, sharing of needles amongst drug users, unprotected sexual intercourse, and from a mother-to-child in the womb, during birth, or through breastfeeding. In the past, there had been cases of individuals acquiring HIV from blood transfusions, however, all blood products are now screened. The most common method of transmission is due to unprotected sexual intercourse, with a higher risk of transmission seen with anal intercourse. (14) According to the UNAIDS (2021), the risk of acquiring HIV is highest for people who inject drugs. (16)

1.1.4 HIV progression markers

As HIV targets CD4 cells, the CD4 count is a key predictor of HIV disease progression in the clinical care of people living with HIV (PLWH). (17) CD4 counts below 350 cells/mm³ are associated with higher morbidity and mortality. Viral load, the amount of virus (HIV RNA) in the plasma, is a direct marker of viral replication

and thus declining viral load is a direct indicator of treatment success. Viral load levels below 20-50 copies/mL are considered ‘undetectable’ and the overall aim of HIV treatment. (18-20)

1.1.5 Anti-retroviral treatment

Major advances in the treatment of HIV and the care of PLWH, transformed a once life-threatening condition into a complex chronic condition. Decreases in the number of opportunistic infections and deaths among PLWH were initially seen in 1987 with the introduction of azidothymidine (AZT), also known as zidovudine, the first effective drug approved by the U.S. Food and Drug Administration for treating AIDS. (21) However, AZT’s benefits were short-lived as serious consequences of side effects and rapid drug resistance developed in PLWH. (15) AZT belonged to the first class of drugs known as nucleoside reverse transcriptase inhibitors (NRTIs). (10)

The production of new classes of ART, including protease inhibitors (PI) in 1995 and non-nucleoside reverse transcriptase inhibitors (NNRTIs) in 1996, led to dramatic declines in mortality but it quickly became evident that combination therapy was key in preventing resistance. (10, 15, 21) Therefore, the use of combination anti-retroviral therapy (ART), also known as highly active antiretroviral therapy (HAART) began in 1997, which comprised of two NRTIs serving as a backbone combined with either a NNRTI or PI. (21) Patients were no longer dying of AIDS, as PLWH found themselves granted “a new lease of life”, leading to the so-called ‘Lazarus effect’. (22) The range of drugs continued to grow with additional classes such as fusion inhibitors, chemokine receptor type 5 (CCR5) antagonists (e.g. maraviroc) and integrase inhibitors (e.g. dolutegravir). ARVs are categorised according to the steps affected in the HIV life cycle (Figure 1.3) they interrupt. The production of ARV co-formulations has allowed for a reduction in pill burden and increased adherence to ART. (21) Recent advances in HIV treatment include long-acting, injectable therapies (e.g. cabotegravir and rilpivirine) that are intended for monthly administration but there is limited evidence around impact on patient outcomes (e.g. medicine burden, or adherence). Studies are also investigating the use of broadly neutralising antibodies and therapeutic vaccines for the treatment of HIV. (23) There is a need for more research into patient experiences of new and recent therapies. Chapters 4 and 5 of this thesis explore and compare the medicine-related experiences of older and younger PLWH, whilst chapter 6 uses qualitative methods to understand these experiences further.

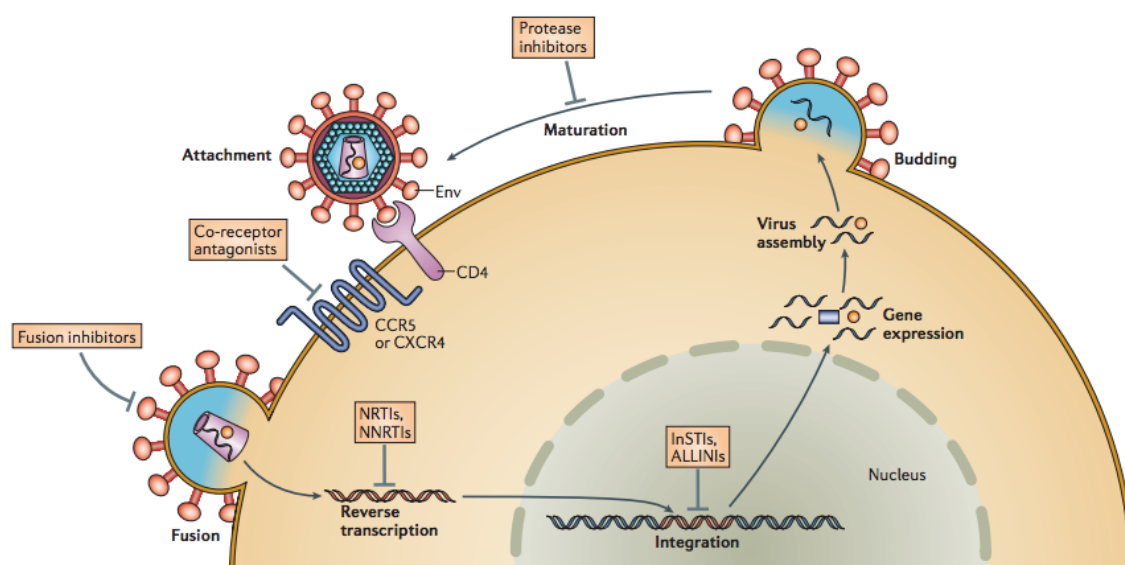


Figure 1.3. The HIV life cycle and antiretroviral drug targets.

Source: A mechanistic theory to explain the efficacy of antiretroviral therapy, 2014. (21)

1.1.6 Undetectable = Untransmittable (U=U)

The World Health Organisation and over 750 other organisations globally state in agreement that individuals with a stably suppressed HIV viral load, cannot sexually transmit the virus. There is a large amount of evidence supporting U=U. (23–27)

1.2 HIV in older adults

1.2.1 Defining an older adult

The term ‘older adult’ can be defined in various ways, such as chronological age, changes in social roles, and functional abilities. (28) While there are multiple definitions to describe an older adult, in the absence of a standard definition, 50 years and older is often used as a cut-off age in HIV literature. (19,20,29) Therefore, for the purposes of this thesis and for uniformity, an ‘older adult’ is someone aged 50 years or older.

1.2.2 Ageing with HIV

Due to great advances in ART, PLWH are now surviving longer and with near to normal life expectancies. It is estimated that by 2030 nearly three-quarters of individuals living with HIV are going to be 50 years or older. (30-31) This is due to better ART regimens as well as an increased number of people over the age of 50 years old being diagnosed with HIV. (19) Data published in 2019 by Public Health England (PHE), now known as UK Health Security Agency, showed that the highest percentage of late diagnoses was seen in individuals who are ≥ 65 years old at approximately 65%. (32) According to PHE, a late HIV diagnosis is an individual who has a CD4 count of <350 cells/mm³ within 91 days of being diagnosed. (4) Reasons why older individuals may be at a higher risk of acquiring HIV, being undiagnosed, and receiving treatment later is five-fold. Firstly, the older population are less likely to need contraception in terms of the risk of becoming pregnant and not recognising the potential risk of sexually transmitted diseases, they are unlikely to use a male or female condom. Secondly, erectile dysfunction is seen more commonly in older men, consequently condom use could be problematic for these men, again exposing them to not using protection and the consequences that could follow. Thirdly, due to vaginal dryness and a rise in vaginal epithelium fragility, post-menopausal women may

be more vulnerable to acquiring HIV through sexual intercourse. Fourthly, signs of ageing (e.g. weight loss and fatigue) are also signs of recent HIV infection and for this reason could be dismissed or overlooked. Finally, a stereotype of assuming older people are not sexually active could lead to healthcare professionals being less likely to ask about sexual behaviours or suggesting a HIV test. (33)

Moreover, older PLWH may experience geriatric syndromes, polypharmacy, frailty, and falls, around 15-20 years prior than in HIV-negative individuals. (34) This increases their risk of drug-toxicity, potential drug-drug interactions (PDDIs), and non-adherence to treatment.

1.2.3 Comorbidities

As PLWH on ART are getting older they are at an increased risk of age-associated chronic comorbidities and increased mortality rates. (35,36) Examples of comorbidities include cardiovascular disease, chronic kidney disease, diabetes, and hypertension. (37,38) Studies have shown that the frequency of comorbidities increases over time and commonly occur earlier than in HIV-negative individuals. (37,39,40) This could be due to several factors, such as changes to normal age-related physiological functioning, accelerated or accentuated ageing processes or higher rates of lifestyle and behavioural risk factors. Substantial evidence from epigenetic studies support the existence of accelerated ageing in PLWH as a potential contributory factor to the incidence of comorbidities amongst this population. (41) For instance, a decline in DNA methylation linked to HIV infection has been demonstrated to predict lower CD4:CD8 T-lymphocyte ratio, which is related to disease progression and ageing. (42-43) Other studies show that accentuated ageing also has a role in some comorbidities, for example, diabetes, renal and cardiovascular disease, which are seen frequently in all ages of PLWH. (19) Treatment toxicity is another factor contributing to the ageing process, including in the development of renal, hepatic and cardiovascular diseases. (44)

1.2.4 Frailty in older PLWH

As the HIV population is progressively getting older, frailty is becoming an increasingly common issue of concern amongst those who manage the care of PLWH, due to frailty's critical impact on clinical care and health outcomes. (45-46) Frailty can be defined as a late-stage clinical syndrome consisting of an elevated vulnerability due to the lowering of physiological reserve and resiliency seen as one becomes older. (47) Higher rates of frailty have been seen amongst PLWH when compared to non-HIV individuals of the same age. (48) Several pathophysiological and immunological impairments that are present in ageing are also present in HIV infection, these combine to increase the risk of frailty. (49-50) Fried and colleagues described frailty as meeting three or more out of five frailty criteria (weakness measured by hand grip strength, unintentional weight loss, self-reported fatigue, low physical activity, slowness). (46-47) This Fried Frailty Phenotype criteria categorises patients into frail, pre-frail or fit groups. Similarly, in a multicentre AIDS cohort study, in which up to 50% of PLWH over the age of 50 years old were identified as being frail, frailty was defined as possessing three out of four of the following criteria: exhaustion; slow walking speed; low physical activity; and unplanned weight loss. (45) The negative outcomes of frailty include increased hospitalisation, falls, depression, poor quality of life, and mortality risks. (46) Studies have shown that the presence of comorbidities and long-term ART toxicity may increase frailty rates in older PLWH. (51) Using the Frailty criteria on older PLWH could establish clinical risks of adverse outcomes in patients, and aid interventions in preventing or slowing its progression. (47)

1.3 Medicine-related concerns in older PLWH

The WHO's third global patient safety challenge, launched in 2017 under the theme *Medication Without Harm*, aimed to reduce medication-related harm globally by 50% over five years. (52) Although the initial timeline has elapsed, the initiative remains a cornerstone of efforts to enhance medication safety worldwide, with continued emphasis on reducing severe and avoidable harm associated with medicines. The challenge had five objectives: assess the extent and nature of the preventable harm and improve monitoring systems that can detect and trace harm; create frameworks to aid improvements in ordering, prescribing, preparation, dispensing, administration and monitoring practices; develop guidance, materials and tools to support the creation of safer medication use systems for decreasing medication errors; engage significant stakeholders, partners and industry to raise awareness of the issue and create methods to improve medication safety; empower patients, their carers, and families to be dynamically involved and engaged in care or treatment decisions, in order to effectively manage their medications. (52) Tackling this challenge amongst PLWH is becoming increasingly important as studies have shown that the number of comorbidities and medications taken increases with age. (53)

Medicine-related burden refers to the challenges and difficulties that patients experience in managing their medications. From the patient's perspectives, this burden can include the complexity of treatment schedules, side effects, financial costs, and the physical and psychological demands of adherence to their medicines.

1.3.1 Polypharmacy

Polypharmacy has widely been defined as the use of 5 or more medicines across literature. (53-56) A cut-off that has been linked to increased risks of adverse health outcomes. (57) However, a study on PLWH found that participants were taking an average of 13 medications, of which 8 were non-antiretroviral medications. (58) The King's Fund report on polypharmacy and medicines optimisation, published in 2013, proposed the terms 'appropriate polypharmacy' and 'problematic polypharmacy'. Appropriate polypharmacy is defined as being optimised medicines prescribed for a patient with a complex condition or multiple conditions and according to best evidence, whereas problematic polypharmacy is defined as the prescription of multiple medicines inappropriately, or where there is no clear intended benefit of the medication. (59) The risks associated with polypharmacy include potential drug-drug interactions (PDDIs), adverse drug reactions (ADRs), increased toxicities, and regimen complexity, which may lead to a non-adherence and hospitalisation. (53,56,60) A study investigating non-ARV polypharmacy in PLWH and individuals without HIV found a correlation between the number of non-ARV medications taken and adverse health outcomes in older individuals of both groups. (60)

Identifying at risk individuals could prevent and reduce the effect of ADRs, particularly since they could lead to a prescribing cascade, where additional medicines are given to treat adverse symptoms caused by polypharmacy. (53) Tools such as the Beers criteria, Screening Tool of Older Persons Prescriptions/Screening Tool to alert doctors to Right Treatment (STOPP/START) criteria and the Medication Appropriateness Index, amongst others, have been used to identify and evaluate potentially inappropriate medicines. (59,61) The Medication Appropriateness Index assesses the appropriateness of medicines using ten questions along with a three-point Likert rating scale, requiring thorough analysis of clinical records. (61-62) The Beers criteria, created in 1991 to reduce the prescribing of high-risk drugs in adults over the age of 65 years old, comprises of a list of potentially inappropriate medicines. (61,63) Since 2011, the American Geriatrics Society has updated the criteria several times, with the latest being in 2023. (63) Although the Beers criteria has value, it

does not take into account several patient factors, such as patient preference, the prescriber's knowledge of the patient, and life expectancy. The STOPP/START criteria, which has been extensively validated in the UK, includes a set of 87 indicators to assess the appropriateness of prescribing for older adults. (59) A study focusing on a pharmacist led program to reduce polypharmacy and potentially inappropriate prescribing (PIP) amongst older PLWH, identified PIP in 54% and 63% of patients when using the STOPP and Beers criteria respectively. (64) Furthermore, at least 69% of patients had at least one medication stopped and almost 10% had six or more stopped after the pharmacist visit. (64) Furthermore, the greatest risk of polypharmacy is seen in older adults with multiple comorbidities, who see several doctors, and receive prescriptions from multiple pharmacies, which is common amongst PLWH due to the segregated services and funding for HIV patients in the UK. (53,65-67)

1.3.2 Medicines optimisation

The National Institute for Health and Care Excellence (NICE) defines medicines optimisation as 'a person centred approach to safe and effective medicines use, to ensure people obtain the best possible outcomes from their medicines'. (68) Moreover, the Royal pharmaceutical society published four guiding principles to describe medicines optimisation in 2013. (69) The four principles are: aim to understand the patient's experience, evidence-based choice of medicines, ensure medicines use is as safe as possible, and make medicines optimisation part of routine practice. Following the four principles is expected to lead to improvements such as, reducing harm from medication errors, increasing patient satisfaction with outcomes from their medicines, improving quality of life and life expectancy rates for those living with long-term conditions, and reducing preventable mortality and morbidity. With increases in life expectancies, comorbidities, and medications among people living with HIV, it is vital to understand the inter-relationship between HIV and ageing when developing interventions to improve health outcomes for the ageing HIV population.

Medicines optimisation is fundamental in tackling the challenges presented by polypharmacy, inappropriate prescribing, and drug-drug interactions. However, the prescribing of non-HIV medications being undertaken by primary care or other speciality areas creates challenges for both the patient and prescribers. The lack of a combined dispensing record due to fragmentation of care increases the risk of potentially inappropriate or interacting medications being prescribed. This would be a particular risk for older PLWH due to their increased likelihood of having a higher number of comorbidities and consequently multiple medicines. When addressing this concern, the British HIV Association (BHIVA) guidelines state that drug histories should be undertaken at every clinic visit and a full medication review to be conducted by specialist HIV pharmacists every year. (20) However, compliance with the latter is not widespread due to limitations in capacity, finance and fragmentation of HIV and sexual health since the 2012 reforms. (19) Healthcare professionals must rely on the patient listing all of their medications themselves and/or having access to their summary care record (electronic records of patient information created from General Practitioner medical records). However, patients may forget some medicines, or their summary care record may not be up to date.

Specialist HIV pharmacists have several roles in medicines optimisation for PLWH, which include: answering medicines-related queries from other healthcare professionals and patients; assisting with recommendations of treatment; initiating or switching ART during patient consultations; conducting medication reviews. (19)

Pharmacists in primary care settings or within community pharmacies need to be vigilant for drug-drug interactions within prescribed or non-prescribed (e.g. vitamins, herbal, or other over-the-counter products) medicines taken by PLWH. Moreover, studies have shown that HIV counselling from pharmacists have led to increased adherence and decreases in viral load and secondary infections. (70) However, the lack of disclosure of an individual's serostatus to community pharmacists is a major obstacle to this. Stigma could be a factor for PLWH deciding not to share their serostatus within a community pharmacy setting; there is only a small body of research on this area focusing on PLWH with mental health and substance use disorders. (71)

In order to target medicine optimisation interventions to those who would benefit the most and evaluate the effectiveness of the intervention, a measure of patient centred experiences with multiple medicines is required.

1.3.3. HIV services in the UK

HIV services are free and confidential in the United Kingdom. (72) HIV outpatient clinicians are responsible for prescribing and managing ART and other HIV-related medications for PLWH in the UK. Patients stable on ART typically visit the clinic every 6-12 months, with routine blood tests undertaken prior to/at appointments to monitor health (e.g. viral load and toxicity monitoring of renal and hepatic function). The BHIVA guidelines state PLWH stable on ART and having suppressed viral loads on two sequential occasions at least a year apart and a CD4 count over 350 cells/mm³ no longer require CD4 count blood tests. (20) Studies have shown that PLWH who have lower retention in care experience increased rates of mortality and antiviral resistance. (73)

1.3.4 Funding and fragmentation of care

Responsibility for different aspects of HIV treatment and care is split between the local authority public health commissioners, the Clinical Commissioning Group (CCG), and NHS England (Figure 1). Local authority public health commissioners are responsible for HIV prevention and testing; NHS England is in charge of commissioning HIV treatment and care services and has separate specialised commissioning arrangements for prison HIV services and testing as part of antenatal screening; CCGs commission testing and diagnosing HIV within other treatment episodes that they fund, and the treatment of most other comorbidities experienced by those living with HIV. Commissioning of primary care is largely undertaken by NHS England, however, increasingly CCGs are taking commissioning responsibility. Moreover, local authorities and, in some cases CCGs, are primarily commissioning HIV support such as counselling or peer support which plays a crucial role in HIV treatment and care.

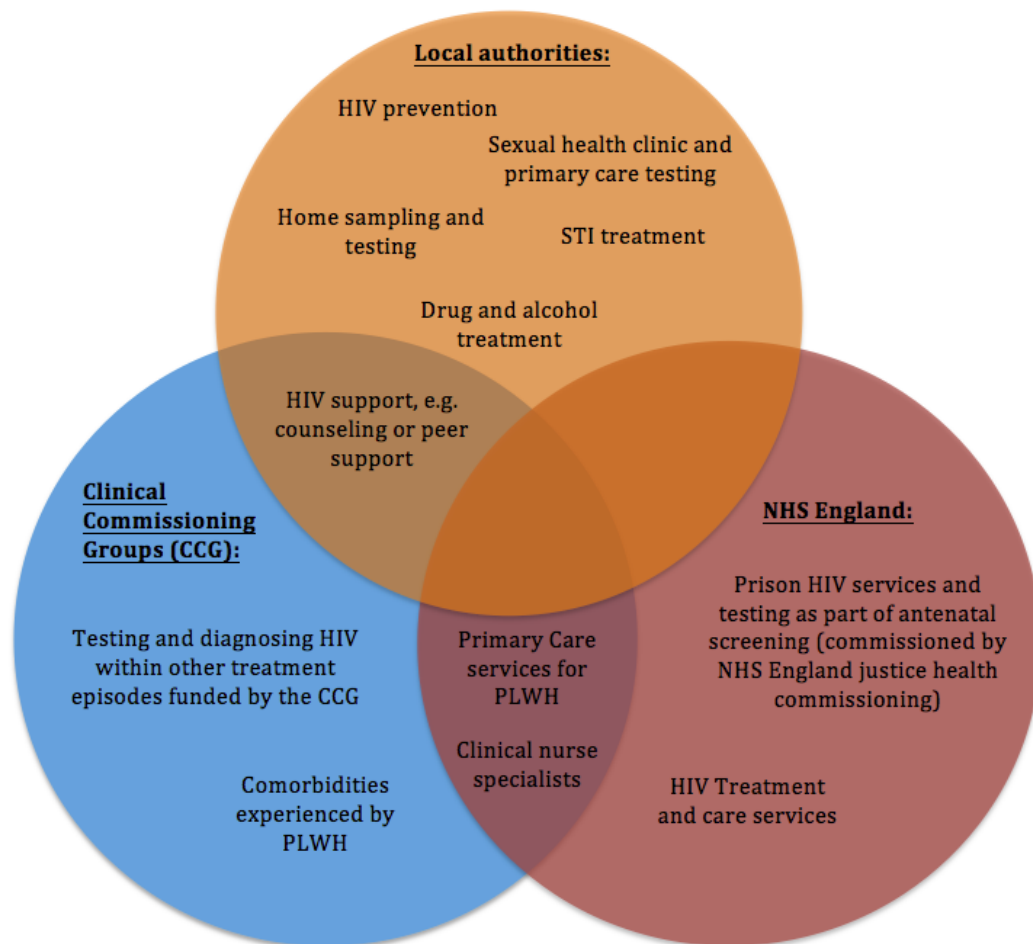


Figure 1.4. A diagram illustrating the complexities around HIV services since the 2012 reforms in the UK.
Source: Adapted from the Kings' Fund report (2017) - The future of HIV services in England.

Due to the Health and Social Care Act (2012), there are several issues that have arisen due to the impact of the 2012 reforms and resulting fragmentation of responsibility. Firstly, the arrangement of different responsibilities and commissioning can lead to a fragmentation in HIV services. For example, the treatment of sexually transmitted infections (STIs) and HIV services being separated, PLWH with another STI would possibly need access to two separate services, resulting in destabilising services, increasing the likelihood of clinical risks, and staff needing to spend more time to co-ordinate care and share information. (65,74) Secondly, there are concerns that CCGs are unlikely to consider the needs of PLWH (e.g. maternity care, psychological services that are too complex for management in primary care, etc.) when commissioning HIV services as they do not directly commission the treatment and care of PLWH. (75) This highlights that enhanced engagement is required by the CCG as they take on primary care responsibilities. Thirdly, there is a possibility that due to increasing financial pressures, the NHS and local authorities opt for disconnected strategies when dealing with reduced funding. Local authorities have introduced several positive developments, however they have also been required to make significant reductions on the overall spend on many areas of sexual health services, which has created risks (e.g. the level of resourcing available for prevention activity). (65) Fourthly, many argue in favour of locally, in comparison to centrally, tailored approaches to HIV services due to the diversity in populations of PLWH in different areas. Nonetheless, an oversight nationally is still needed in prevention of HIV as it has high treatment costs. The exact role of national bodies alongside local services come into question and whether a 'hands-off' or a more involved approach would be better suited. (65)

Despite these concerns, there are certain aspects of existing HIV services that are important in achieving positive health outcomes and are appreciated by PLWH, such as the access to HIV services without the need for referral from primary care and the choice of HIV clinic they would like to receive treatment from. (75) Nevertheless, a holistic approach to care where GPs would be able to view a patient's overall treatment including ART medications alongside non-ART medications could potentially reduce the risk of potentially inappropriate prescribing. This would be particularly useful in older PLWH who have several comorbidities and are subject to polypharmacy. However, there are concerns that due to increasing pressures that primary care are already under in England, they will not be able to undertake further services. (65) In addition to this, studies have shown PLWH to be dissatisfied with primary care services, reporting differential treatment from their GP care provider due to their HIV status, lacking knowledge of their condition, being insensitive to the psychological impact of HIV and related stigma, or experiencing stigmatizing behaviour from staff in primary care. (65,75) The fragmentation and complexity of HIV services in the UK has further added to the difficulty of ensuring that there is a coordinated process in response to changing needs and to deliver integrated care for HIV patients. (65)

1.4 HIV and Stigma

Stigma is a multifaceted social phenomenon that reinforces societal power structures. It is created by the way our minds categorize behaviors and people in order to understand the world around us. Based on the theoretical work defined by Goffman, stigma is conceptualized as a "deeply discrediting" attribute that society views as being different or deviant, which leads to the possessor being branded from "a whole and usual person to a tainted, discounted one", resulting in a "spoiled identity". (76) Certain behaviors that have led to the transmission of HIV are particularly subject to social judgment, such as needle sharing for drug use and perception that HIV is a consequence of sexual intercourse with multiple partners. The label of deviating from usual or acceptable standards socially contributes to PLWH viewing themselves as being undesirable or discredited. (76-77) Furthermore, this negative experience is worse for bisexual, gay and black African communities in the UK, as they are subjected to homophobia and racism that is intertwined with HIV-related stigma. (78)

HIV/AIDS related stigma is an ongoing and pernicious issue faced by PLWH of all ages. Stigma has been acknowledged as a major barrier to testing, increased risk behaviors, non-disclosure and evasion of treatment and support services. (79) This is detrimental, as effective management of HIV requires timely testing and prompt action of the individual to learn of their serostatus and access care, lessening the spread of the disease. (80-81) According to the UK Stigma survey 2015, 1 in 8 participants would avoid clinical care due to an expectation of being treated differently. (82) Moreover, in one study conducted in South Africa and another in France, it was seen that PLWH who experienced stigma or discrimination were more likely to engage in higher risk behaviors and were less likely to disclose their HIV serostatus to a sexual partner. (83-84) Characteristics seen in higher levels of stigma, such as diseases that are perceived to be the bearer's responsibility, degenerative or incurable, contagious and readily apparent to others, are also found with HIV. (85)

In order to understand how HIV-related stigma affects PLWH, the Earnshaw and Chaudoir's Health Stigma Framework (HSF) suggests three stigma mechanisms; enacted, anticipated, and internalised. (86-87) Enacted stigma involves experiences of discrimination, prejudice, stereotyping, and devaluation by others in the past or

present due to HIV. Anticipated stigma refers to the expectation one has of future negative encounters due to living with HIV. Internalised stigma represents the acceptance and endorsement of negative perceptions, feelings, and beliefs of HIV, and applying it to themselves. It is hypothesized by Earnshaw and Chaudoir that distinguishing between the three stigma mechanisms within research is an integral part in understanding how stigma impacts health and wellbeing outcomes on an individual level for PLWH. (87) Stigma has a significant effect on the physical and mental wellbeing of PLWH; being subjected to direct discrimination has been linked to lower treatment adherence rates and outcomes. (88-89) Studies have shown HIV-related stigma to be associated with psychosocial and interpersonal issues of guilt, fear, shame, anger, self-hatred and depression. (85)

It was suggested by Orel, Spence and Steele that ageing PLWH face two-fold stigma, firstly due to their positive status and secondly related to ageism, which is defined as a negative attitude against ageing. (90) Several studies have also shown that older people of colour are subjected to higher rates of stigma due to socially stigmatised behaviours linked to the transmission of HIV. (85) Moreover, stereotyping experienced by participants in a mixed-method study on older PLWH showed that society remains to hold ageist beliefs about ageing, sexual orientation, sexuality and views older adults as asexual and heterosexual. (85)

1.5 Overview and aims of the thesis

More potent, less complicated, and better tolerated ART has led to more PLWH achieving undetectable HIV viral loads. (91) However, disruptions in the HIV care continuum, such as late diagnosis, disengagement with care, and low adherence to medicines, are significant barriers to optimal treatment outcomes for PLWH. (91) Treatment as prevention is a strategy providing treatment to those living with HIV to successfully achieve viral suppression and preventing the spread of HIV. (92) Therefore, reducing late diagnosis among those aged 50 years and older, improving engagement with care, and medicine optimisation is an urgent research priority. The primary focus of this thesis was to investigate the medicine optimisation needs and concerns of older PLWH.

CHAPTER TWO

Ageing with HIV. Medicine Optimisation Challenges and Support Needs for Older People Living with HIV: A Systematic Review

Acknowledgements

The work presented in this chapter was published as Open Access in *Drugs & Aging*, under the Creative Commons Attribution v4.0 International Licence (CC BY). Authors retain the copyright and grant the publisher a license to publish the article, identifying itself as the original publisher. As the first author, I designed and conducted the literature search, data abstraction, and drafted preliminary versions of the manuscript. The supervision team (RC, SC, BK) contributed to all stages of the systematic review, including independent screening of titles, abstracts and/full articles. All authors reviewed and agreed the final version of this paper.

2.1 Introduction

Globally, about 38 million people continue to live with HIV (93). Advances in treatment have transformed HIV into a complex chronic condition (94) and more people living with HIV (PLWH) have a near-normal life expectancy (95). New diagnoses among PLWH over the age of 50 years are on the rise (19). In the UK, nearly two-thirds (65%) of late HIV diagnoses were among those aged ≥ 65 years (32). It is estimated that by 2030 nearly 75% of all PLWH will be 50 years or older, with the median age expected to increase gradually over the years (30). A number of age cut-offs have been used to define older PLWH, ranging from 45 to 55 years old with 50 years and older used frequently across most literature (19,20,29). For the purposes of this review, an 'older person' will include anyone aged 50 years or older.

Ageing within the context of HIV is associated with multimorbidity and polypharmacy (53,96). Polypharmacy has widely been defined as the use of five or more medicines, (54) and is linked to adverse health outcomes (57). A recent multinational patient survey conducted in 24 countries including North America, Europe, Australia, and China (n=2112), reported a significantly higher level of polypharmacy among older PLWH (54.6%) compared with younger participants (36.5%, $p < 0.001$) (96). The survey also found that people experiencing polypharmacy used an average of 6.5 pills per day, and willingness to change antiretroviral (ARV) regimens to those with a fewer number of medicines was significantly higher among older adults (79.9%) than those under 50 years old (70.1%, $p < 0.001$) (96). An earlier study on older PLWH found that participants were taking a median of 13 (range 9-17) medicines, of which 8 (range 4-14) were non-ARV medicines (58). Polypharmacy is associated with regimen complexity, medicine burden, lower treatment satisfaction, potential drug-drug interactions (PDDIs), adverse drug reactions (ADRs), hospitalisation, non-adherence, and contributes to poor health outcomes (53,56-57,60,96). A study investigating polypharmacy among PLWH found a correlation between the number of non-ARV medicines used and adverse health outcomes in older individuals (60). There is a need to understand treatment experiences of older PLWH.

NICE guidelines defines medicines optimisation, as 'a person centred approach to safe and effective medicines use, to ensure people obtain the best possible outcomes from their medicines', which is fundamental in tackling the challenges presented by polypharmacy among older adults (68). Medicine experiences are the summation of events involving drug therapy that one has encountered in their lives. (97) According to the UK's Royal Pharmaceutical Society, medicines optimisation aims to understand patients' experiences and to improve

patient outcomes from a holistic perspective (69). Across the literature, medicines optimisation is implemented through various interventions including medicine reviews (98), deprescribing (56), medicine reconciliations (54,98), identifying potentially inappropriate prescribing (PIP) (98,99), providing social support, and increasing antiretroviral therapy (ART) adherence (54). A recent systematic review of interventions for frail older persons focused on medicines optimisation in secondary care settings (100), but was not specific to PLWH. Moreover, little is known about medicines optimisation interventions targeted at older PLWH. In some studies, older PLWH have reported concerns around stigma. Older PLWH may experience stigma two-fold due to their HIV diagnosis and ageing (90). It is therefore vital to understand the needs and concerns of older PLWH and to investigate interventions aimed at improving medicines optimisation outcomes for this population.

The aim of this review was to investigate medicines optimisation needs and interventions for older PLWH. The specific objectives were to determine: a) the priority issues and concerns of older PLWH about their medicines; b) the types of medicines optimisation interventions developed for older PLWH, how they are implemented, and their effectiveness.

2.2 Methods

The systematic review was conducted and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines. The review was registered with the international Prospective Register of Systematic Reviews PROSPERO prior to data abstraction (CRD42020188448) (101).

2.2.1 Study eligibility – inclusion & exclusion criteria

We included various study designs, including but not limited to randomised controlled trials, before and after experimental studies (controlled and non-controlled), observational studies (cohort studies, case-control, cross-sectional surveys), qualitative research studies, and retrospective and prospective reviews of prescription and/or dispensing records. Case reports and case series were excluded regardless of age composition. Service evaluations and audits conducted to improve medicine-related outcomes in a specific health facility or organisation were excluded. We included studies composed of HIV-positive older adults as the main participants or where the vast majority of participants were of mean/median age 50 years or older. Studies focusing on other age groups besides older persons were excluded (i.e. children, adolescents, and younger adults under the age of 50). Abstracts did not always report participants' age, and therefore extra screening of full texts was done to determine if studies met the age eligibility criterion. For studies not reporting the mean/median age of participants within the abstract, the full text was reviewed to ascertain age composition of participants (Supplementary information: Appendix 1). Studies of HIV-negative older adults were excluded from the review. Studies relating to any aspect of medicines optimisation, medicine reviews, medicine reconciliation, deprescribing, or strategies being undertaken to support older PLWH with safe and effective use of ART and/or non-HIV medicines were included. Studies that did not discuss any aspect of medicines optimisation or issues relating to medicines experience or that concerned older persons' needs in relation to their medicines were also excluded. The search was limited to studies published in English.

2.2.2 Information Sources and Search strategy

A range of electronic databases were searched from date of inception to February 2022. We searched MEDLINE, CINAHL, PsycInfo, PsychArticles, the Cochrane Database of Systematic Reviews, the Cochrane Controlled Register of Trials, Abstracts in Social Gerontology, and Academic Search Complete. We also searched grey literature via OpenGreyTM, including doctoral theses, research reports and other publications. We searched reference lists of included studies and relevant systematic reviews to identify additional studies. A digital referencing manager, Zotero (5.0.89), was used to manage all searches and to remove duplicates. To answer the research question, our Population Intervention Comparison Outcome (PICO) search strategy (102) included key words to maximise our ability to find relevant articles (Supplementary information: Appendix 1). Examples of search terms used include: HIV, AIDS, Ageing/Aging, older/elderly, medicines, antiretrovirals, HAART/ART, optimis*, intervention, pharmaceutical, medicine-related problems, concerns, needs, issues, outcome. Full list of search terms provided in Supplementary information (Appendix 1). The same search strategy was adapted for all databases, with minor changes to the wildcard symbols and truncations for searching different words with similar prefixes.

2.2.3 Selection of studies

Titles were screened for eligibility by one author (PS). Abstracts and full texts were then independently reviewed by three authors (PS, RC, BK) using pre-specified screening criteria (Supplementary information: Appendix 1). Each study was then categorised into: ‘definitely include’, ‘possibly include’, and ‘definitely exclude’. Full texts for all studies in the ‘definitely include’ and ‘possibly include’ category were retrieved for assessment against eligibility criteria by PS and then a sample (20%) independently reviewed (RC, SC, BK) (103). Disagreements at any stage of screening were resolved through discussions among the research team.

2.2.4 Data extraction, synthesis methods, and risk of bias assessment

Data from eligible articles were extracted using a standardised data extraction form (Supplementary information: Appendix 1). One reviewer (PS) led data extraction and a sample of the results (20%) were independently reviewed by two reviewers (RC, SC). Discrepancies in data extracted were resolved by discussion and consensus among the research team.

Synthesis- research papers were categorised thematically (e.g. polypharmacy, treatment burden, medicine burden, adherence) and by the interventions reported (Supplementary information: Appendix 1).

The Critical Appraisal Skills Programme (CASP) checklist and the Appraisal tool for Cross-Sectional Studies (AXIS) were used to assess the risk of bias in and quality of the studies included in the final pool. Specific checklists were used as appropriate for each study design. Any disagreements were resolved through discussion with the team. Each question in the appraisal tool was graded as 1 or 0 for meeting or not meeting predefined criteria respectively; scores and percentages were then calculated to assess overall quality. Overall, studies achieving 0-49% were defined as poor quality, 50-69% were fair quality and 70-100% were of excellent quality.

2.3 Results

2.3.1 Study selection

The search identified 26,154 articles from electronic databases and 3 articles from grey literature. After duplicate removal, 21,350 articles were title screened, of which 1,305 were found to be eligible for abstract screening. Of the 1,305 abstracts, 768 full texts were searched to determine whether they met the age criterion. One hundred and thirty-nine remaining articles were then assessed for other eligibility criteria, of which, 60 articles were excluded due to either the study not having outcomes of interest (n=17), the trial being discontinued (n=1), incomplete study/no results (n=30), and unable to access due to journal restrictions (n=12). Overall, seventy-nine (n=79) studies were included in this review (Figure 1).

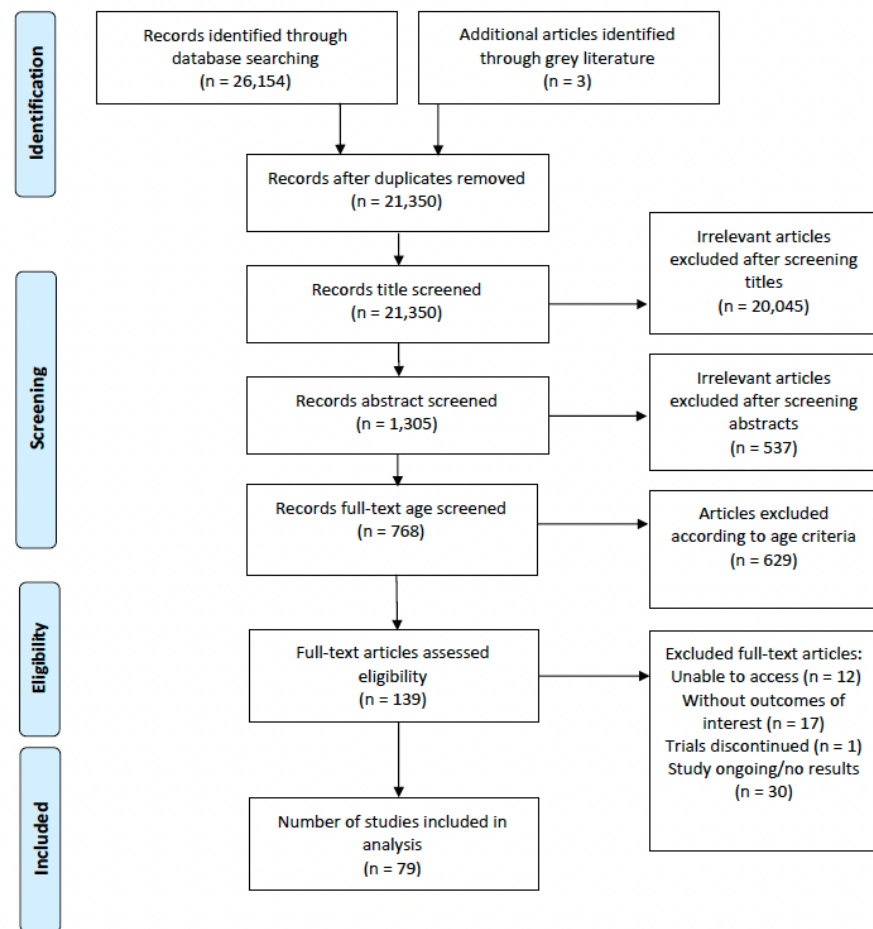


Figure 2.1 PRISMA flow diagram of the systematic review.

2.3.2 Study characteristics

The review included 46 cross-sectional studies, 20 qualitative studies, 5 cohort studies, 4 randomised controlled trials (RCT), and 4 mixed-methods studies. Overall, all articles included were of excellent quality (70-100%). The mean score for the cross-sectional studies was 84% (range 73-90%) based on the AXIS quality assessments. Mean quality scores of 91% (range 70-100%), 91% and 79% (range 71-93%) were obtained for qualitative, RCTs and cohort studies, respectively.

The seventy-nine studies that met the inclusion criteria were largely from the USA (n=36). A few studies originated from Australia (n=5), Canada (n=5), Spain (n=9), and the UK (n=5). Ten studies originated from Sub-Saharan Africa (Kenya n=1, South Africa n=6, Tanzania n=1, Uganda n=1, Zimbabwe n=1). The rest of the studies were from China (n=1), France (n=1), Germany (n=1), Italy (n=1), the Netherlands (n=1), Pakistan (n=1), Switzerland (n=1), Saudi Arabia (n=1), and Ukraine (n=1). Publication dates ranged from 2002 to 2022. Sample sizes ranged from 10 to 15602 across individual studies.

2.3.3 Issues affecting older PLWH

The studies reviewed showed a wide range of issues affecting older PLWH that impacted on their needs for and experiences of using medicines including comorbidities, polypharmacy, drug interactions, adverse drug reactions, adherence, stigma, medicine burden, treatment burden, health-related quality of life, patient and provider relationships (Appendix 2).

2.3.3.1 Comorbidities and health related quality of life

Most older PLWH are affected by multiple comorbidities (37,51,56,104-139). One study reported 93% of participants having one or more comorbidities, with a mean of 3.2 conditions per person (107). Similarly, other studies have also shown the mean number of co-morbidities to range from 2.4 to 3.6 (115-116,118).

Older PLWH are more likely to be affected by anxiety, depression, cancer, chronic kidney disease (CKD), chronic pain, diabetes, hypertension, osteoporosis, hepatitis B/C infections than HIV-negative individuals (37,108,110,112,115,118-121,123,127,131,134,137). A study comparing HIV-positive older males to their HIV-negative counterparts found that older participants were six times more likely to be diagnosed with osteoporosis (37). Similarly, cardiovascular disease (CVD) and CKD are more common in older males living with HIV (37). Other studies indicate a higher incidence of mental conditions in PLWH over the age of 50 years (107,109,112-113,119-120,140-141). One study (119) reported over half (58%) of participants experiencing depression, with a greater proportion having received treatment for depression in the year prior to the study. Poorer health outcomes have been associated with depression in ageing PLWH (142), and depression has also been linked non-adherence behaviour (142). The duration since HIV diagnosis and time since ART initiation are predictors of comorbidity, and both factors are associated with frailty (112,116). Frailty is linked to higher mortality rates among older PLWH, and its incidence increases with age, presence of comorbidities, falls, and disability (48,51,105). The presence of one or more comorbidities also increases the risk of falls in PLWH (126). Among older PLWH, poor health-related quality of life (HRQOL) is associated with comorbidities, especially AIDS-defining illnesses, longer time since ART initiation, loneliness, and a lower level of education (104,130,138,141,143-145). A study focusing on women living with HIV showed that physical HRQOL was lower in older participants than in younger age groups (144). Older PLWH are also more likely to have poor mental HRQOL than patients with other non-HIV conditions (104).

Concerns about comorbidities and ageing have been reported by older PLWH in the qualitative studies reviewed (105,117,146). One older participant expressed their frustration of having to manage HIV, ageing, and comorbidities, particularly when they do not know which is the cause of a health issue they are experiencing (117). Another participant reported not knowing if they were tired due to getting older, their

comorbidities, or side effects of their medicines (146). Many PLWH who were diagnosed in the 1990s or just after the 2000s do not view HIV as their most pressing concern, but rather prioritise comorbidities- their HIV is perceived to be under control due to adherence to ART (131).

2.3.3.2 Polypharmacy, *Drug interactions, and Adverse Drug Reactions*

Polypharmacy

The average number of concomitant medicines used by older PLWH varies (58,56,108-109,114-116,125,128,137,145,147,149). Several studies have found that older PLWH experience more polypharmacy than HIV-negative participants (56,106,116,147,150). One study reported 35% of participants received 16 or more medicines and 16% were using ≥ 20 long-term medicines. Two studies reported that 66% of participants experienced polypharmacy even when ARVs were excluded from the analysis (58,99). Comorbidities are expectedly a precipitating factor for polypharmacy in older PLWH (114), and some studies have demonstrated a positive correlation between the number of conditions and the number of concomitant medicines used ($p < 0.0001$) (116). Cardiovascular and gastrointestinal medicines were identified as the most common classes of concomitant medicines used by older PLWH in several studies (56,58,115-116,120,128,147). Similarly, another study identified 667 potentially inappropriate medicines in 482 older PLWH with 60.8% (292) involving benzodiazepines, 27.2% (130) involving non-steroidal anti-inflammatory drugs, and 14.9% (71) involving anticholinergic drugs (99).

Drug interactions

With higher prevalence of polypharmacy, drug interactions among older PLWH are common, including those occurring between ARVs and non-ARV medicines, or between two or more non-ARV medicines (37,48,56,59,106,114,116-117,120,122,124,137,146,149,150,152). A large number of drug-drug interactions have been identified in the ageing HIV population, as demonstrated in several studies reviewed, with up to 2,552 potential drug-drug interactions (PDDIs) being identified in 1,947 participants (56,58,106,120,137,152). A study comparing PDDIs between older and younger PLWH showed that a significantly higher proportion of older PLWH had at least one PDDI consisting of both an ARV and non-ARV combination than those in the younger group (i.e. 913 compared to 201 potential interactions respectively, $p = 0.001$) (56). Moreover, older PLWH had a larger number of interactions that were classified as “Do not co-administer” than the older HIV-negative or younger HIV-positive groups (56).

In a study using the Beers criteria for PIP, the authors reported one or more potentially inappropriate medicines in half (52%) of all participants (58). The most frequent drugs implicated were testosterone ($n = 20$), ibuprofen ($n = 15$), zolpidem ($n = 9$), and lorazepam ($n = 5$) (58). Other studies measuring drug-drug interactions have listed the same drug groups, among others, as interacting with ART (56,58,106,114,116,120,125,137,148,152). PLWH were more likely to have a high anticholinergic burden, with 17% having a score of ≥ 3 , in contrast to 4% seen among HIV-negative participants (58). One study reported that statins have a high involvement in severe interactions (24%), followed by inhaled corticosteroids (15%) (152). One study showed that 80% of participants were prescribed at least one sedating medicine, and the risk for a non-fatal overdose to occur in the past year was higher with each additional sedating medicine and non-ARV medicine, but this association was only marginally significant ($p = 0.048$) (109). Another study assessing PIP and therapeutic complexity in

older PLWH found at least one medication to deprescribe based on the STOPP criteria or the list of evidence-based deprescribing for chronic patients (LESS-CHRON) criteria in 70% of participants (125). Meeting STOPP or LESS-CHRON criteria was significantly associated with the number of concomitant prescriptions ($p=0.008$) (125).

Similarly, another study assessed the incidence and severity of drug interactions before and after ART simplification. In this study, the authors reported lower rates of PDDIs after regimen simplification, with median interaction scores being 3 (1-6) and 1 (0-2) respectively (106). Moreover, this study showed that their participants were taking a median of three ARV pills a day, and discontinuing a protease inhibitor during ART simplification was a strong predictor for lowering the number of PDDIs (106). Another study found that 70% of older participants had at least one drug-drug interaction that was categorised as 'consider therapy modification' and 11% had an interaction that was categorised as 'avoid combination' (58).

Adverse Drug Reactions

Adverse drug reactions such as cognitive impairment, delirium, dry mouth, and constipation have all been reported among older PLWH (58,99). A study led by pharmacists in the USA to evaluate and reduce PIP, identified an increase of 85% for the likelihood of an adverse drug event occurring with each inappropriate prescribing that occurs in older PLWH (114).

A mixed methods study with older African-American PLWH, highlighted the effects caused by adverse drug reactions, with one participant explaining the stress caused by drug toxicity associated with her medicines on her body over time: *"Even though I'm taking medicine to keep my immune system up and everything like that, it is still somewhat 'wear and tear' on my body"* (140). Long-term ART toxicity has been linked to early onset-and/or a higher incidence of frailty among PLWH (48). This uncertainty of adverse outcomes makes it difficult for older PLWH to predict their future care needs (105,117). In addition, physical changes experienced by PLWH relating to the condition, treatments and side effects can increase stigma levels, treatment burden, mental health and lower quality of life (104,153).

2.3.3.3 Adherence

Several studies showed that older PLWH were more adherent to their ART than younger PLWH (108,125,130,151,154-157). Two studies found older women living with HIV were more likely to be adherent to ART, and subsequently be virally suppressed (144,154). McInnes et al (2013) demonstrated that increasing age was associated with higher medicine adherence for PLWH. PLWH aged 55-64 years and those ≥ 65 years were twice or thrice as likely to adhere than those under 45 years (156). Two studies reported high adherence rates for ART among older PLWH but low adherence when taking their concomitant medicines (115,120). A study comparing adherence rates in older PLWH taking single-tablet or multiple-tablet ART regimens found that patients on a single-tablet regimen had significantly greater adherence than patients on a multiple-tablet regimen ($P < 0.001$) (158). Simplifying medicine regimens can increase adherence in older PLWH (113,124).

Several factors may explain higher rates of adherence to ART among older people, particularly longevity. It is likely that living longer allows older people to be better at taking their medicines throughout life and subsequently continue to live longer. Living longer with HIV may lead to many older PLWH experiencing

HIV-related loss of friends/family, these experiences may have reinforced adherence behaviour (113), although newly-diagnosed older people may not be affected by this concern. The association between social support and adherence to ART has been reported in studies (155,159). Older PLWH living with someone who knows their serostatus may increase their adherence rates due to increased social support (e.g. medicine reminders) (117,121,160-161).

Nonetheless, barriers to achieving optimal adherence may affect older PLWH (142), including comorbidities, regimen complexity and fatigue, mental health conditions and cognitive impairment, lack of social support and social isolation, and stigma (107,112-113,130-131,137,140,142,155,161-162). Practical difficulties (e.g. those associated with obtaining refills) can lead to medicine non-adherence among older PLWH (137,156). Some studies found that financial concerns, for instance costs of travel to clinic appointments, prescription costs or lacking basic necessities such as food, can lead to nonadherence in older PLWH (110,133,161,163).

2.3.3.4 Treatment- and medicine- burden

Treatment burden is a broad concept and has been defined as the ‘work’ of being a patient, requiring significant investment of time, effort, attention, and cognitive energy (164). With a higher number of comorbidities in older PLWH, polypharmacy can increase medicine burden (137). Medicine burden is associated with regimen complexity, number, size and taste of daily pills, and side effects (46,56,58,149,165). Side effects (e.g. diarrhoea, hyperlipidaemia) could result in additional prescribing cascades to manage symptoms, adding to the complexity of a treatment regimen (58,109,149).

Fragmentation of care can lead to missed diagnoses, inappropriate management of comorbidities (105), and some patients may receive conflicting information from clinicians (133). In another study, the desire for a comprehensive care programme for older PLWH including primary care, geriatric consultations and speciality care for comorbidities was noted (105). HIV-only clinics, which may not offer other services, may cause access challenges for older patients (e.g. poor co-ordination of appointments, travel difficulties, fatigue from prolonged waiting times at different facilities) (105,111,132-133). Many older PLWH may struggle with travel to and from clinic appointments due to physical difficulties, access to public transport or a personal vehicle/driving licence, or parking difficulties (105,124,134,140). A lack of transportation could lead to disengagement from care (133,140). Engagement in care is also related to everyday life demands and financial concerns (110,121,124,133,140,163). Older PLWH face significant burden with everyday tasks, such as shopping, managing medicines and keeping to daily treatment regimens, especially for those that require assistance with these tasks (108,121).

One study measured treatment burden in older PLWH (mean age, 53 years) using a validated outcome measure (i.e. the Treatment Burden Questionnaire-13). Using a self-reported measure, Schreiner et al (2019) found a mean treatment burden score of 22.8 (SD=24.6) with overall findings indicating low level of treatment burden (58%, n=60) in the sample population (118). High levels of treatment burden were associated with remembering to take medicines throughout the day and associated limitations, and adhering to prescribed exercise regimens, administrative paperwork (118).

Medicine burden in older PLWH was measured using the Living with Medicines Questionnaire (Chinese version). Zheng et al (2022) found that polypharmacy was associated with moderate-high levels of medicine burden (137). Socioeconomic status, particularly lower income was associated with higher medicine burden. Females were also reported to experience significantly more medicine burden than males (110.5 vs 102.5, $p=0.002$). Adherence levels were negatively associated with overall medicine burden ($r=-0.3$, $p=0.001$). Analyses of medicine burden domains showed similar correlations between adherence to ART and practical difficulties ($r=-0.3$), communication /relationships with other HCPs ($r=-0.3$) and interferences to day-to-day life ($r=0.2$, $p<0.05$). Nonetheless, the authors acknowledged challenges of self-reported data and small sample size ($n=185$) recruited from two clinics within the Chinese Hunan province, limiting generalisability of findings from this study. Moreover, another study reported that 80% of caregivers strongly agreed/agreed that “My care recipient’s medicines are a burden to them” (166). A study investigating women’s interest in long-acting injectable ART reported that the majority of participants preferred long-acting injectable ART (56%) over daily pills. (167) A participant in this study with a history of drug use indicated that injectable drugs users have unpredictable lifestyles that make daily pill taking challenging, whereas an appointment every one or two months would be more manageable. (167)

2.3.3.5 Stigma and need for social support

Stigma

Findings from the studies reviewed indicate that stigma is still prevalent among PLWH, and more so in older persons (105,110,113,117,119,124,126,131,140,142,146,153,159,161,168-171). Several studies have reported that older PLWH experience more stigma than younger PLWH due to the HIV condition and age-related stigma (110,117,119,140,161,172). Many HIV-positive participants experience psychological burden arising from being stigmatised by partners, family members, friends, work colleagues, insurance companies, housing departments, law enforcement officials, and healthcare professionals (131,168). Studies have also suggested that poor mental wellbeing or anxiety among older PLWH may be linked to greater stigma levels (104,171). Older PLWH who are long-term survivors of HIV may also experience stigma from healthcare professionals, leading to instances of disengagement from care (131,140). HIV-related stigma can create barriers to accessing support, and increase non-adherence rates (110,113,119,131,142,161). A study exploring stigma and engagement in HIV care among older PLWH found that there was a significant correlation between negative self-image stigma and engagement in care ($r=-0.38$, $p=0.03$) (140). Similar to the general population, some older PLWH may worry about being recognised by a friend or family member while attending appointments at an HIV clinic (110,140). Stigma can affect an older person’s sense of self-worth and contributes to mental distress (168). Moreover, many older PLWH want more support services to address mental health, stigma and isolation (105,110). Furthermore, studies exploring stigma in older African American PLWH found individuals experienced stigma due to ethnicity, gender identity, sexual orientation, and socio-economic status (113,140,171,172). Another study comparing older and younger PLWH reported that participants over 55 years experienced less internalised stigma than the younger groups under the age of 40 years old, possibly due to learning to cope and manage negative aspects of living with HIV and the associated stigma over time (140,169).

Need for Social Support

Themes around social isolation, loneliness and a need for support among the ageing HIV population have been highlighted in the studies reviewed (105,108,110,117,124,143-144,146,153,155,159,162,169,173). A study focusing on geriatric assessments in older PLWH indicated that up to 50% had low social support and nearly 60% showed some form of loneliness (108). One study reported lower levels of social support among older HIV-positive women than younger HIV-positive woman ($p<0.001$) (144). In another study, those who reported more instances of hostility, temper outbursts and arguments tended to alienate potential allies and therefore do not receive vital sources of emotional support (144,153). Lower mean social support scores were reported among participants who had a high prevalence of mental conditions, psychosocial stressors and disrupted social systems (153,155). Older PLWH's need for improved social support networks was evident in the studies reviewed, with one patient suggesting: *"We should have. . . somewhere we can go and socialise. . . have lunch and have social workers there, if we need to get stuff done. For me, I live alone, I have friends but sometimes my friends work and I like to get out and be around other people socially during the day, I have groups but they are in the evening, but in the daytime I'm just stuck at home"* (105,108). One study observed a statistically significant association between adherence and social support in older PLWH ($p=0.02$) (155). Similarly, other studies have shown that support from family members was highly rated as a facilitator for medicine adherence and engagement in care (110,162).

A recent study on older PLWH and substance use disorders found that social support is critical to minimising treatment interruptions (173). Studies have also suggested the usefulness of peer support groups, particularly to counteract the social isolation and stigma experienced by older HIV-positive people (110,117). One study showed that older adults accessed fewer HIV-related health information sources than the younger participants, including primary care physicians, family/friends, the HIV clinic, support groups, and the Internet (172). Moreover, one study found only 14.8% (76) of participants reported being linked to one or more HIV support groups or communities (160). Older adults living with HIV have suggested the need for age-specific peer support groups as some have felt out of place at support groups consisting of younger participants (110,172). One study suggested that social welfare programmes and primary health promotion should focus on educating older PLWH and their service providers on methods to cope with health and social difficulties of ageing with HIV (121).

A study conducted in Canada reported that all participants attended at least one mental health service, including local drop-in services, support and self-help groups, and visiting therapists (168). Participants described achieving resilience by lowering the space that HIV occupies in their lives, creating lifestyle changes around the illness and engaging in social support (168). Another study found that older and younger PLWH access a similar number of social and emotional supports, and the older group reported fewer barriers to accessing medical and social services than the younger groups, but this was not statistically significant (172).

2.3.3.6 Patient and healthcare provider relationships

Older person's wants and desires for comprehensive and integrated care are noteworthy. Some older persons want healthcare professionals to consider different HIV- and age-related co-morbidities, with one participant describing concerns with their HIV doctor focusing on viral loads and not their comorbidities as they aged (105). Some older PLWH reported that provider perceptions may negatively impact HIV care and lead to late

diagnoses. Perceptions about sexual activity among older people are associated with poorer care around sexually transmitted infections (154).

In addition, a study investigating the pharmacist's role in HIV care in France reported that 21.6% (n=233) of participants would agree to interviews with pharmacists during ARV dispensing to improve their knowledge and help manage their ART, and 18.9% (n=204) would participate to improve their follow-up and compliance (135). It was reported by 94% of pharmacists recruited in this study that more training would be required for them to manage and address the needs of PLWH (135). One study using patient and provider focus groups found that healthcare providers need a deeper knowledge base to care for the ageing HIV population (105). 83.8% of participants in another study reported that they would be willing to stop one or more of their regular medicines if their doctor said it was possible (166).

Some older PLWH have reported concerns regarding fragmentation of HIV care services (56,105,107,110-111,131,133,140). A study evaluating the impact of integrated HIV care on patient health outcomes, found that patients attending HIV clinics that also offered other services (e.g. hepatitis treatment, psychological- and social services) were three times more likely to achieve better clinical outcomes (e.g. viral suppression) than patients attending HIV-only clinics ($p<0.001$) (107).

2.3.4 Interventions used in studies of older PLWH

A total of nine interventions were presented in the studies reviewed (Appendix 3) (113-114,129,162,170,174-178). Five of the interventions were designed to improve adherence to medicines, two utilised medicine reviews and two interventions focussed on self-management apps.

2.3.4.1 Adherence interventions

SMS reminders were used as ART adherence support in one study (113). This involved a six-week campaign, where reminder messages were sent to each participant's mobile phone by the study co-ordinator. The campaign randomly assigned participants to two intervention groups and one control group. Two intervention groups received two-way SMS reminders three and two times per week, respectively. Intervention groups were required to reply immediately, with the first SMS being "Stop, drop and pop. Take your ART meds now. Have you taken ART drugs on time in the last 48 hr?", if the response was "Yes", the next SMS would be "Perfect med adherence. Great job!", if the response was "No" or "Not yet", the following SMS would be "Please take your meds ASAP. If you need any help, please contact BGF." The control group received one-way non-specific greeting messages once weekly and were not required to respond and received a general SMS, such as "G'day, BGF wishes you a nice day!" The author reported no statistically significant differences between the intervention and control arms at the end of the SMS campaign (113). The intervention was useful for adherence support and reassurance for some participants, but others perceived limited effectiveness especially those on established long-term ART.

In another adherence intervention, a Smartphone app (SteadyRX) was tested through an RCT. The intervention group received the smartphone app and usual care, whilst the control group received usual care only (174). Each participant was given login details to access three sections of the app: a) the "PillWatch" section allowed users to upload video recordings within in a 6-hour dosing window with SMS notifications sent daily 30-

minutes before the start of the dosing window, b) The “MyRewards” section allowed users to view their monetary incentives for adherence, for example, the number of consecutive days of adherence, countdown to bonus earnings, total earnings, and current balance, c) The “InTouch” section provided additional resources e.g. adherence-related documents, a user guide/manual, and contact information. Study participants were followed up monthly for six months, and adherence was measured by Medicine Event Monitoring System (MEMS) caps. The percentage of adherent participants in the control group reduced across the study duration, with a significant difference between the control and intervention group being evident at six months ($p=0.037$), with the latter being more adherent (174).

A mobile health intervention app, Rango, designed to support care engagement and treatment adherence for PLWH was evaluated in a pre/post-intervention study (129). The app consisted of three primary components. Firstly, a social network interface to facilitate social support, secondly, personalised medication and appointment reminders, and thirdly, access to services within the app for social services referrals based on each patient’s needs (129). Participants responded positively to the app and found it acceptable. Lower patient activation of the app was associated with reports of missed doses (129). A statistically significant difference was evident in the number of participants with unsuppressed viral loads becoming suppressed post-intervention with the Rango app ($p=0.006$) (129).

Acceptance-based behaviour therapy was used in another study to promote ART adherence. This intervention used direct cognitive and emotional control strategies e.g. encouraging participants to accept HIV-related distress, and to focus their own values (162). Intervention activities included experiential group exercises, role playing, and homework completed in weekly sessions lasting 60-minutes. Most participants (75%) found the groups to be helpful (162). The study reported that qualitative observations suggested that the acceptance-based intervention strategies were well suited to the target population (162). The sessions emphasised psychological acceptance of the condition and medicines and avoiding denial. The participants reflected on medicine effectiveness, side effects and taste (162). The study emphasised social support when living with HIV. This intervention was perceived as less judgmental than compared to traditional approaches for increasing adherence (162).

A randomised controlled trial using cognitive behavioural therapy utilised psychoeducation to discuss HIV disparities, discrimination, and treatment adherence. Adherence was measured electronically using Medication Event Monitoring System (MEMS) bottle caps and through a self-reported questionnaire. A significant improvement in self-reported adherence was seen among participants ($p=0.02$) (170). Electronically monitored adherence showed an increase in adherence, however this was not significant ($p=0.06$) (170). The study reported high intervention acceptability by participants.

2.3.4.2 Pharmacist-led medicine reviews

Medicine reviews/reconciliations were conducted by pharmacists in a study evaluating polypharmacy and PIP in older PLWH ($n= 248$) (114). This study found 54% and 63% of older people had PIP when using the Screening Tool of Older Persons’ Potentially Inappropriate Prescriptions (STOPP) and Beers criteria respectively (114). Pharmacist-led reviews led to discontinuation of PIP in older PLWH with two medicines stopped, on average, per patient. At least one medicine was stopped in over two-thirds (69%) of older PLWH,

while six medicines were stopped in $\geq 10\%$ of older persons (114). Pharmacists play a big role in optimising medicines for older PLWH and this study found that nearly half of participants had one or more medicine-related problems (e.g. drug interactions, duplication of medicines, high dosage, use of medicines with higher anticholinergic burden) that needed urgent attention by the pharmacist. The study provides useful insight regarding how pharmacist involvement in HIV care can potentially improve pharmaceutical care outcomes. Regardless, the authors recognised limitations around sample selection and excluding potentially inappropriate prescriptions that required a multidisciplinary approach. The study lacked a control/comparator and did not appear to report effectiveness of this pharmacist-led intervention.

A Medicines Management Optimisation Review (MOR) toolkit aids the identification and reviewing of patients that are high risk for polypharmacy and PDDIs to improve patient safety (177). It consists of a user guide, a patient-orientated questionnaire promoting self-report and adherence to medications named 'My Clinic Companion', and the 'MOR consultation form' that is used to record the information elicited in the patient consultations and primary care/hospital records, and to identify beneficial interventions, such as adherence education and smoking cessation (177). A RCT evaluating the toolkit reported 93 medication-related problems (MRP) (for example, PDDIs, dose adjustments, and potential adverse drug reactions) in the intervention group and two in the standard care control group at baseline. Six to eight months later, 33 new MRPs were identified in the intervention group compared to three in the control group ($r=0.4$, $p=0.001$) (177). More participants in the intervention group had polypharmacy compared to the control group. A reduction in non-ART drugs was evident at 6 months in the intervention arm, however this was not significant ($p=0.217$) (177). There were no significant changes in HRQOL in both groups throughout the study. Thirty-eight patients completed patient satisfaction questionnaires, and all agreed that the service provided was excellent or very good, most agreed that they had an increased confidence in managing their medicines post intervention (177).

2.3.4.3 Self-management interventions

A self-management app (mVIP) covers 143 self-care strategies for different symptoms including anxiety, depression, sleeping difficulties, cough/shortness of breath, diarrhoea, memory difficulties, fatigue, dizziness, fever, chills/sweats, neuropathy, nausea/vomiting, skin issues, and weight loss/wasting. App users are guided through questions relating to symptoms, and based on their responses self-care strategies are recommended (175-176). In a RCT, weekly surveys were given through the app asking participants if they had experienced one of the symptoms in the past seven days and how much they were bothered by the symptoms (175). For bothersome symptoms, the intervention group was given self-care strategies and illustrative videos. After the RCT was complete, the follow-up study used convenience sampling to recruit participants to focus groups (176). Common symptoms reported by participants included difficulty sleeping, anxiety, neuropathy, and depression (175). The intervention group showed improvements in 12 out of 13 symptoms compared to the control group (175). The RCT trial study did not find a significant difference in HRQOL between the groups; improvement in ART adherence was found in the intervention group (175-176). The intervention group found the app useful for self-care strategies to manage their HIV-related symptoms (175). Participants suggested the addition of more languages to the app (175-176). The ability of the intervention group to review symptoms previously logged was reported as being useful and could potentially aid interactions with healthcare providers (176).

The CARE (Technology Enhanced Competence, Autonomy, and Relatedness Intervention for Elderly women with HIV) uses a web-based app to provide users with interactive features and functionality within modules to enhance physical and psychosocial functions and increase self-determination of older PLWH (178). A study conducted a pre/post-test intervention using The CARE app (178). Overall, participants found the app and information useful, despite some encountering challenges navigating the contents of the modules. Participants found the social support aspect of the intervention positive, with one participant stating "...support groups are so important because I would die to have somebody to share with daily..." (178). During the post-intervention focus group, all seven participants agreed that they would recommend the app to other PLWH (178). Although not statistically significant, slight improvements were seen post intervention for treatment confidence, seeking help, and internal motivation for treatment entry and adherence (178).

2.4 Discussion

This systematic review was designed to identify the main issues and concerns in relation to medicines in the ageing HIV population, the interventions available to target these concerns and for medicines optimisation, and how effective the interventions are. There were a variety of tools used among the studies to identify and quantify issues, such as stigma, polypharmacy, drug-drug interactions, and frailty. However, the studies reviewed were largely descriptive, with only nine intervention studies reported out of the 79 appraised. A majority of the studies included were conducted in the USA, whereas only five were conducted in the UK, highlighting the need for further research in this population.

The priority issues and concerns identified in the studies reviewed were comorbidities, HRQOL, polypharmacy, drug interactions, adverse drug reactions, adherence, medicine burden, treatment burden, stigma, social support, and patient-healthcare provider relationships. The results of the review showed that these issues are interrelated with complex impacts on each other, and so must be considered holistically when optimising the medicines of older PLWH. A higher number of comorbidities have been reported among the ageing HIV population compared to younger PLWH and the HIV-negative population of the same age. The studies reviewed have shown that older PLWH have an average of three comorbidities, with duration since HIV diagnosis and ART initiation being predictors of comorbidity. As the number of concomitant medicines taken by older PLWH increases with the number of presenting comorbidities, this leaves this population vulnerable to potential drug-drug interactions. There is evidence from the included studies that the conditions that affect this population the most are gastrointestinal, mental health, cancer, CKD, diabetes, CVD, chronic pain, and osteoporosis. It has been reported that this population hold uncertainty about the physical, psychological, and social impacts of ageing with HIV. Moreover, there are concerns that certain conditions are being overlooked in older PLWH, this could lead to late diagnosis and the potential addition of medicines that could have been avoided if earlier screening occurred. A poor physical HRQOL can be observed in older PLWH, and has been associated with a history of AIDS, a longer duration since ART initiation, multiple comorbidities and loneliness (104,143-144). Lower mental HRQOL has been observed in HIV-positive adults compared to HIV-negative adults (104). Moreover, depression has been linked to poorer health outcomes in this population (142). Mental health conditions in older PLWH has been mentioned as a concern across several studies in this review, including depression, anxiety, and although not as common one study showed PTSD in 12.5% of long term survivors of the disease (108,168). A participant from one study described his fallout and

anger that he experienced when unexpectedly surviving HIV with the term “reactive depression” (168). This suggests support for further research in this area and in HIV survivorship (179-180). Moreover, one study reported mental disorders as being the most prevalent comorbidity in older PLWH with other studies also reporting high incidences of mental illness (107,109,112-113,119,140).

The studies reviewed have shown that older PLWH experience higher rates of polypharmacy than younger PLWH and HIV-negative people (56,106,116,147,150). Several studies in this review have identified a high number of drug-drug interactions in the ageing HIV population. Commonly prescribed concomitant medicines in older PLWH have been reported to interact with ART, examples include statins, proton pump inhibitors, antidepressants, phosphodiesterase-5 inhibitors, and inhaled corticosteroids. These interactions can result in negative and unpleasant effects for the patient. Older PLWH have expressed drug toxicity of medicines causing stress on their body over time. Adverse drug reactions and physical changes relating to their HIV disease can increase the stigma, treatment burden, mental health, and lower quality of life experienced by older individuals with HIV. Long-term ART toxicity and the presence of comorbidities has been reported to increase the incidence of frailty (48,51,105). Frailty is an emerging concern among the ageing HIV population, and can have a significant impact on clinical care and health outcomes (181). The STOPP and Beers criteria are validated tools that are useful in identifying PIP, drug-drug interactions, drug-disease interactions and medicine to avoid in older adults (59). Several studies in this review highlighted the usefulness of using such tools and medicine reconciliations in older PLWH (58,99,114,125,148), with the Beers criteria evident in over 50% of participants in two studies and over 60% of participants with the STOPP criteria in one study (58) (114). Moreover, medicine reconciliation leading to an average of two medicines being stopped per patient in one study is incredibly important, particularly when each PIP can increase the likelihood of ADRs by 85% (114). Simplified medicine regimens leading to increased adherence rates and less adverse drug reactions of medicines can potentially reduce the number of further medicines needed. It is important that the cause of ADRs are identified and treated to prevent further inappropriate prescribing. Pharmacist reviews are therefore effective in reducing both polypharmacy and potentially inappropriate prescribing (114-115). The findings from this review suggest that using medicine reviews to target individuals affected by polypharmacy, would have the highest yield and greatest impact in reducing PIP (114). Medicine reviews can lead to ART simplification, reducing polypharmacy, pill burden, PDDIs and improve health outcomes (106).

Comorbidities, polypharmacy, regimen complexity, medicine refill difficulties, stigma, mental health disorders, poor finances, and low social support are all factors that lead to suboptimal adherence in the ageing HIV population. Older adults who have been living with HIV for a long-time and have witnessed the loss of friends and family to the disease have reported that the importance of medicine adherence has been reinforced within them through these experiences (113). This may be the reason for higher adherence rates of ART reported in some studies among older PLWH compared to their younger counterparts. A higher adherence rate for ARTs compared to concomitant medicines suggest that some patients prioritise medicine based on their beliefs and perceptions of their importance (115,120). Medicine regimen complexity may leave patients confused on how to take their medicines, this in addition to the number of medicines taken, pill size/shape, and dosing instructions can increase medicine burden. Comorbidities, polypharmacy, and adverse drug reactions increase the medicine burden experienced by older HIV-positive adults. Further to medicine burden, the difficulties experienced by older PLWH adhering to their medicines and treatment regimens can lead to

treatment burden. This includes the time and effort taken to manage medicines, attending clinic appointments, laboratory tests, lifestyle changes and self-monitoring. A higher number of comorbidities can lead to higher requirements to maintain the treatment of each condition, thus augmenting treatment burden.

Despite the advances in HIV care, older PLWH are still facing stigmatisation not only for their serostatus but also due to ageism. In addition, race, gender identity, and sexual orientation have also been reported to cause stigmatisation (113,140,171-172). This has led to an increase in mental burden, decrease in mental wellbeing and lower engagement in care (104,140). Stigma can create barriers to accessing care services and subsequently lower adherence in older PLWH (110,113,119,142). Moreover, previous mistreatment and stigmatisation from healthcare professionals and the anticipation of future instances can cause disengagement from care (140). Other examples of stigma experienced include stigma due to misinformation, physical appearances, discrimination and compounded stigma (142,146,153,168).

The need for social support was a common theme across the studies reviewed. Lower levels of social support have been seen in older PLWH compared to younger PLWH (144). Several studies have reported an association between social support and adherence to medicines (117,121,155,160). Social support has also proven critical for PLWH with substance use disorders to help them avoid treatment interruption (173). Low social support has been observed among older PLWH who have a higher prevalence of psychiatric illness and psychosocial stressors (155). Older HIV-positive individuals have expressed a need for more support services focusing on mental health, stigma and isolation (105,110). Targeting vulnerable individuals and providing this support could help to prevent negative health outcomes in this population. Current peer support groups for PLWH of all ages have left older HIV-positive adults feeling out of place and wanting age specific groups (110,172). Social support among older PLWH is of particular interest within the UK as in 2017 it was reported that 82% of this population experienced moderate to high levels of loneliness (182). Understanding the role of stigma and resilience is vital, since these factors may contribute to mental health comorbidities and the addition of further medicines in older PLWH.

The fragmentation of services for PLWH is particularly of concern, due to difficulties of travelling between care facilities, time taken for visits, and finances (105,107,110-111,124,132). Older PLWH have expressed concerns of missed diagnoses of comorbidities as they age due to fragmentation of care (105). They have also suggested a need for specific care programmes tailored to their requirements. Studies have shown the effectiveness of integrated HIV care with patients being three times more likely to be virally suppressed than clinics with HIV services alone (107). Therefore, providing integrated care for the management and treatment of comorbid conditions is vital for long-term care in this population (107,110,131-132).

Implications for research and practice

The medicines optimisation interventions in the studies reviewed targeted medicine reviews, adherence, and physical and psychological self-management methods. Five interventions were technology based, requiring a mobile phone and/or internet accessibility. The interventions were well received by most of the participants, showing the desire and usability of medicines optimisation interventions among this population. The reported interventions exhibited positive outcomes in adherence among participants. For instance, SteadyRX, a Smartphone app, utilising daily SMS reminders, monetary incentives for adherence, and adherence-related

documents reported increases in participant adherence (174). Similarly, another mobile intervention app, Rango, providing daily reminders, access to social services referrals, and facilitating social support, demonstrated increases in suppressed viral loads among participants post-intervention (129). Participants in one study using acceptance-based behaviour therapy to increase adherence found it helpful and perceived it as less judgemental than traditional adherence interventions (162). In addition, increases in adherence were reported in participants using mVIP, a self-management app (175-176). The web-based app, The CARE showed small improvements in treatment confidence and internal motivation for adherence among participants through modules to increase physical and psychosocial functioning with a social support aspect, however, the difference was not significant. Medicine reviews/reconciliations and a MOR toolkit to reduce PIP and PDDIs were effective among intervention studies, with an average of two medicines being discontinued per patient in one study (114), and significantly more MRPs being identified in intervention groups compared to the control ($p=0.001$) in another study (177). However, the majority of the key issues of concern for older PLWH regarding their medicines, as identified in this review, were not reflected in the few studies with interventions. The need for social support and its importance was highlighted in the studies included as a fundamental medicines optimisation intervention. The lack of medicines optimisation interventions targeted specifically for older PLWH reinforces the need for further research exploring these key issues within this population, utilising a variety of qualitative and quantitative methods. This would then inform subsequent work for the design, implementation, and evaluation of medicines optimisation interventions in older PLWH with the intention to improve patient health outcomes.

Study Limitations

Many of the studies included in our review had a small sample size. The adherence interventions reported in the studies reviewed focus on adherence of ART and have not considered concomitant medicine, which is prevalent in the older HIV population. A majority of the studies include people who have been living with HIV for many years and therefore, the data may not be generalisable to newly diagnosed PLWH 50 years old and over. Although searches of multiple databases and grey literature were conducted, it may be possible for some relevant papers to have been missed in this review.

Conclusion

This systematic review synthesised available data on the priority issues and concerns of older PLWH about their medicines, and the type and effectiveness of interventions developed to tackle optimising their medicines. Our findings provide evidence that the ageing HIV population are at high risk for comorbidity, polypharmacy, drug interactions adverse drug reactions, medicine burden, treatment burden, and stigma. Mental health and social support have been identified as important factors that need attention to improve patient health-related outcomes. Moreover, the fragmentation of care diminishes the relationship between the patient and healthcare providers has created several barriers and issues for the ageing HIV population. The interventions identified in this review, although sparse, show the potential for medicines optimisation to improve patient health-related outcomes in the ageing HIV population. The use of acceptance-based therapy, SMS reminders and apps for medicines optimisation interventions has high potential, however, the usability and acceptability need to be investigated further in older PLWH. There is a need for further medicines optimisation interventions and the involvement of targeted support groups in the ageing HIV population.

2.5 Chapter Summary

Medicine optimisation takes a holistic approach to improve health-related outcomes by aiming to understand patient experiences. The papers reviewed showed the multitude of issues and concerns older PLWH face with their medicines as they age, particularly comorbidities, polypharmacy, drug interactions, ADRs, medicine burden, treatment burden, stigma, mental health, and the need for social support. The research evidence from the systematic review helped to identify the main issues affecting this population, but also highlighted gaps in the literature on this topic.

This chapter revealed a scarcity of interventions focusing on improving medicine experiences for older PLWH. Of the nine interventions identified among 79 articles, five focused on medicine adherence, two on medicine reviews and another two on self-management apps, and all required a mobile phone and/or internet access.

Most significantly, the systematic review showcased paucity of relevant research conducted within the UK, with only five out of 79 articles located within the UK. Thus, the next empirical chapters (chapters 4, 5, 6 and 7) comprise studies designed to fill this gap and investigate older PLWH's experiences and concerns with their medicines, and stigma, and desire for social support. Chapters 4 and 5 compare older and younger PLWH nationally to identify any differences between the two age groups, whilst Chapter 6 uses semi-structured interviews on older PLWH to further understand their experiences and desires for their care. Chapter 7 presents healthcare professional perspectives of older person's care and what is working well and any further areas for improvement.

CHAPTER THREE

METHODS

3.1 Introduction

This chapter presents an overview of the general methods used within this thesis to address the aims and objectives of the empirical studies conducted. To effectively address the research questions that inquired about medicine-related needs of older people living with HIV (PLWH), it was important to design and implement mixed-method studies to collect suitable data. Therefore, the rationale for choosing a mixed methods approach is described in this chapter. For specific methods used for each empirical chapter, please refer to the methods sections of each chapter (chapters 4-7).

The disruption of Covid-19 within the first few months of planning and executing the studies for this thesis brought several challenges, for instance, there was a lot of uncertainty surrounding lockdown and other restrictions. This led to several delays with recruitment and interviews for qualitative studies within the NHS trust due to restrictions with access and staff shortages. Thus, the decision was made to conduct the two quantitative studies in chapter 4 and 5 as a reanalysis and a national online survey, respectively. However, the recruited sample in chapter 5 may not have been fully representative of the wider population of older PLWH. Factors such as socioeconomic background, digital literacy, and healthcare access influenced participation, potentially skewing the data towards those who were more engaged with healthcare systems or research and able to use technology.

3.2 Health services research

The goal of health services research is to determine the most effective ways to organise, manage, fund, and provide high-quality care by understanding the structural, organisational, political, behavioural, psychological, and social factors affecting access to and delivery of effective care. (183) This information is then provided to clinicians, institutions, and systems to enhance medical services and improve the health of individuals and the public. Quantitative methods are often used to measure the prevalence of health conditions, and in this thesis used to estimate the magnitude of medicine-related problems affecting a sample population. Qualitative methods were used to explore the individual experiences and patient perspectives related to living with a long-term condition and to understand healthcare professionals' viewpoints. (184) Understanding patients' experiences is important for healthcare professionals to focus on providing optimal care. (185)

The primary focus of this thesis was to investigate the medicine optimisation needs and concerns of older PLWH. A series of studies were undertaken, with information from each study informing the next one:

- Quantitative survey methodology: to evaluate medicine-related burden in older PLWH (Chapter 4).
- Quantitative survey methodology: to identifying medicine-related support needs in older PLWH (Chapter 5).
- Qualitative interviews: to explore the medicine support needs and medicine optimisation experiences of PLWH aged 50 years and older in areas of southeast England (Chapter 6).

- Qualitative interviews: to investigate experiences of healthcare professionals on medicine optimisation needs of older PLWH (Chapter 7).

The findings generated from these studies will enhance the existing evidence base of medicine optimisation interventions for older PLWH, which is particularly sparse within the UK as discussed in Chapter 2. It is anticipated that by understanding older PLWH's views and experiences with medicine use, the findings of this thesis could inform evidence-based HIV care for those aged 50 years or older.

3.3 Epistemological and ontological stance

The philosophical foundations of using both quantitative and qualitative research methods in the social sciences are underpinned by two epistemological positions: positivism and interpretivism/constructivism. Each being based on differing assumptions about the nature of reality, the role of the researcher, and the chosen methods to gather and analyse data. Positivism uses empirical observation, measurement, and experimentation to discover objective truths pertaining to the natural world. Positivists often use quantitative research methods, such as experiments and surveys, as they are seen as providing objective and measurable data, which can be analysed statistically. (186) On the other hand, interpretivism/constructivism emphasises understanding the experiences of subjects and the cultural and social contexts in which they occur by often using qualitative research methods, such as interviews and ethnography. This can help capture detailed data of the complexity and nuance of human experience. (187)

However, it is possible that selecting a single approach to research will yield only a partial understanding of the phenomenon investigated. (188) Whereas the advantage of a mixed methods approach is the ability to address multiple research questions, obtain a more holistic view of the research topic, and enhance the reliability and validity of the findings. (188-189) For instance, patterns and relationships between variables can be established with quantitative data, whilst the meanings and experiences of participants can be explored in greater depth with qualitative data. (190-191) Some researchers view mixed methods as a way of extending, enhancing and improving a research study. (185) As stated by Johnson et al. (2007), 'mixed methods research is, generally speaking, an approach to knowledge (theory and practice) that attempts to consider multiple viewpoints, perspectives, positions, and standpoints (always including the standpoints of qualitative and quantitative research)'. (192) Pragmatism is a philosophical framework commonly used in mixed methods research, focusing on answering research questions using pluralistic approaches and enabling individual researchers the freedom of choice when selecting their desired research methods, techniques and procedures. (187,189) Therefore, to effectively address the research questions of each study within this thesis, a pragmatic mixed methods approach was selected.

As illustrated by Creswell and Clark (2011), there are six major mixed methods research designs options for researchers to select for their studies (Figure 3.1). An explanatory sequential design was chosen for the studies included in this thesis, where quantitative findings were acquired and analysed first, then qualitative data were obtained and analysed to explain, or elaborate on, the initial quantitative findings for a better understanding. (189) For instance, the surveys aimed to investigate medicine burden, adherence, social support in older PLWH in comparison to younger PLWH and the semi-structured interviews aimed to explore the views and experiences of older PLWH in relation to these issues in greater detail. The philosophical assumptions in the

studies included in this thesis change and shift from positivism in chapters 4 and 5, to interpretivism/constructivism in chapters 6 and 7. A summary of the methods, including epistemological positions used in each study are outlined in Table 3.1.

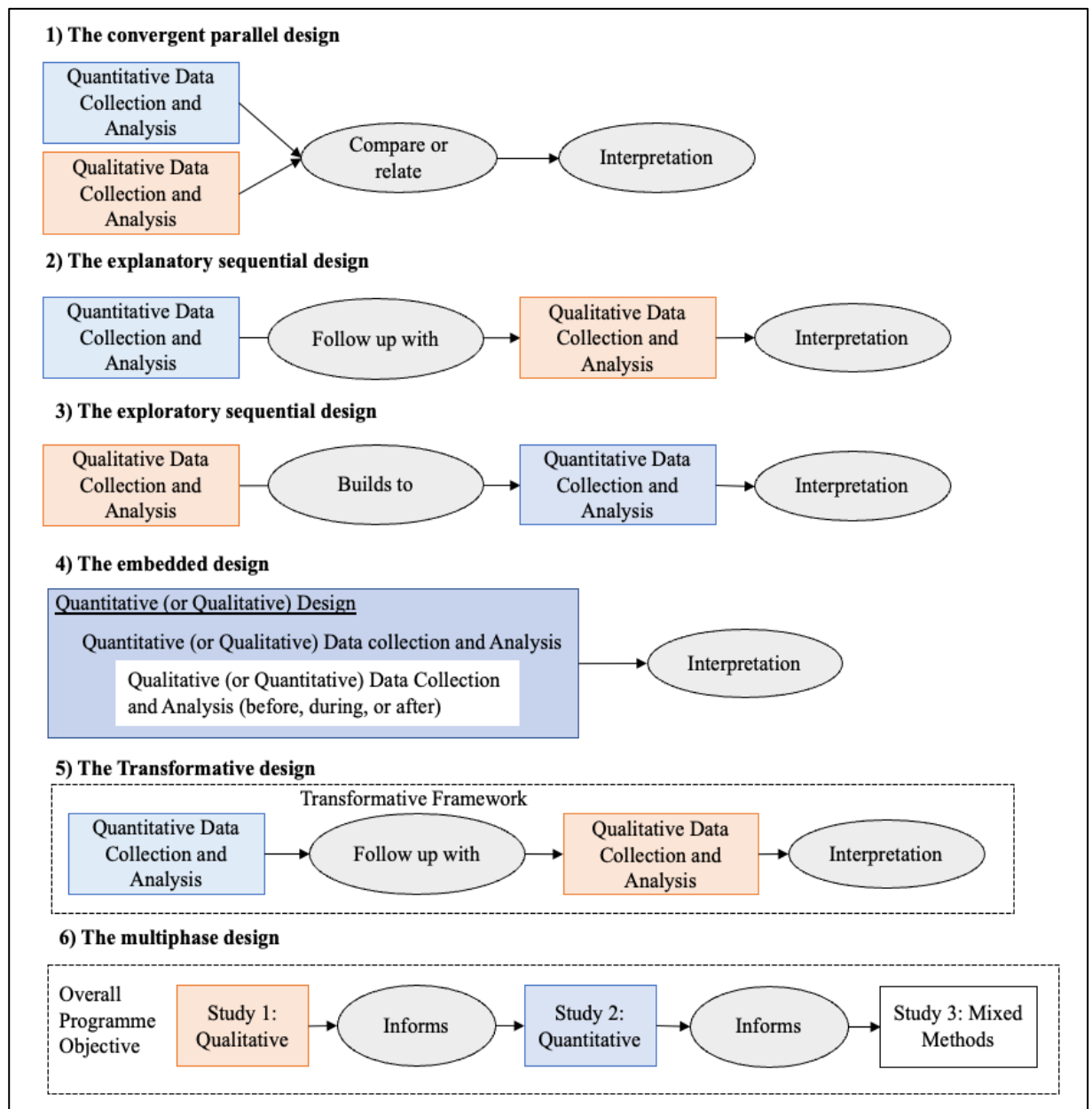


Figure 3.1 Outline of the Six Major Mixed Methods Research Designs. Source: Figure based on Creswell and Clark (2011).

Table 3.1. Summary of the methods used in each study contained within the chapters of this thesis. *Abbreviations: PLWH - People living with HIV; LMQ – Living with Medicines Questionnaire; ARVs – Antiretrovirals; HBM – Health belief Model.*

Study (chapter)	Aims	Research method	Sample	Data collection methods	Data analysis
Evaluating medicine-related burden in older PLWH (chapter 4)	Analyse secondary data to explore and identify differences in medicine-related burden, stigma and disclosure experienced by PLWH according to age	Quantitative	PLWH aged 18 years or over, using ARVs for at least six months, living in the UK and can read and write in English	Online and paper questionnaires	Demographic analysis, age comparison of medicine-related burden, stigma, and disclosure
Identifying medicine-related support needs in older PLWH (chapter 5)	Identify the medicine-related and social support needs of older PLWH and to test the mini-Living with Medicines Questionnaire	Quantitative	PLWH aged 18 years or over, using ARVs and at least one non-HIV medicine prescribed for another long-term condition(s), living in the UK and can read and write in English	Online questionnaires	Demographic analysis, age comparison of medicine-related burden, perceived social support, primary care engagement and disclosure, and compare the mini-LMQ findings to the full LMQ
Exploring the medicine optimisation needs and experiences of PLWH aged 50 years and older in South East England (chapter 6)	Explore the extent to which medicine burden and treatment burden affects older PLWH, the medicine optimisation interventions currently implemented in practice, and the medicine support needs of older PLWH	Qualitative	PLWH aged 50 years and older receiving HIV care in South East England, using ARVs for at least 6 months, and able to read, write and speak in English	Individual semi-structured interviews	Framework analysis using themes identified in the systematic review discussed in chapter two
Views and experiences of healthcare professionals on medicine optimisation needs of older PLWH (chapter 7)	Explore the views and experiences of healthcare professionals on medicine optimisation and social support needs of older PLWH	Qualitative	Healthcare professionals, working in England, and able to read, write and speak English	Individual semi-structured interviews	Framework analysis using themes identified in the systematic review discussed in chapter two, underpinned by the HBM components

3.4 Study setting

Chapter 4 included both a national online survey and a paper survey distributed within sexual health clinics within a Trust across South East England. Due to COVID-19 and the corresponding restrictions in place, chapter 5 included only a national online survey. Chapters 6 and 7 included semi-structured interviews with participants recruited via the Trust once COVID-19 restrictions were lifted and recruitment was allowed. All necessary precautions were taken to protect both the researcher and participants.

The Trust consists of two main clinics with 3 satellite clinics. Services were also provided by the Trust to prisons, however, this location was not included in the studies conducted in chapter 6 and 7. One of the two main clinics was located in a separate building on the same grounds as a hospital (clinic 1) with the other isolated from other health services near a town centre (clinic 2). Satellite clinics 3, 4 and 5 were all based in community health centres. All clinics were used for HIV and sexual health, with shared rooms for both services. HIV services ran on particular days and times during the week at each clinic, therefore, in some instances both the HIV and sexual health services would be running simultaneously. Each clinic had one HIV and GUM consultant with at least one other healthcare professional. Clinic 1 had the highest number of staff members, with satellite clinics having the least and clinic 3 and 4 sharing the same nurse (Table 3.2). Due to staff shortages at the time of the research study, clinic 2 did not have a pharmacist, and the pharmacist within clinic 1 supported all clinics. However, normally a pharmacist would be permanently based within clinic 2 with the clinic 1 pharmacist covering clinic 1 along with the satellite clinics. The stress on staff members due to the staff shortage was evident, however, morale appeared high, and staff seemed to manage well despite this.

Table 3.2. The number of staff at each HIV clinic within the Trust.

Type of Staff	Clinic 1	Clinic 2	Clinic 3	Clinic 4	Clinic 5
HIV and GUM consultant	2	1	1	1	1
Pharmacist	1	0*	0	0	0
Pharmacy Technician	0	1	0	0	1
Nurse	2	1	1**	1**	0
HCA	1	1	0	0	0
*At the time this study was conducted ** The same nurse covered clinic 3 and 4					

Previously to the COVID-19 pandemic, all clinics had a waiting area that is shared between HIV and sexual health services. However, post pandemic, clinics became appointment only and did not allow walk-ins. For clinics 1, 3, 4 and 5, individuals would turn up only at their appointment time, press the buzzer and wait to be let in by staff. Whereas, in clinic 2, individuals for HIV or sexual health appointments shared a waiting area and would be called into one of the rooms by a healthcare professional.

The total number of PLWH receiving HIV treatment from the Trust decreased from 2018 to 2022, from 974 to 884, respectively (Table 3.3). However, the number of PLWH 50 years or older receiving HIV treatment from the Trust had increased from 387 to 447 in the same period.

Table 3.3 The number of people living with HIV receiving treatment from the Trust over the last 5 years.
Source: Request for information under the Freedom of Information Act to the Trust.

Age group	2018	2019	2020	2021	2022
<50	587	571	430	429	437
≥50	387	399	374	421	447
Total	974	970	804	850	884

3.4.1 The Coronavirus disease (COVID-19) pandemic

The COVID-19 pandemic, caused by the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), affected people's lives and healthcare provision around the world. (193-194) Many countries implemented periods of mandatory isolation, social distancing and mask wearing. (195) The pandemic caused disruption to health services and patient access to care during 2020 and 2021. (196) Restrictions due to the pandemic affected HIV testing access, PrEP and Post-Exposure Prophylaxis (PEP), and HIV outpatient care services and access to general practice and hospitals. When designing the research studies, it was imperative to ensure any research conducted was within government and NHS guidelines and kept both the researcher and participants safe. Thus, distributing surveys online via several platforms was deemed the most suitable choice and was utilised during periods of restriction (chapter 5). For the safety and comfort of participants, semi-structured interviews were offered (chapter 6) over the phone, in person or on Microsoft teams. These options allowed flexibility for participants to take part in this study. Staff members interviewed in chapter 7 were given the same options, allowing for easier coordination of interviews according to their work schedules.

3.5 Ethical considerations and approvals

Both quantitative and qualitative research require ethical considerations and approvals to ensure that participants' rights and dignity are protected. Ethical approval was granted for each study. Chapter 4 used secondary data collected from a previous study. Data collected using online questionnaires were approved by the Medway School of Pharmacy School Research Ethics Committee (REF 001018) and data collected within NHS sites in South East England, received approval from the NHS Health Research Authority Northeast Newcastle and North Tyneside Research Ethics Committee (REF 18/NE/0321). For chapter 5, data collected using online questionnaires were approved by the Medway School of Pharmacy School Research Ethics Committee (REF 000820). Similarly, studies conducted in chapter 6 and 7 were approved by the NHS Health Research Authority Hampshire B Research Ethics Committee (REC) (REF 22/SC/0029) (Appendix 4).

The UK policy framework for health and social care research provides a set of good practice principles in the management and conduct of health and social care research, taking into account legal requirements and other

standards (Table 3.4). (197) These policies were adhered to, where appropriate. In addition, adherence to the National Institute for Health and Care Research (NIHR) Good Clinical Practice (GCP) was upheld to ensure the protection of the rights, safety, and welfare of study participants, as well as the reliability of research data, which assures patients and the general public. (198) The Introduction to Good Clinical Practice eLearning was completed prior to commencing the research studies. Assurances of anonymity and confidentiality of data were made, and written consent was obtained from participants in all studies. Participants in all studies were reassured that they did not have to answer any questions that made them feel uncomfortable and were signposted for support if distressed.

Regarding the potential benefits of participating in the research studies participants were given an avenue to share their views, feelings, thoughts, and lived experiences about living with HIV and long-term medicines. This may be particularly beneficial as many PLWH may not share their stories of living with HIV outside of their specialist clinics.

All necessary COVID-19 precautionary measures were considered to protect both the interviewer and interviewee for the studies conducted in chapter 6 and 7. Interviews conducted in person were socially distanced whilst wearing masks and in a well-ventilated room.

Table 3.4 Summary of the of principles for good practice in the management and conduct of health and social care research. Source: Figure based on the Health Research Authority UK Policy Framework for Health and Social Care Research.

Principle	Summary
1: Safety	An individual's safety and wellbeing are prioritised over the interests of science and society
2: Competence	Everyone involved in the research project are qualified by education, training and experience, or otherwise competent to perform their tasks under a suitably qualified person
3: Scientific and Ethical Conduct	The entire process of the research project is scientifically sound and guided by ethical principles
4: Patient, Service User and Public Involvement	Service users, patients, and the public are involved in the design, conduct, management, and dissemination of research unless otherwise justified
5: Integrity, Quality and Transparency	Integrity, quality, and transparency is ensured in the design, review, management and undertaking of the research project
6: Protocol	The use of a research proposal or protocol, conforming to a standard template and/or specified contents where applicable, that clearly describes and justifies the research design and procedure
7: Legality	Researchers and sponsors are familiar with relevant legislation and guidance for managing and conducting the research
8: Benefits and Risks	Prior to the research commencing, anticipated benefits for participants and other present/future recipients of health and social care should be weighed against foreseeable risks and inconveniences
9: Approval	Favorable review and approval by a research ethics committee and other relevant approval bodies must be obtained prior to the commencement of the research project
10: Information about the Research	Information about research projects (other than those for educational purposes) are made publicly available before they start to avoid waste (unless then research ethics committee agrees to a deferral)
11: Accessible Findings	Other than research for early phase trials and educational purposes, after the research project is finished, findings should be made accessible with adequate consent and privacy safeguards, and in a timely manner whilst complying with any applicable regulatory standards
12: Choice	Participants in the research project are given respect and autonomy, considering their capacity to understand
13: Insurance and Indemnity	Adequate provision is made for insurance or indemnity to cover liabilities that may arise from any aspect of the research project

Table 3.4 Continued. Summary of the of principles for good practice in the management and conduct of health and social care research. Source: Figure based on the Health Research Authority UK Policy Framework for Health and Social Care Research.

14: Respect for Privacy	Data collected for or as part of the research project is recorded, handled, and stored appropriately protecting the confidentiality of individuals
15: Compliance	Sanctions may be imposed by funders, employers, regulatory bodies, and other relevant organisations for non-compliance with these principles

3.6.1 Quantitative studies

3.6.1.1 Sampling technique

A secondary analysis was conducted on the data in chapter 4; convenience sampling was employed for the regional data and purposive sampling, using specially designed social media platforms (X, formerly known as Twitter, Facebook and Instagram), for the national online data. A purposive sampling method was also chosen for chapter 5 using social media platforms and by sharing the survey link through HIV organisations. Regular posting on social media, the use of hashtags, and reposts by other organisations or public accounts were used as methods to distribute the survey link. These sampling methods were chosen to maximise recruitment as this population is still considered to be hard-to-reach in many settings, due to stigma, discrimination, and the fear of disclosure.

The inclusion criteria were defined for the two studies (chapter 4 and 5), as shown in Table 3.5.

Table 3.5. Chapter 4 and 5 inclusion and exclusion criteria.

	Inclusion criteria	Exclusion criteria
Chapter 4	<ul style="list-style-type: none">Adults aged 18 years or older living with HIV.Using ARVs for at least six months.Can read and write in English.Living in the UK.	<ul style="list-style-type: none">Under 18 years old.Not living with HIV.Not on ARVs for at least six months.Unable to read and write in English.Does not live in the UK.Too unwell to complete the survey.
Chapter 5	<ul style="list-style-type: none">Adults aged 18 years or older living with HIV.Using ARVs and at least one non-HIV medicine prescribed for another long-term condition(s).Can read and write in English.Living in the UK	<ul style="list-style-type: none">Under 18 years old.Not living with HV.Not using a long-term prescription medicine(s) in addition to ARVs.Unable to read and write in English.Does not live in the UK.Too unwell to complete the survey.

3.6.1.2 Study instruments

Questionnaires were used for data collection in chapters 4 and 5. A cross-sectional survey was chosen as they allow the collection of data from a large number of participants, over wide demographic populations, and in relatively short periods of time, enabling the analysis of trends and patterns. (199) They are cost effective, efficient, and allowed standardisation of questions within each study, which ensures participants are being

asked the same questions and responding in a consistent manner. (200-201) Moreover, as surveys can be conducted anonymously, this may have encouraged more participants to participate and answer more freely.

Screening questions were displayed at the start of the survey, and only those who fulfilled the inclusion criteria, confirmed they understood the study and gave consent were able to access the questionnaire. Questionnaires were designed for self-completion, this allowed participants to understand and answer questions in their own time and perspective. Self-completion permitted the research in chapter 5 to be conducted despite the COVID-19 pandemic, as access to face-to-face recruitment was challenging given the circumstances. Thus, potential participants were engaged with remotely through online organisations and social media, whilst maintaining principles of participant confidentiality. However, this method of survey distribution limited responses only to those with computer/mobile device and internet access.

Survey development & Pilot testing

Both questionnaires in chapter 4 and 5 were created on Qualtrics™. As chapter 4 contained an analysis of secondary data, the researcher was not involved in the development of the questionnaire. However, participant feedback from the survey highlighted the need for revisions of the questionnaire for chapter 5, thus the design and layout of questions were modified to increase participant recruitment and survey completion rates. The following changes were made to increase ease of completion and decrease time taken to complete the survey: the mini-LMQ was used instead of the LMQ-3; Extra answer options were added to some questions, such as “all that apply” and “not applicable”; An ‘other’ text box was included to allow more information to be given if desired; A progress bar was included to notifying participants of how much of the survey was completed with encouraging statements such as “You are halfway through the survey, thank you so much, your responses are important to us”; Institutional logos were added to the survey to increase credibility of the questionnaire.

The chapter 4 questionnaire consisted of the Living with Medicines Questionnaire version 3 (LMQ-3), the Stigma Scale for Chronic Illnesses 8-item version (SSCI-8), and questions regarding sharing of HIV status. The chapter 5 questionnaire consisted of the Mini- Living with Medicines Questionnaire (mini-LMQ), the Multidimensional Scale of Perceived Social Support (MSPSS) and questions regarding engagement with primary care. Table 3.6 displays the components of both questionnaires in chapter 4 and 5.

Table 3.6 The components of the questionnaires in chapter 4 and 5.

Chapter 4	Chapter 5
The Living with Medicines Questionnaire – 3 (LMQ-3).	The mini- Living with Medicines Questionnaire (mini-LMQ).
The Stigma Scale for Chronic Illnesses 8-item version (SSCI-8).	Multidimensional Scale of Perceived Social Support (MSPSS).
Questions regarding sharing of HIV status.	Questions regarding engagement with primary care.

The Living with Medicines Questionnaire (LMQ)

The LMQ is a measure that was developed to investigate several aspects of medicine burden from the patient's perspective. It was used within the questionnaire for chapters 4 and 5, with chapter 4 using the LMQ-3 and chapter 5 using the mini-LMQ.

The LMQ-3 consists of 41-items measuring medicine burden in 8-domains, and a visual analogue scale (VAS) of 10cm with anchors signifying “no burden at all” to “extremely burdensome”, to evaluate the overall medicine burden a patient experiences. (90) The Eight domains include: 1) Relationships/communication with healthcare professionals (5 items), 2) Practical difficulties (7 items), 3) Cost-related burden (3 items), 4) Side effects burden (4 items), 5) Lack of effectiveness (6 items), 6) Attitudes/concerns about medicine use (7 items), 7) Impact/interference to day-to-day life (6 items), and 8) Autonomy/control over prescribed regimen (3 items). The items in each domain were scored from 1 (strongly agree) to 5 (strongly disagree). As the LMQ-3 had a mixture of positively- and negatively- phrased statements to reduce the likelihood of automatic responding by participants, all negatively worded items had to be reverse scored. By recoding the negatively worded items, it gave a higher weight to those that agree with the statement. This was to ensure that a higher score reflected a worse medicine-related experience. For example, a strongly-agree response for a negatively worded item (e.g. I worry that my medicines may interact with each other) was initially coded as 1, but after reverse scoring, a score of 5 would be given to indicate a worse experience. The sum of all item scores within a domain produce the final domain score and the sum of all domain scores provide the total LMQ-3 medicine-related burden score. Total LMQ-3 scores range from 41-205; A higher score indicates a higher burden. Scores were categorised into the following groups to identify level of burden: no or minimal burden (41-87), moderate burden (88-110), and a high burden (111-205) (Table 3.7). The VAS scores range from 0-10, with 0 being ‘no burden at all’ and 10 being ‘extremely burdensome’. Internal consistency of the LMQ-3 was evaluated using Cronbach's alpha, with all domains showing good internal consistency ($\alpha > 0.7$) apart from “Autonomy/control over prescribed regimen” ($\alpha = 0.692$). (202)

Due to feedback from participants in chapter 4, suggesting that the survey was too long, the mini-LMQ, a shortened version of the LMQ-3 was used in chapter 5. The mini-LMQ was chosen over the full-length LMQ-3 due to a shorter completion time, whilst still capturing key aspects of medicine use experiences. The mini-LMQ still contained the 8 domains as mentioned above but with only one item per domain compared to the previous 42-items contained in the LMQ-3, decreasing the time needed to complete the survey. As with the LMQ-3, the items on the mini-LMQ were scored as 1 (strongly agree) to 5 (strongly disagree), and all negatively worded statements were reverse scored. The total mini-LMQ score was the sum of all 8 domain scores, this meant that the mini-LMQ scores can range from 8 to 40, with a higher score indicating a greater medicine-related burden (Table 3.7).

Table 3.7 Scoring categories for medicine-related burden using the LMQ-3 and the mini-LMQ.

Level of burden	LMQ-3	Mini-LMQ score
Minimal	41-87	8-17
Moderate	88-110	18-22
High	111-205	23-40

The Stigma Scale for Chronic Illnesses 8-item version (SSCI-8)

The SSCI-8 is a shorter version of the original 24-item measure assessing internalised and enacted stigma. The 24-item SSCI has been validated among people living with neurological conditions and people living with HIV. (203,204) However, the need for an adapted more efficient measure was evident. (205) The SSCI-8 has therefore been developed and validated, and includes 2-items evaluating internalised stigma, 5-items evaluating enacted stigma, and 1-item evaluating both types of stigma. Each item is scored as 1 (never), 2 (rarely), 3 (sometimes), 4 (often), or 5 (always). The sum of the 8-item scores gives the total stigma score, with a higher score signifying a higher level of stigma. Overall scores range from 8-40. The SSCI-8 has good internal consistency of items ($\alpha=0.89$) and item-total correlation (≥ 0.45). (205)

The Multidimensional Scale of Perceived Social Support (MSPSS)

The MSPSS is a tool comprised of 12-items, with four items per subscale that measures perceptions of support from family, friends, and a significant other (Appendix 5). Responses are measured using a 7-point Likert scale (0= very strongly disagree to 7= very strongly agree); Mean scores are calculated and categorised into low support (1-2.9), moderate support (3-5), and high support (5.1-7). (11) The tool has good internal reliability across subject groups. (12) Several studies globally have used the MSPSS tool to measure social support in PLWH. (13-16)

3.6.1.3 Data management and analysis of quantitative data

All survey datasets from chapters 4 and 5 were downloaded, cleaned, and coded from Qualtrics™ into International Business Machines (IBM™) Statistical Package for Social Sciences (SPSS) (version 27). Questionnaire responses were analysed using simple descriptive statistics (such as frequencies, percentages,

and overall burden scores) to illustrate the experiences and inferential statistics (Chi-square and Mann-Whitney) were used to assess the effect of demographic variables on medicine burden, stigma, disclosure, and social support. Spearman's and Pearson's correlations (size and direction, as positive/negative) were used to examine relationships between variables. To answer the research questions to determine whether there were differences in medicine-related burden, stigma and disclosure between age groups, composite mean scores were compared. Statistical tests used were chi-square and Pearson's correlation. Qualitative data from free-text questions were analysed thematically to identify additional issues self-reported by participants.

Outliers and missing data

For chapters 4 and 5, datasets were examined for missing data. Not all responses were fully complete, with some participants only completing certain parts of the surveys. For example, LMQ and not the MSPSS may have been completed or both measurements were completed but not demographic questions. Responses with incomplete answers for the LMQ were deleted as it was necessary to have comparative data on participants medicine-related burden as measured by this tool. Pairwise deletion of missing data was conducted for analyses of other variables (i.e. the SCCI-8, disclosure, and demographic questions for chapter 4 and the MSPSS social support measure, sharing of HIV status, and demographic questions for chapter 5), where data on the variables of interest were retained. This resulted in varying sample sizes across analysis in this chapter, however, listwise deletion would have reduced the sample size significantly. (17)

3.6.2 Qualitative studies

3.6.2.1 Sampling technique

For chapter 6, a convenience sampling method and snowball sampling was used. These techniques were adopted as whilst significant progress has been made within HIV research, PLWH are still considered a hard-to-reach population in many settings. Several factors influence this such as the stigma and discrimination associated with HIV and a fear of disclosure. The Trust agreed to assist with recruitment by handing out patient information leaflets (Appendix 6) to eligible participants at clinic visits, through support groups, and by displaying posters (Appendix 7) in their waiting area. Recruitment sites are discussed in further detail in section 3.4. Staff were provided with information sheets for study recruitment (Appendix 8). Moreover, a snowballing technique was used where participants could provide study details to their friends who may be interested in taking part in the study, where both parties have mutually shared serostatus'. Specific numbers were not set for the recruitment of participants; instead, recruitment and data collection were continued until data saturation was reached.

Attempts to recruit a more ethnically diverse sample, particularly individuals of Asian ethnicities, proved challenging. Despite targeted outreach efforts, recruitment within this group proved particularly difficult. Informal feedback revealed that some individuals hesitated to participate upon hearing the researcher's name, which signalled an Asian ethnicity. This raised concerns for them around confidentiality and fear of community exposure, given the stigma around HIV within many Asian communities. To mitigate this barrier in future research, alternative recruitment strategies should be considered. For instance, if concerns about confidentiality persist despite clear explanations of ethical guidelines, interviews could be conducted by a non-Asian member of the research team, such as a member of the supervisory team. This approach may encourage broader participation from minority communities, ensuring the inclusion of diverse perspectives.

For chapter 7, a convenience sampling method was utilised. Multidisciplinary meetings were utilised to provide staff with information on the study and for recruitment. The co-investigator working at the trust aided recruitment through emails to other staff members providing information and study contact details for those interested.

Potential interviewees for chapter 6 and 7 were supplied with a Participant Information Sheet to facilitate their decision of participating in the research study (Appendix 6). Written consent was obtained from participants prior to the interview, and they were verbally reminded of participation being voluntary before the interview commenced (Appendix 9).

The inclusion criteria were defined for the two studies (chapter 6 and 7), as shown in Table 3.8.

Table 3.8. Chapter 6 and 7 inclusion criteria.

	Inclusion criteria	Exclusion criteria
Chapter 6	<ul style="list-style-type: none"> Adults, aged 50 years old or over. Using HIV medicines (ART) with or without other non-HIV medicines prescribed for other long-term conditions (duration of ART, at least 6 months). Receiving HIV care in South East England. Able to read, write, or speak English. 	<ul style="list-style-type: none"> Under 50 years of age Too unwell to complete the interview based on self-assessment and/or clinician's decision. Unable to read, write, or speak English Not receiving HIV care in South East England Not using HIV medicines (i.e. ART) long-term (over 6 months).
Chapter 7	<ul style="list-style-type: none"> Healthcare professionals (doctors, pharmacists, nurses, pharmacy technicians, healthcare assistants and support group mentors). Working within HIV clinics in South East England. Able to read, write, or speak English. 	<ul style="list-style-type: none"> Healthcare professionals not working in England. Healthcare professionals not involved in the care of HIV patients.

3.6.3.2 Study design

Semi-structured interviews

Semi-structured interviews were used for data collection in chapters 6 and 7. Interviews are the most commonly used data collection method in qualitative research. (185) In health research, this approach enables exploration of both the healthcare professionals' perspectives and the client's interpretations of provided care with interviews focusing on the past, present, and the essential experience of participants. Lofland et al. (2002),

have suggested a presence of *quid pro quo*, where knowledge is gained by the researcher from the interviewee, and in turn, the interviewee has a listener to voice their feelings and reflections. (207) Many participants have stated that discussions in research interviews are the first time they have disclosed their thoughts on the topic. (185) A semi-structured interview format is commonly used in qualitative research and within the healthcare context, due to flexibility and versatility. (207) Guided by a schedule that reflects the aims and objectives of the study, semi-structured interviews provide a basis of consistency for interview questions whilst still allowing the researcher and interviewee to expand or explore desired topics further. (185) Studies have shown that semi-structured interviews are suitable for obtaining an individual's perceptions, opinions, and complex or emotionally sensitive issues. (207)

Using semi-structured interviews necessitates some prior study in the research topic area, as the interview questions are based on previous knowledge. (207) The interview schedules in chapter 6 and 7 were created for the purpose and method of the studies according to the themes identified in the systematic review. The systematic review (chapter 2) investigated medicine optimisation interventions in older PLWH and revealed several emerging themes among the target population. The themes included: comorbidities, polypharmacy, adverse drug reactions, health-related quality of life, stigma, medicine burden, and treatment burden. Feasibility of the interviews was assessed in the initial interviews with participants and any necessary reformulations of the questions were made to ensure comprehensibility of the questions.

Study instruments

The interview schedules for chapter 6 and 7 (Appendix 10) were designed to ensure that the content was relevant to the target population and addressed the research questions. The themes identified in chapters 2, 4, and 5 were used to develop the interview schedule. For instance, questions were formulated around medicine burden, treatment burden, disclosure, medicine reviews, provider relationship, social support needs and ageing with HIV. The feasibility of conducting the interviews was assessed in the initial interviews with participants and this allowed the researcher to ascertain the comprehensibility of the interview questions and reformulate these where needed.

Potential interviewees were supplied with a Participant Information Sheet to facilitate their decision of participating in the study (Appendix 6). Written consent was obtained from participants prior to the interview (Appendix 9), and they were verbally reminded of participation being voluntary before the interview commenced. All contact information provided by participants were deleted within a week of the interview taking place.

Interviews were conducted in person, via an online video call or a telephone call. Participants were given the choice to choose which option they would prefer. It was important to have these options in place due to the COVID-19 pandemic, in anticipation of any further government restrictions. Video or telephone interviews allowed individuals to participate from the comfort of their own homes and in privacy, upholding anonymity. All interviews were recorded using a Dictaphone and uploaded into a password-protected secure folder on the University's server before being deleted on the device.

3.6.3.3 Researcher's positionality

When embarking on this research, I was aware that my personal, academic, and professional background would shape my approach. My interest in the experiences of older PLWH and their interactions with medicines stemmed from both scholarly and personal motivations.

Being a pharmacist, my academic background provided me with a strong foundation in understanding ageing, chronic illness, and medication use. My training and practice shaped my understanding of medicines as essential tools for managing health conditions, but also as complex interventions influenced by individual, social, and structural factors. Prior to starting this research, I was actively involved in online HIV support communities, providing guidance and assistance to individuals navigating their diagnoses and treatments. This experience gave me early insights into the challenges of living with HIV beyond the clinical perspective, particularly the emotional, psychological, and social dimensions of managing medications. Additionally, my previous involvement in HIV support communities may have shaped my initial assumptions about the challenges PLWH face. I entered this research with an awareness of stigma, healthcare inequalities, and potential barriers to accessing care, which may have led me to anticipate narratives of struggle or systemic neglect. Whilst these issues were undoubtedly present in participant accounts, I remained reflexive and open to the full spectrum of participants' experiences, including those who found empowerment, routine and security in their medications.

To address these potential biases, I actively engaged in reflexivity throughout the research process. Keeping a reflexive journal, discussing my interpretations with supervisors, and critically examining how my professional and personal perspectives influenced my analysis helped me remain attentive to participants' voices rather than imposing my own expectations. By acknowledging my positionality, I aimed to conduct research that was both rigorous and sensitive to the diverse realities of ageing with HIV. Ultimately, acknowledging my positionality has been crucial in producing a nuanced and ethically sound research that respects the diversity of experiences among older PLWH and their engagement with medicines.

3.6.3.4 Data management of qualitative data

For chapters 6 and 7, interviews were digitally recorded using a Dictaphone and uploaded into a password-protected secure folder based on the University's server before being deleted on the device. The data were downloaded, cleaned, and coded by the researcher using NVIVO (release 1.7.1). All data files were stored on password-protected computers and transferred to the University's restricted cloud storage. These will be kept securely for up to 5 years post submission, after which they will all be deleted from the University computers.

Due to time constraints, the interview recordings were transcribed verbatim by an external transcription service (Business Friend™), an approved supplier for the University of Kent and Greenwich and have been used by NHS research studies in the past. This amendment was submitted to and approved by the Hampshire B REC. Business Friend™ assured confidential services, using password protection, and excluding all personal names/identifiable information from transcripts. All Business Friend™ staff sign and adhere to confidentiality, non-disclosure and GDPR agreements.

To ensure confidentiality of data, all transcribed interviews with participant data were pseudonymised for purposes of processing and analysis, with personally identifying information stored separately from the working dataset. When the study was complete and there was no further need to link individuals to the data, the linking key was destroyed, so that the data were fully anonymised. This avoided instances of accidental disclosure.

3.6.3.5 Qualitative data analysis

The qualitative data collected via semi-structured interviews in chapters 6 and 7 were coded and analysed using framework analysis on NVivo (release 1.7.1) according to the themes identified in chapter 2, and initially underpinned by the components of the Health Belief Model (HBM) (Table 3.9). However, as the researcher was coding data, they found that the HBM was not compatible with the interview data.

Table 3.9 Themes identified from the systematic review (chapter 2) and the Health Belief Model (HBM) components used for interview data analysis in chapter 6 and 7.

Themes identified from systematic review	The components of the HBM
Comorbidities	Perceived severity
Polypharmacy	Perceived susceptibility
Adverse drug reactions	Perceived barriers to behaviours
Health-related quality of life	Perceived benefits to behaviours
Stigma	Cues to action
Medicine burden	Self-efficacy
Treatment burden	

Framework analysis involves a seven-stage process of transcription, familiarisation with interviews, coding, developing a working analytical framework, applying the analytical framework, charting data into the framework matrix, and interpreting the data (Figure 3.2). (208-209) Using the Framework Method, themes and codes can be identified using a deductive approach, where they are pre-selected using previous literature, themes or based on the research questions, or using an inductive approach, where they are generated from the data through open coding and then refinement of the themes. (208) For chapters 6 and 7, a mixed approach was adopted, where themes and codes were identified from the systematic review in chapter 2 and an inductive approach was taken where certain codes were created from the data, allowing for space for any discoveries of unexpected aspects of a participant's experiences. When coding the interview data, a line-by-line coding method was chosen, this allowed close attention to be paid to each individual's experiences and prevented the possibility of coding the data according to preconceptions and prejudices. (210) Experiences of participants in the studies were compared to identify any patterns and associations between the themes identified.

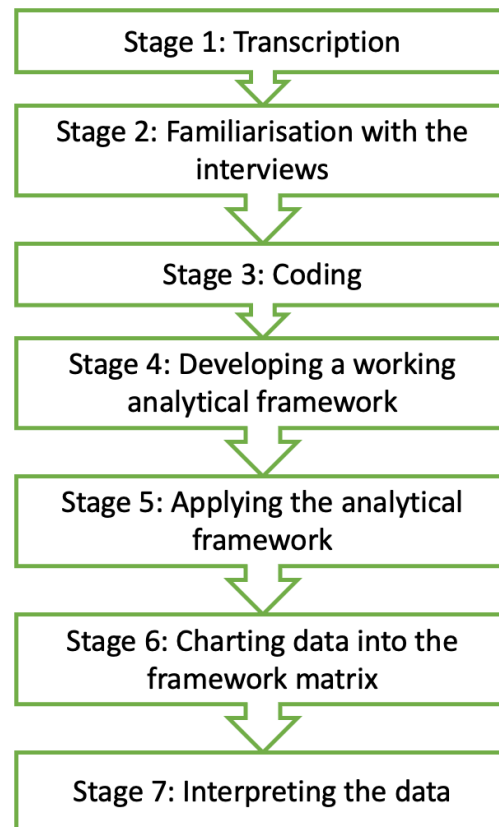


Figure 3.2 Seven-stage Framework analysis process

3.7 Chapter summary

This chapter has described and provided rationale for the mixed methods research undertaken in chapters 4 to 7. This included questionnaires in chapters 4 and 5, and semi-structured interviews in chapters 6 and 7.

A mixed methods approach was adopted to provide a comprehensive understanding of the medicine-related needs of older PLWH, underpinned by a pragmatic framework that facilitated the integration of quantitative and qualitative data. The explanatory sequential design allowed for the identification of statistical patterns through quantitative analysis (chapters 4 and 5), followed by qualitative exploration (chapters 6 and 7) to contextualise and elaborate upon the quantitative findings. Quantitative data analysis employed descriptive and inferential statistics, including chi-square and Pearson's correlation tests, to assess relationships between variables such as medicine burden, stigma, and social support. Initially, qualitative data analysis was framed by the Health Belief Model, however, the model was found to be unsuitable for the emerging data, leading to the adoption of a more inductive framework analysis approach alongside the themes identified in the systematic review (chapter 2). This structured, thematic analysis enabled a nuanced and theoretically grounded interpretation of participant experiences, ensuring that the mixed methods design effectively addressed the research questions.

CHAPTER FOUR

Evaluating medicine-related burden in older people living with HIV

4.1 Introduction

As highlighted in Chapter 2 of this thesis, older PLWH who are 50 years or older face many issues and concerns such as comorbidities, polypharmacy, medicine- and treatment-related burden, adverse drug reactions, stigma, poor health-related quality of life, and a need for social support. Chapter 3 outlined the rationale for the study design used in this chapter.

The increase in the diagnosis of comorbidities, and a subsequent demand for the prescription of further medicines to manage these other conditions, is evident among the ageing HIV population. Following complex medication regimens, large pill sizes, taking multiple medicines, and experiencing adverse events can lead to medicine-related burden (211); Studies have shown that the workload of organising and adhering to multiple regular medicines, can be burdensome for people living with chronic conditions. (212) However, there is a lack of literature on the medicine-related burden experienced by PLWH, particularly those aged 50 years and older.

Moreover, illness-related stigma can adversely affect HIV-related care engagement, ART adherence, HIV status disclosure, mental health, and social support. (213–215) As described in detail in chapter 1, stigma experienced by PLWH, can be classified as enacted, anticipated, and internalised. (2) Studies have shown that PLWH with higher levels of internalised stigma, represented by the beliefs that individuals hold about themselves, had a lower likelihood of sharing their serostatus to any type of social relationship and lower HIV care engagement. (215-216) PLWH may experience personal benefits when sharing their serostatus to others, the extent to which this improves psychosocial management of HIV and adaptive coping is evident in the literature. (215) Therefore, it is important to understand disclosure choices and experiences of PLWH.

The objective of the study outlined in this chapter was therefore to quantify medicine-related burden and explore the stigma and disclosure experiences of PLWH, and to investigate any age-related differences within this population.

Objectives:

This study aimed to analyse secondary data to explore and identify differences in medicine-related burden, stigma and disclosure experienced by PLWH in the UK according to age.

The research questions posed were:

1. To identify differences in medicine-related burden experienced by younger (18-49 years) and older (50+ years) PLWH in the UK.
2. To identify differences of stigma experiences and HIV status sharing decisions by younger (18-49 years) and older (50+ years) PLWH in the UK.

4.2 Summary of Methods

Data used for this secondary analysis were collected through a cross-sectional survey conducted between October 2018 to January 2020. Figure 4.1 displays a summary of the methods that have been presented in further detail in chapter 3.

This survey included the following components, which are discussed in further detail in chapter 3: The Living with Medicines Questionnaire version 3 (LMQ-3), The Stigma Scale for Chronic Illnesses 8-item version (SSCI-8), questions regarding sharing of HIV status.

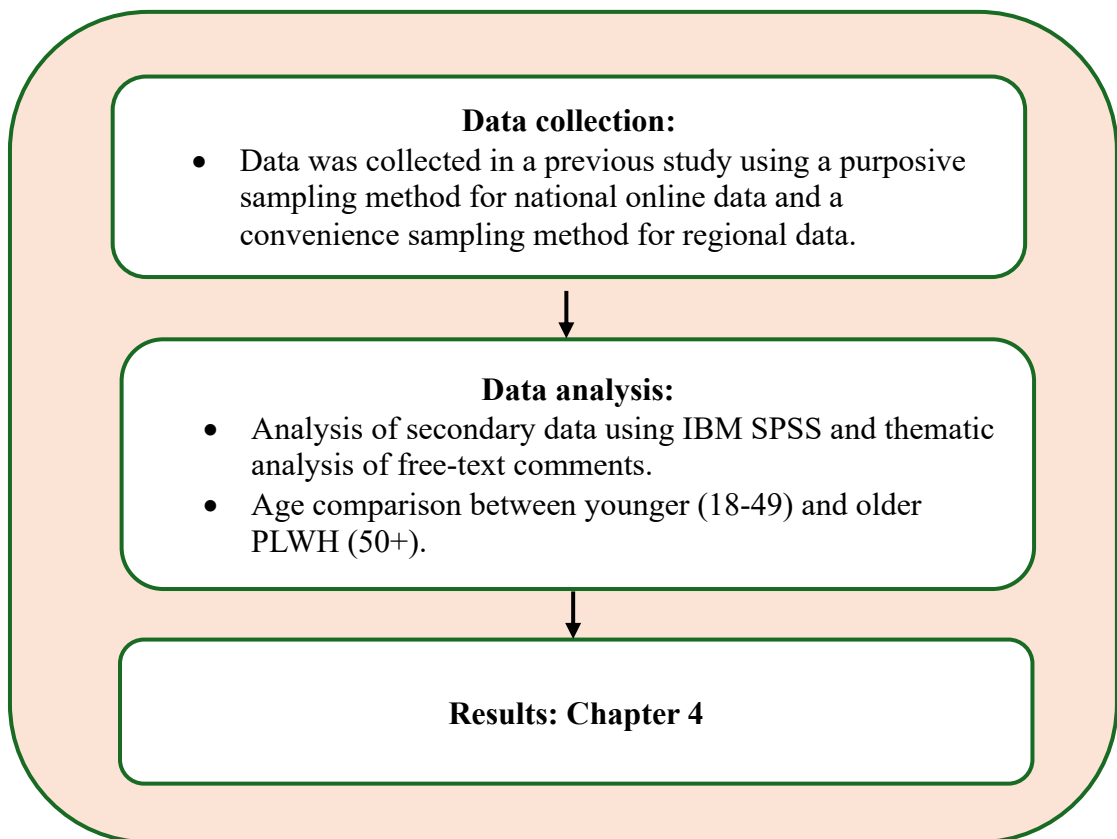


Figure 4.1. Summary of chapter 4 methods.

4.3 Results

4.3.1 Participant characteristics and response rate

Overall, 245 participants engaged with the survey. One hundred and forty-one participants completed the LMQ-3 in full, 140 participants completed the stigma scale in full, and 133 participants completed both in full. One hundred and thirty participants completed all questions related to disclosure of their serostatus (Figure 4.2)

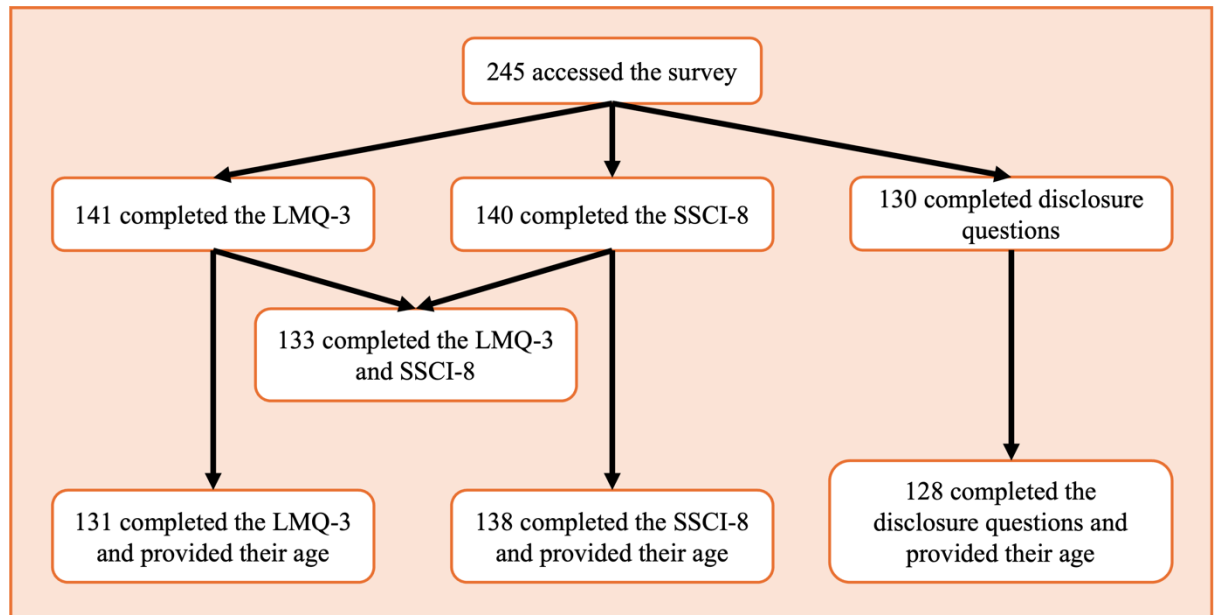


Figure 4.2 Participant response rate for components of the survey.

Among the 141 participants who completed the LMQ-3, 63.8% (n=90) were recruited online through social media, websites, and patient organisations from around the UK and 36.2% (n=51) were a subsample recruited from clinics in South East England. Ten participants out of the 141 who completed the LMQ-3 did not provide their age, therefore these responses were excluded from age comparison analysis. The mean age of participants was 48.0 (SD±11.8) and 49.6% (n=70) were aged 50 years or older. The mean age of the older group was 58.0 (SD±5.9). Most participants in this sample were male (69.5%, n=98) and predominantly of white ethnicity (76.6%, n=108). Half (n=66) of all participants included were educated to university level, and 69.2% (n=90) were in employment. Participants' characteristics are presented in Table 4.1.

Participants were taking a median of 3 (range=1-20) prescription medicines. The number of medicines taken by participants increased with age ($r=0.346$, $p<0.01$). Overall, 24.2% (29/120) participants across all ages and 41.7% (25/60) of those aged 50 years and over were taking five or more medicines ($r=0.409$, $p<0.01$) (Table 4.1).

Table 4.1 Chapter 4 participant characteristics. *All variables are expressed as a number of participants (% total). Between group differences were determined using a Pearson's Chi-square test.*

Characteristic		National online dataset (n=90)	South East England clinic dataset (n=51)	Combined Dataset (n=141)	p-value
		Frequency n (%)			
Gender		n=81	n=51	n=132	0.382
	Male	57 (63.3)	41 (80.4)	98 (74.2)	
	Female	23 (25.6)	9 (17.6)	32 (24.2)	
	Other	1 (1.1)	1 (2.0)	2 (1.5)	
Age		n=81	n=43	n=131	0.603
	18-29	7 (7.8)	3 (5.9)	11 (8.4)	
	30-49	30 (33.3)	23 (45.1)	59 (45.0)	
	50-64	37 (41.1)	11 (21.6)	49 (37.4)	
	65 and over	7 (7.8)	6 (11.8)	12 (9.2)	
Education level		n=81	n=51	n=132	0.140
	School	15 (16.7)	11 (21.6)	26 (19.7)	
	Technical college/Apprenticeship	18 (20.0)	19 (37.3)	37 (28.0)	
	University	46 (51.1)	20 (39.2)	66 (50.0)	
	Other	2 (2.2)	1 (2.0)	3 (2.3)	
Employment status		n=79	n=51	n=130	0.086
	Employed	50 (50.6)	40 (78.4)	90 (69.2)	
	Unemployed	10 (11.1)	4 (7.8)	14 (10.8)	
	Retired	11 (12.2)	5 (9.8)	16 (12.3)	
	Full-time student	2 (2.2)	0	2 (1.5)	
	Other	6 (6.7)	2 (3.9)	8 (6.2)	
Ethnicity		n=80	n=50	n=131	0.175
	White	70 (77.8)	38 (74.5)	108 (82.4)	
	Asian/Asian British	2 (2.2)	1 (2.0)	3 (2.3)	
	Black/African/Caribbean	6 (6.7)	7 (13.7)	13 (9.9)	
	Mixed	2 (2.2)	4 (7.8)	7 (5.3)	
Number of medicines		n=60	n=59	n=120	0.054
	1-4	56 (93.3)	34 (57.6)	91 (75.8)	
	5-9	2 (3.3)	19 (32.2)	21 (17.5)	
	10 or more	2 (3.3)	6 (10.1)	8 (5.7)	
Frequency of use		n=82	n=51	n=133	0.043
	Once per day	57 (63.3)	43 (84.3)	100 (75.2)	
	Twice per day	15 (16.7)	6 (11.8)	21 (15.8)	
	Three times per day	2 (2.2)	1 (2.0)	3 (2.3)	
	More than three times per day	5 (5.6)	1 (2.0)	6 (4.5)	
	Other*	3 (3.3)	0	3 (2.3)	
Formulations used		n=92	n=51	n=140	
	Tablets/capsules	84 (91.3)	51 (100)	132 (94.3)	
	Other**	8 (8.7)	0	8 (5.7)	
Paying for non-ART prescriptions		n=82	n=51	n=133	0.704
	Yes	39 (43.3)	26 (51.0)	65 (48.9)	
	No	43 (47.8)	25 (49.0)	68 (51.1)	
Managing medicines		n=82	n=50	n=132	0.189
	Yes (Requires assistance)	6 (6.7)	1 (2.0)	7 (5.3)	
	No (Autonomous)	76 (84.4)	49 (96.1)	125 (94.7)	
*Different times of the day, week, or month; **Including inhalers, patches, etc.					

4.3.2 Prevalence of medicine-related issues in older PLWH

The national online and South East England regional clinic datasets were pooled together and analysed for significant differences between the two groups (Table 4.1). The only significant difference between responses in both datasets was for the frequency of use of medicines, with 84.3% (n=43) and 63.3% (n=57) of participants in the South East England clinic dataset and the national online dataset, respectively, taking their medicines once a day ($p=0.043$); national respondents were more likely to take their medicines multiple times a day. As no other significant differences were found in both the national online and the regional South East England clinic participant responses, both datasets have been combined and analysed further comparing the younger (18<50 years) and older (≥ 50 years) age groups.

Over half (54.3%, n=38) of younger PLWH had no or minimal medicine burden, 28.6% (n=20) had moderate burden, and 17.1% (n=12) reported high burden (Table 4.2). Similarly, 52.5% (n=32) of older PLWH reported no or minimal burden, 29.5% (n=18) had a moderate degree of burden, and 18% (n=11) had a high medicine burden.

Table 4.2 Comparison of the LMQ-3 medicine-related burden scores between older and younger PLWH. *All variables are expressed as a number of participants (% total). Between group differences were determined using a Pearson's Chi-square test.*

Total LMQ-3 score	PLWH < 50 (n=70) n (%)	PLWH ≥ 50 (n=61) n (%)	P-value
No or minimal burden	38 (54.3)	32 (52.5)	0.834
Moderate degree of burden	20 (28.6)	18 (29.5)	0.906
High burden	12 (17.1)	11 (18.0)	0.894

Comparing the LMQ-3 results to the self-reported VAS (Table 4.3) also showed a high proportion of participants reporting low medicine burden, with 64.3% (n=45) and 78.7% (n=48) of the younger and older groups reporting no or minimal medicine burden, respectively. However, those reporting high burden on the VAS remained approximately one in every six participants with 20% (n=14) of younger PLWH and 16.4% (n=10) of older PLWH self-reporting within this category.

Table 4.3 Self-reported medicine burden levels using the VAS in older and younger PLWH. *All variables are expressed as a number of participants (% total).*

Self-reported medicine burden	PLWH < 50 (n=70)	PLWH ≥ 50 (n=61)
No or minimal medicine burden n (%)	45 (64.3)	48 (78.7)
Moderate medicine burden n (%)	11 (15.7)	3 (4.9)
High medicine burden n (%)	14 (20)	10 (16.4)

Domain-level analysis of the LMQ-3 data across the age groups was conducted (Table 4.4) (Figure 4.3). However, there were no statistically significant differences for each domain between the age groups.

Table 4.4 Domain-level analysis of the LMQ-3 between PLWH<50 years and PLWH≥ 50 years. *All variables are expressed as median score (range). Between group differences were determined using a Pearson's Chi-square test.*

LMQ-3 domain statements	PLWH < 50 (n=70)	PLWH ≥ 50 (n=61)	p-value
	Median score (range)		
Relationships/Communication with healthcare professionals	9.0 (5-24)	9.0 (5-23)	0.112
Practical difficulties	12.5 (8-23)	13.0 (10-22)	0.285
Cost-related burden	5.0 (3-14)	5.0 (3-15)	0.555
Side effect burden	8.0 (4-20)	9.5 (4-20)	0.294
Lack of effectiveness	10.0 (6-20)	9.0 (6-20)	0.353
Attitudes/Concerns about medicine use	19.5 (11-33)	17.0 (8-35)	0.177
Impact/Interference to day-to-day life	12.0 (6-26)	12.0 (6-28)	0.314
Autonomy/control over prescribed regimen	12.0 (5-15)	12.0 (4-15)	0.266

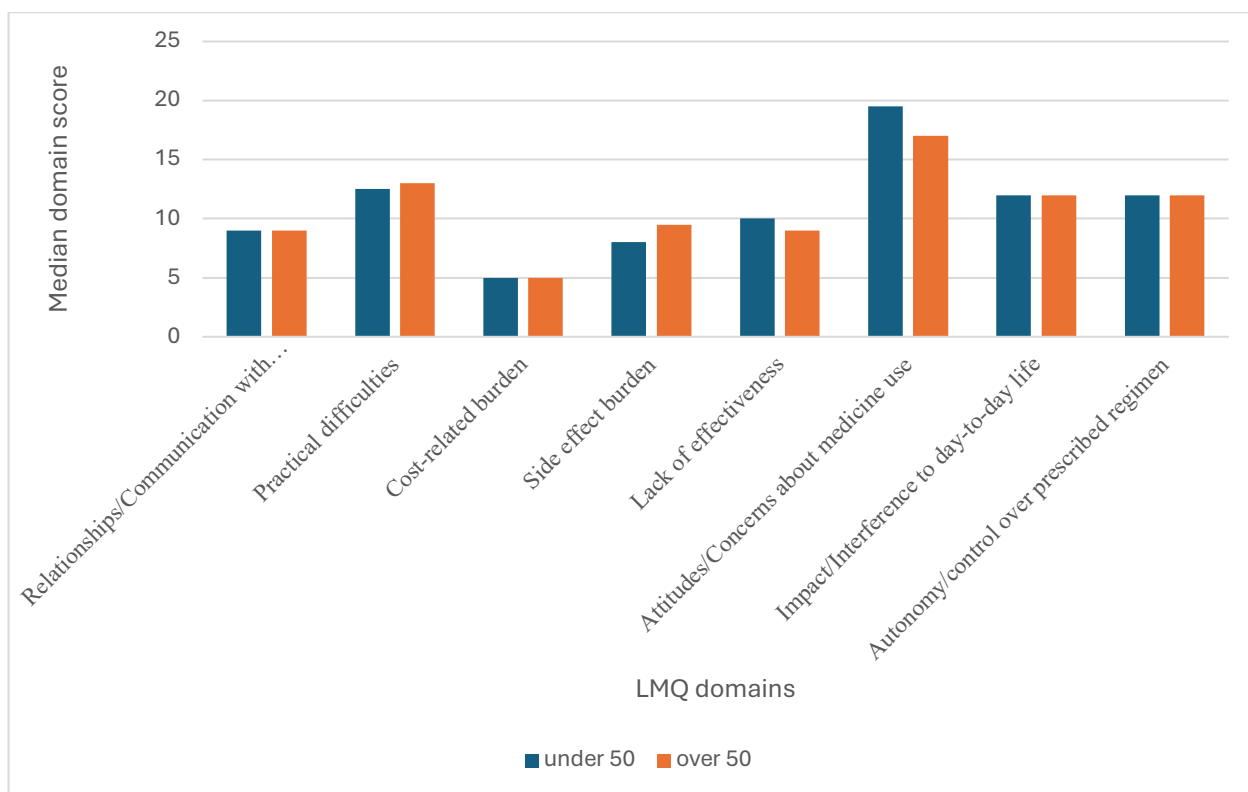


Figure 4.3 Domain level analysis of the LMQ-3 between older and younger PLWH.

To further analyse the data, item-level analysis of the LMQ-3 was conducted for each dataset (Table 4.5). There were a few significant differences between the age groups, which will be outlined below with sample quotes from the free-text comments relating to each domain to illustrate the findings.

Table 4.5 Item-level analysis of the LMQ-3 between PLWH<50 years and PLWH≥ 50 years; p-values ≤0.05 are statistically significant. *All variables are expressed as a number of participants (% total). Between group differences were determined using a Pearson's Chi-square test.*

LMQ-3 domain statements	PLWH < 50 (n=70)			PLWH ≥ 50 (n=61)			p-value
	Strongly Agree/Agree n(%)	Neutral opinion n(%)	Strongly Disagree/Disagree n(%)	Strongly Agree/Agree n(%)	Neutral opinion n(%)	Strongly Disagree/Disagree n(%)	
Relationships/Communication with healthcare professionals							
I trust the judgement of my doctor(s) in choosing medicines for me	62 (88.6)	6 (8.6)	2 (2.9)	52 (85.2)	7 (11.5)	2 (3.3)	0.671
My doctor(s) listen to my opinions about my medicines	51 (72.9)	12 (17.1)	7 (10.0)	52 (85.2)	6 (9.8)	3 (4.9)	0.302
My doctor(s) take my concerns about side effects seriously	53 (75.7)	11 (15.7)	6 (8.6)	48 (78.7)	10 (16.4)	3 (4.9)	0.502
I get enough information about my medicines from my doctor(s)	59 (84.3)	6 (8.6)	5 (7.1)	49 (80.3)	5 (8.2)	7 (11.5)	0.936
The health professionals providing my care know enough about me and my medicines	58 (82.9)	9 (12.9)	3 (4.3)	49 (80.3)	4 (6.6)	8 (13.1)	0.300
Practical difficulties							
I find getting prescriptions from the doctor difficult	5 (7.1)	4 (5.7)	61 (87.1)	6 (9.8)	5 (8.2)	50 (82.0)	0.118
I find getting medicines from the pharmacist difficult	4 (5.7)	5 (7.1)	61 (87.1)	5 (8.2)	6 (9.8)	50 (82.0)	0.086

I am comfortable with the times I should take my medicines	63 (90.0)	4 (5.7)	3 (4.3)	54 (88.5)	3 (4.9)	4 (6.6)	0.885
I am concerned that I may forget to take my medicines	24 (34.3)	12 (17.1)	34 (48.6)	17 (27.9)	10 (16.4)	34 (55.7)	0.610
It is easy to keep my medicines routine	58 (82.9)	3 (4.3)	9 (12.9)	54 (88.5)	2 (3.3)	5 (8.2)	0.815
I find using my medicines difficult	6 (8.6)	6 (8.6)	58 (82.9)	2 (3.3)	6 (9.8)	53 (86.9)	0.372
I have to put a lot of planning and thought into taking medicines	12 (17.1)	9 (12.9)	49 (70.0)	17 (27.9)	10 (16.4)	34 (55.7)	0.209
Cost-related burden							
I worry about paying for my medicines	12 (17.1)	13 (18.6)	45 (64.3)	13 (21.3)	13 (21.3)	35 (57.4)	0.874
I sometimes have to choose between buying basic essentials or medicines	5 (7.1)	1 (1.4)	64 (91.4)	4 (6.6)	4 (6.6)	53 (86.9)	0.358
I have to pay more than I can afford for my medicines	3 (4.3)	5 (7.1)	62 (88.6)	5 (8.2)	11 (18.0)	45 (73.8)	0.165
Side effect burden							
The side effects I get are sometimes worse than the problem for which I take medicines	12 (17.1)	8 (11.4)	50 (71.4)	11 (18.0)	9 (14.8)	41 (67.2)	0.762
The side effects I get from my medicines interfere with my day-to-day life (e.g. work, housework, sleep)	15 (21.4)	4 (5.7)	51 (72.9)	16 (26.2)	12 (19.7)	33 (54.1)	0.031
The side effects I get from my medicines are bothersome	16 (22.9)	9 (12.9)	45 (64.3)	14 (23.0)	20 (32.8)	27 (44.3)	0.046

The side effects I get from my medicines adversely affect my well-being	15 (21.4)	6 (8.6)	49 (70.0)	15 (24.6)	11 (18.0)	35 (57.4)	0.201
Lack of effectiveness							
I am satisfied with the effectiveness of my medicines	62 (88.6)	5 (7.1)	3 (4.3)	52 (85.2)	5 (8.2)	4 (6.6)	0.717
My medicines prevent my condition getting worse	70 (100.0)	0	0	57 (93.4)	2 (3.3)	2 (3.3)	0.112
My medicines live up to my expectations	63 (90.0)	6 (8.6)	1 (1.4)	53 (86.9)	6 (9.8)	2 (3.3)	0.860
My medicines allow me to live my life as I want to	61 (87.1)	5 (7.1)	4 (5.7)	52 (85.2)	4 (6.6)	5 (8.2)	0.776
My medicines are working	66 (94.3)	2 (2.9)	2 (2.9)	58 (95.1)	1 (1.6)	2 (3.3)	0.241
The side effects are worth it for the benefits I get from my medicines	40 (57.1)	25 (35.7)	5 (7.1)	44 (72.1)	14 (23.0)	3 (4.9)	0.190
Attitudes/Concerns about medicine use							
I worry that I have to take several medicines at the same time	16 (22.9)	9 (12.9)	45 (64.3)	8 (13.1)	10 (16.4)	43 (70.5)	0.587
I would like more say in the brands of medicines I use	16 (22.9)	31 (44.3)	23 (32.9)	17 (27.9)	19 (31.1)	25 (41.0)	0.556
I feel I need more information about my medicines	17 (24.3)	21 (30.0)	32 (45.7)	6 (9.8)	20 (32.8)	35 (57.4)	0.211
I am concerned about possible damaging long-term effects of taking medicines	48 (68.6)	12 (17.1)	10 (14.3)	34 (55.7)	11 (18.0)	16 (26.2)	0.213
I am concerned that I am too reliant on my medicines	21 (30.0)	9 (12.9)	40 (57.1)	10 (16.4)	14 (23.0)	37 (60.7)	0.056
I worry that my medicines may interact with each other	29 (41.4)	12 (17.1)	29 (41.4)	26 (42.6)	12 (19.7)	23 (37.7)	0.986
I am concerned that my medicines interact with alcohol	14 (20.0)	15 (21.4)	41 (58.6)	8 (13.1)	14 (23.0)	39 (63.9)	0.830

Impact/Interference to day-to-day life							
My medicines interfere with my social or leisure activities	12 (17.1)	4 (5.7)	54 (77.1)	7 (11.5)	8 (13.1)	46 (75.4)	0.394
My medicines interfere with my sexual life	22 (31.4)	8 (11.4)	40 (57.1)	16 (26.2)	9 (14.8)	36 (59.0)	0.770
Taking medicines affects my driving	2 (2.9)	14 (20.0)	54 (77.1)	1 (1.6)	13 (21.3)	47 (77.0)	0.103
My medicines interfere with my social relationships	17 (24.3)	11 (15.7)	42 (60.0)	10 (16.4)	9 (14.8)	42 (68.9)	0.486
Taking medicines causes me problems with daily tasks (such as work, housework, hobbies)	10 (14.3)	8 (11.4)	52 (74.3)	9 (14.8)	3 (4.9)	49 (80.3)	0.514
My life revolves around using my medicines	18 (25.7)	8 (11.4)	44 (62.9)	17 (27.9)	12 (19.7)	32 (52.5)	0.204
Autonomy/control over prescribed regimen							
I can vary the dose of the medicines I take	2 (2.9)	6 (8.6)	62 (88.6)	7 (11.5)	7 (11.5)	47 (77.0)	0.316
I can choose whether or not to take my medicines	15 (21.4)	7 (10.0)	48 (68.6)	13 (21.3)	6 (9.8)	42 (68.9)	0.975
I can vary the times I take my medicines	22 (31.4)	10 (14.3)	38 (54.3)	21 (34.4)	5 (8.2)	35 (57.4)	0.916

4.3.2.1 Communication with healthcare professionals about medicines

A majority of participants from both the older and younger datasets reported positively regarding relationships and communication with healthcare professionals about their medicines. For instance, 72.9% (n=51) and 85.2% (n=52) of younger and older participants respectively, felt that their doctor(s) listen to their opinions about their medicines. Similarly, 82.9% (n=58) and 80.3% (n=49) of younger and older participants respectively, thought that the healthcare professionals providing their care know enough about them and their medicines. However, a participant in the younger group expressed concerns within the free-text comments regarding communications with their healthcare professionals about medicines.

'My medication brand changed recently which caused me some concern. I hadn't been informed about it so when the medication arrived, I didn't recognise the packaging or the ingredients in the tablets. It did mean I wasn't 100% sure I should take them and spent over an hour trying to clarify'.

Male, age 47

Moreover, a participant in the older group argues that PLWH are highly engaged in their own care and use sources other than their healthcare professionals to seek information on their medicines.

'People with HIV are often highly engaged in their healthcare and many people use resources such as aidsmap for information about their treatment'.

Male, age 52

4.3.2.2 Practical difficulties

Overall, in the domain-level analysis of the LMQ-3, older participants had a marginally higher burden score (13.0) compared to the younger participants (12.5), however this was not statistically significant ($p=0.285$). In the item-level analysis, some participants reported concerns that they may forget to take their medicines. For instance, 34.3% (n=24) and 27.9% (n=17) of younger and older participants, respectively, agreed or strongly agreed to this statement compared to 48.6% (n=34) and 55.7% (n=34) disagreeing or strongly disagreeing respectively.

One participant in the older group stated difficulties remembering to take their medicines despite using adherence aids and another participant described difficulties working nightshifts and taking their medicines.

'I am happy to take this life saving medication. As I live my life sometimes the days are so normal, I forget to take my medication even with my alarm and dosette box'.

Female, age 57

'I do have some difficulty in juggling my meds with working nights and it does cause some issues in taking them or missing sometimes...'

Male, age 54

4.3.2.3 Cost-related burden

Most participants from both the younger and older groups stated that they did not have any concerns about paying for their medicines (64.3% vs 57.4%), choosing between buying essentials and medicines (91.4% vs 86.9%), or having to pay more than they can afford for their medicines (88.6% vs 73.8%). Moreover, there were no differences between the overall median LMQ-3 domain score for cost-related burden for both younger and older PLWH. Due to their geographical area within the United Kingdom, having comorbidities that exempt them from charges, or their age, 45.7% (n=32) and 59.0% (n=36) of participants in the younger and older group, respectively, have reported that they receive free prescriptions.

4.3.2.4 Side effect burden

Significantly more younger PLWH (72.9%, n=51) disagreed/strongly disagreed that the side effects from their medicines interfere with their day-to-day life, compared to older PLWH (54.1%, n=33) (p=0.031). Similarly, more younger PLWH (64.3%, n=45) than older PLWH (44.3%, n=27) reported that they did not find side effects from their medicines bothersome (p=0.046). Fourteen participants reported experiencing side effects with ART in the free-text comments, with four experiencing nausea, three having fatigue, two experiencing diarrhoea, two with loss of appetite, and two having erectile dysfunction among other side effects. Older participants expressed difficulties surrounding comorbidities and interactions between the medicines for each condition.

'My medicine sometimes causes nausea and diarrhoea as a side effect, but it is not a constant side effect, other side effects for me personally are restless sleep and suppressed appetite'.

Female, age 30

'It's hard when you HIV and have diabetes as well when both drugs fight against each other'

Female, age 52

4.3.2.5 Perceived effectiveness

A higher number of older PLWH (72.1%, n=44) reported that the side effects from their medicines were worth it compared to younger PLWH (57.1%, n=40), although the difference was not statistically significant ($p=0.190$). Both age groups agreed or strongly agreed that they were satisfied with the effectiveness of their medicines (88.6%, n=62, and 85.2%, n=52, of younger and older PLWH, respectively). A hundred percent (n=70) of all younger participants agreed that their medicines prevent their condition from getting worse, whereas 94.4% (n=57) of older participants agreed to the same statement. The free-text quotes highlighted the perceived effectiveness of ART among both age groups.

‘Medicines appear to be working as described and I am happy with my progress to date’.

Male, age 49

‘There is no choice as I have HIV. No one wants to take medicines for life. But if I did not, I would be long dead so I'm lucky effective treatment for HIV exists’.

Female, age 65

4.3.2.6 Medicine use concerns and attitudes

A higher proportion of younger PLWH (30%, n=21) were concerned that they are too reliant on their medicines than older PLWH (16.4%, n=10) ($p=0.056$). Over double the proportion of younger PLWH (24.3%, n=17) felt they needed more information about their medicines compared to older PLWH (9.8%, n=6), however this difference was not significant ($p=0.211$). Although participants generally responded positively to attitudes and concerns surrounding their medicines, the free-text comments highlight that some individuals did have concerns.

‘...I worry that my meds will interact with my antidepressants so much that I avoid taking my antidepressant despite being told many times by professionals that I'm ok to take my antidepressants with my meds’.

Female, age 30

‘I am concerned about taking so many different meds and the interactions and long-term implications...’

Male, age 66

4.3.2.7 Interference to daily life

Overall, participants from both groups responded positively to all items relating to the impact of their medicines on their day-to-day life. However, free-text comments illustrated that side effects from medicines could interfere with sexual relationships and social plans. An older male explained how his life was not affected by his medicines, apart from having to collect them from the pharmacy.

'Side effects have caused me problems that continue today, even though I have changed from the meds that gave me problems...old HIV drugs left me with lipodystrophy and peripheral neuropathy. I take meds for the pain, but these cause erectile dysfunction, which affects my sex life...'

Male, age 66

'The need for food with my ART means I must always have an evening meal (my chosen time of day to take it), This is sometimes annoying when, say, going to a concert'

Female, age 59

'My life isn't affected in any way apart from having to collect the medicines from the pharmacy! My medicines keep me healthy and alive!'

Male, age 52

4.3.2.8 Autonomy/control over prescribed regimen

The majority of participants from both younger and older groups disagreed/strongly disagreed that they can vary the dose of the medicines they take (88.6% vs 77.0%, respectively), choose whether or not to take their medicines (68.6% vs 68.9%, respectively), and vary the times they take their medicines (54.3% vs 57.4%, respectively).

Free-text quotes showed that PLWH view their medicines as essential to staying alive.

'Take my medicines or die.... no contest!'

Male, age 54

4.3.3 The Stigma Scale for Chronic Illnesses

One hundred and forty participants completed the Stigma Scale for Chronic Illnesses 8-item version (SSCI-8), however, only 138 stated their age and thus were included within age analysis. A significant difference between stigma scores across the age groups was not evident (Table 4.6). The median stigma score for the full dataset was 16 (range=8-39). Although the median stigma score reported was higher in younger PLWH (Median=17, range=8-32) than older PLWH (Median=14.5, range=8-35), the highest score was reported by a participant aged 57 years old taking 6 medicines and experiencing side effects from their ART. The presence and effect of stigma is evident within the free text comments, with participants describing experiences of stigma.

‘Stigma around my condition and taking the medication I do is something I am very aware of’.

Male, age 47

‘Some medicines are arguably difficult to take in front of people as this may lead to being stigmatised. Also lack of clear understanding makes it hard at times for people to accept you’.

Male, age 49

‘It’s not the medicines that affect me, but the attitude of people towards me when they find out what my meds are for’.

Male, age 63

‘I don’t like the size of some of them as it makes it difficult to be discreet when taking them in public’

Female, age 58

Table 4.6 Stigma scores in older and younger PLWH using the Stigma Scale for Chronic Illnesses Questionnaire-8 (SSCI-8). *All variables are expressed as a number of participants (% total). Between group differences were determined using a Pearson's Chi-square test.*

SSCI statements	PLWH < 50 (n=73)					PLWH ≥ 50 (n=65)					p-value
	Never n(%)	Rarely n(%)	Sometimes n(%)	Often n(%)	Always n(%)	Never n(%)	Rarely n(%)	Sometimes n(%)	Often n(%)	Always n(%)	
Because of my illness, some people avoided me	20 (28.6)	19 (27.1)	24 (34.3)	6 (8.6)	1 (1.4)	23 (37.7)	13 (21.3)	18 (29.5)	5 (8.2)	2 (3.3)	0.551
Because of my illness, I felt left out of things	24 (34.3)	24 (34.3)	13 (18.6)	9 (12.9)	0	24 (39.3)	10 (16.4)	16 (26.2)	10 (16.4)	1 (1.6)	0.099
Because of my illness, people avoided looking at me	40 (57.1)	17 (24.3)	11 (15.7)	1 (1.4)	0	39 (63.9)	8 (13.1)	9 (14.8)	4 (6.6)	1 (1.6)	0.181
I felt embarrassed about my illness	8 (11.4)	14 (20.0)	22 (31.4)	11 (15.7)	14 (20.0)	15 (24.6)	15 (24.6)	14 (23.0)	10 (16.4)	7 (11.5)	0.121
Because of my illness, some people seemed uncomfortable with me	14 (20.0)	10 (28.6)	24 (34.3)	9 (12.9)	2 (2.9)	19 (31.1)	17 (27.9)	17 (27.9)	5 (8.2)	3 (4.9)	0.687
I felt embarrassed because of my physical limitations	35 (50.0)	15 (21.4)	7 (10.0)	10 (14.3)	2 (2.9)	39 (63.9)	7 (11.5)	8 (13.1)	7 (11.5)	0	0.262
Because of my illness, people were unkind to me	24 (34.3)	30 (38.5)	16 (22.9)	4 (5.7)	4 (5.7)	29 (47.5)	19 (31.1)	6 (9.8)	5 (8.2)	2 (3.3)	0.254
Some people acted as though it was my fault I have this illness	17 (24.3)	9 (12.9)	25 (35.7)	13 (18.6)	4 (5.7)	26 (42.6)	9 (14.8)	15 (24.6)	6 (9.8)	4 (6.6)	0.151

4.3.4 Medicine-related burden and stigma

One hundred and thirty-one participants answered both the LMQ-3 and the SSCI-8 in full, but only 129 participants reported their age. Amongst these participants, it was evident that higher medicine burden was associated with higher stigma ($r=0.643$, $p<0.01$) (Figure 4.4).

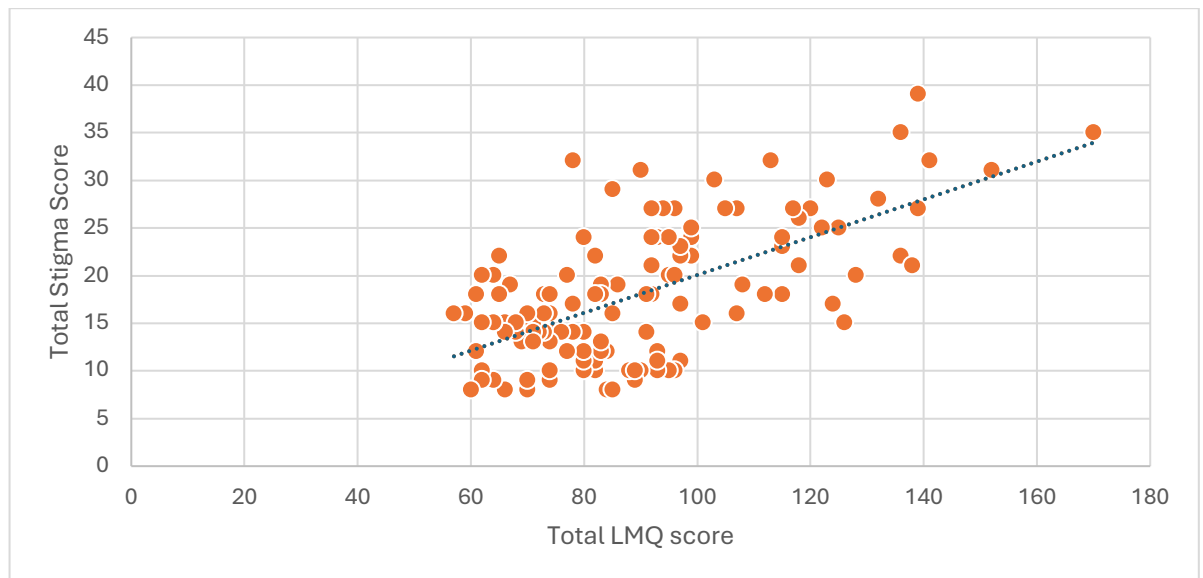


Figure 4.4 The correlation between total LMQ-3 scores and total stigma scores ($r=0.643$, $p<0.01$).

4.3.5 Disclosure

One hundred and thirty participants completed the questions on disclosure, however, only 128 also stated their age and were included in the analysis (Table 4.7). Participants were asked how comfortable they felt to share their HIV diagnosis with their social networks. A higher number of older PLWH (93.5%, $n=58$) had shared their HIV status with someone compared to younger PLWH (87.1%, $n=61$), however, the difference between the groups was not significant ($p=0.218$).

It was found that 41.4% ($n=29$) and 46.8% ($n=29$) of younger and older participants, respectively, felt very comfortable sharing their HIV status with close family. In addition, 41.4% ($n=29$) of younger PLWH reported feeling very comfortable disclosing their status to close friends, whilst fewer older PLWH (37.1%, $n=23$) felt the same ($p=0.053$). Both groups felt very uncomfortable sharing their HIV status with their wider circle or work/school colleagues. Older PLWH were more comfortable sharing their status with other healthcare professionals than younger PLWH ($p=0.155$), with 54.8% ($n=34$) and 40% ($n=28$), respectively, stating that they are very comfortable with this statement.

Table 4.7 Disclosure responses among younger and older PLWH. *All variables are expressed as a number of participants (% total). Between group differences were determined using a Pearson's Chi-square test.*

	PLWH < 50 (n=67)					PLWH ≥ 50 (n=61)					p-value
	Very comfortable n(%)	Comfortable n(%)	Neutral n(%)	Uncomfortable n(%)	Very uncomfortable n(%)	Very comfortable n(%)	Comfortable n(%)	Neutral n(%)	Uncomfortable n(%)	Very uncomfortable n(%)	
Close family	29 (41.4)	7 (10.0)	7 (10.0)	11 (15.7)	16 (22.9)	29 (46.8)	7 (11.3)	3 (4.8)	10 (16.1)	13 (21.0)	0.860
Close friends	29 (41.4)	3 (4.3)	8 (11.4)	18 (25.7)	12 (17.1)	23 (37.1)	11 (17.7)	5 (8.1)	7 (11.3)	16 (25.8)	0.053
Wider social circle	13 (18.6)	6 (8.6)	8 (11.4)	15 (21.4)	27 (38.6)	16 (25.8)	4 (6.5)	9 (14.5)	11 (17.7)	22 (35.5)	0.843
Work/School colleagues	10 (14.3)	4 (5.7)	10 (14.3)	11 (15.7)	34 (48.6)	15 (24.2)	7 (11.3)	8 (12.9)	8 (12.9)	24 (38.7)	0.437
Other healthcare professionals	28 (40.0)	13 (18.6)	7 (10.0)	16 (22.9)	5 (7.1)	34 (54.8)	10 (16.1)	8 (12.9)	6 (9.7)	4 (6.5)	0.155

4.4 Discussion

Using secondary data obtained from an earlier study, this chapter analysed the medicine-related experiences, stigma, and disclosure among PLWH, particularly focusing on evaluating age differences between the variables. The number of medicines taken by PLWH increased with age; Polypharmacy, defined as the use of five or more medicines, was identified in 41.7% of PLWH aged 50 years or older. These findings are supported by recent literature. (217-218)

A majority of PLWH (54.3% younger PLWH and 52.5% older PLWH) reported no or minimal burden, despite older PLWH using more medicines compared to younger PLWH. This contrasts with a study conducted in the general population reporting that medicine burden increases as the number of medicines taken by an individual increases. (211) The self-reported VAS showed similar results between the two age groups, with most participants reporting no or minimal medicine-related burden (54.3% and 52.5% in younger and older groups, respectively). This may be due to PLWH viewing their medicines as imperative to staying alive instead of as a burden, as noted by one participant stating, “take my medicines or die...no contest!”. This suggests that some PLWH feel as though they cannot complain about their medicine-related experiences as they believe they have no choice but to adhere to their treatment. This has been shown in literature as the belief of the necessity of medicines for maintaining health. (219) Some participants expressed gratitude for ARVs, as shown with two older female participants stating, “I am happy to take this life saving medication” and “I’m lucky effective treatment for HIV exists”. Similar to the findings in this study, a low medicine-related burden in older age groups has also been seen in a study using the LMQ-3 on the general population living with chronic diseases. (211) Krska et al., suggested that this may be due to older individuals being on their medicines for a longer period of time, having established routines to manage their medicines, and some individuals not having work disruptions from side effects due to being retired. (211) This may be true for the lower medicine-related burden scores reported in older PLWH, however, as data on time since diagnosis was not collected from participants, this assumption cannot be proven from the findings of this study. Findings also showed that both age categories of PLWH were satisfied with the effectiveness of their medicines, but younger PLWH felt they are too reliant on their medicines than older PLWH ($p=0.056$). Again, it is possible that these findings are due to older PLWH having adjusted to taking their ART over time.

Participants from both age groups responded positively regarding communications with healthcare professionals about their medicines. Although nearly two and a half times the number of younger PLWH felt that they needed more information on their medicines than older PLWH. This could be because the older PLWH in this study have been diagnosed for longer and have had more time to live with and learn about the medicines compared to younger PLWH. However, as this data was not collected, the assumption cannot be proven. A study conducted by Slomka et al., has shown that older PLWH who are long-term survivors have learned to live with HIV and chronic illness compared to younger or newly diagnosed PLWH. (220) This study highlighted three major themes of disease coping that was evident in older PLWH, firstly, the ability to deal with the challenges of taking medicines for HIV; Secondly, effective professional-patient communication allowing the development of a therapeutic relationship, and thirdly, taking charge of their own health. (220) Furthermore, younger PLWH being more uncomfortable to share their HIV status with healthcare professionals than older PLWH could also restrict their ability to seek help, although the difference between the age groups was not significant ($p=0.155$). An older male living with HIV emphasised that PLWH are usually very engaged

in their healthcare and use various sources for information about their medicines, such as websites that provide accurate and accessible information on HIV, such as Aidsmap and the Liverpool HIV drug interactions checker. This is supported by literature, reporting PLWH as being the 'expert patient'. (221-222) However, a free-text comment highlighted the difficulties of a lack of communication between patients and healthcare professionals, particularly when a medicine is changed without informing a patient, as some individuals rely on the colour, size, or shape of the pill to determine which of their medicines it is and what it is for.

A participant in the older group described complications when medicines to treat other comorbidities interacted with their HIV medicines. A study by Greene, et al., 2014, found that older PLWH are at an increased risk of polypharmacy and medication-related problems, with over half of participants (n=46, 52%) having at least one potentially inappropriate medicine prescribed. (223) This highlights the importance of reducing potential drug-drug interactions to improve older PLWH's medicine experiences. Moreover, A thirty-year-old female explained in the free-text section that she had stopped taking her antidepressants due to concerns that it would interact with her ART, despite healthcare professionals telling her otherwise. This suggests that the fear of disrupting ART can cause non-adherence of medication to treat comorbidities, which could result in poorer health outcomes.

Although the majority of participants did not have concerns remembering to take their medicines, 34.3% (n=24) and 27.9% (n=17) of younger and older PLWH, respectively, reported being worried that they may forget. Studies in the general public have shown that the belief that failing to take one's treatment would lead to adverse consequences for oneself, is associated with higher adherence (219), and with ART requiring high adherence rates for treatment success, the high percentage of PLWH not having concerns remembering to take their medicines in this study can be understood. Participants in the older group mentioned difficulties taking their medicines around working night shifts and forgetting to take their medicine due to feelings of living a 'normal' life and thus forgetting the need to take ARVs, despite using adherence aids such as Dossett boxes and alarms.

Whilst most participants did not report any cost-related burden, small groups of both age categories (17.1% and 21.3% of younger and older participants, respectively) had concerns regarding paying for their prescriptions. The free-text comments provide an insight into the low cost-related burden found, with participants in the older group explaining that they do not need to pay due to either their geographical location (living in Scotland or Wales where prescriptions are free) or because they have a comorbidity that renders them exempt from prescription charges.

Overall, a minority of PLWH (17.1% and 18%, respectively) across both age categories experienced high medicine burden. Despite both age categories having similar overall LMQ-3 domain scores, with no significant differences, item-level analysis demonstrated a difference of medicine-related experience with side effects between the two age groups. It was found that significantly more younger PLWH reported that they did not find the side effects from their medicines bothersome nor did it interfere with their daily lives compared to older PLWH (p=0.046 and p=0.031, respectively). The highest domain score with the LMQ-3 was for attitudes/concerns about medicine use, however, there were no statistically significant difference between the age groups.

Over 20% of both groups found the side effects from their medicines bothersome, reporting interferences with their daily lives. Free-text comments left by participants in both groups highlighted these side effects, such as nausea, diarrhoea, restless sleep, and suppressed appetite. Side effects can be the most significant challenge of living with medicines, which can impact one's quality of life negatively. (165) Studies conducted on older PLWH have shown that experiencing side effects can increase stigma, lower quality of life and affect mental health. (104,153) However, the findings show that older PLWH were more accepting of the impact of taking medicines on their day-to-day lives even though they had a higher pill burden; this has also been shown in the general public, with older individuals reporting high satisfaction with healthcare and positive experiences. (224) This reiterates the need to target this group of individuals who require more support with their medicines and additional work is required to determine the reasons why older PLWH perceive lower medicine burden.

Moreover, the findings of this study showed that a higher medicine-related burden score was associated with higher stigma in PLWH ($r=0.643$, $p<0.01$). Free-text quotes from both younger and older PLWH portrayed their experiences of stigma and daily difficulties of using medicines. For example, one participant described feeling the need to be 'discreet when taking them in public'.

Although not significant, it was found that more younger PLWH felt very comfortable sharing their status to close friends compared to older PLWH, suggesting that older PLWH receive less social support, and in contrast, older PLWH reported being very comfortable sharing their status with other healthcare professionals, suggesting that older PLWH may receive more support from healthcare professionals. Additional research would need to be conducted to determine whether a lack of social support in older PLWH due to fear of being stigmatised when sharing one's serostatus leads to higher medicine-related burden.

Implications for research and practice

Although the questionnaire found minimal differences between the age groups relating to medicine burden, free-text comments highlight the issues and concerns some older PLWH are facing. Further research is needed to understand the support needs of the minority of participants who are experiencing high medicine burden and stigma (chapter 5). Moreover, using qualitative methods (chapter 6) would reveal a better understanding of older PLWH's experiences living with HIV, comorbidities, medicines, and enable identification of those who need to be targeted for further support. Future practice could identify PLWH who have 'high burden' and need targeted medicine support.

Study strengths and limitations

Secondary data was used in this study to address new research questions, thus further studies may be needed to cross-validate these findings using primary data. The sample size of the dataset was adequate considering recruiting from a hard-to-reach population, it is worth noting however, that the questionnaire was administered through two different methods (online and face-to-face). It is possible that the lower reported medicine-related burden scores are due to social desirability bias, as despite anonymity, participants may still have underreported medicine-related burden due to a desire to present themselves as adherent or to align with perceived societal expectations, especially in face-to-face data collection. Additionally, the survey relied on self-reported data, which may introduce recall bias, due to participants not accurately remembering or reporting their experiences.

Moreover, it is important to take into consideration the demographic composition of the study sample, with 69.5% of participants being male, 76.6% of white ethnicity, and 50% educated to university level, generalisability of the study findings to other populations are reduced. The older group included in this study had a low mean age of 58.0 years ($SD\pm 5.9$), and there is a possibility that PLWH who are older will have differing experiences to those found in this study.

4.5 Chapter summary

There are very few studies exploring the effect that medicine-related burden has on the ageing HIV population. This study used secondary survey data to determine the medicine-related burden, using the LMQ-3, stigma, and disclosure experiences in younger (under 50 years old) and older (50 years and older) PLWH. The findings showed that overall, both age categories had low medicine-related burden, similar stigma scores, with the majority never, rarely or sometimes experiencing stigma, and that older PLWH felt more comfortable sharing their status with healthcare professionals and younger PLWH felt more comfortable sharing their status with close friends. However, free-text quotes highlighted negative experiences of side effects and stigma among this population. Moreover, a minority of PLWH across both age categories experienced high medicine burden and reported experiences of stigma, suggesting the need to identify and prioritise these individuals for medicine support. These issues are explored further in chapter 5. Qualitative free-text comments in this study showcased the need for further qualitative research (chapter 6) to truly understand the individual experiences of older PLWH regarding their medicines, the care they receive, stigma, and sharing their serostatus. The sum of these findings portrays the importance of considering medication-related concerns in older PLWH and focused strategies to reduce the burden could be beneficial.

As discussed in chapter 3, feedback from participants who completed the questionnaire included in this study indicated that they found the questionnaire to be lengthy and burdensome, which impacted completion rates. Additionally, it was evident that there was a need for more qualitative data as although participants reported low medicine burden via the structured tools provided, free-text quotes often revealed experiences of medicine burden that were not captured by the quantitative measures. Therefore, the questionnaire was adapted for the study included in chapter 5 (discussed further in chapter 3).

Findings from this study were accepted for a poster presentation at the 2022 BHIVA conference (Appendix 11).

CHAPTER FIVE

Identifying medicine-related support needs in older PLWH

5.1 Introduction

Chapter 4 showed that although low medicine burden was self-reported by the majority of older PLWH, some participants experienced high medicine burden, and the free-text quotes elaborated on experiences of stigma and day-to-day difficulties managing ARVs and non-ARV medicines (e.g. side effects and drug-drug interactions). As discussed in chapter 4, risk-benefit assessments, and patient beliefs about necessity of antiretrovirals may influence their perceived medicine burden. Therefore, it is important to consider ways to support individuals with medicines use, even though for the majority their perceived medicine burden is low/moderate. This chapter will focus on older people's support needs in terms of medicines use and compare it to younger PLWH.

At the time of writing this thesis, HIV services in the UK were provided mostly by specialist healthcare professionals within hospital settings or in outpatient clinics (secondary care). With early initiation of ART, the care required for older PLWH has gradually changed from the treatment of opportunistic infections (e.g. tuberculosis) towards the prevention and management of other chronic conditions (e.g. cardiovascular disease and mental health). (225) Many PLWH are living with comorbidities and need to access primary care to manage these. There is not enough evidence about PLWH's preferences of care; primary versus secondary. One study showed that most PLWH were registered with and shared their serostatus with a General Practitioner (GP). However, barriers to primary care were reported including poor communication between the HIV clinic and the GP, concerns regarding confidentiality, discrimination, discussing sexual matters, and the GP's HIV knowledge. (226) In the USA, studies have highlighted the significant role community pharmacists have in supplying and counselling PLWH on both ARVs and non-HIV medicines (227-228), and pharmacists are often trained to identify adverse effects, and drug-drug interactions between ARVs and non-ARVs (229-230). Moreover, the BHIVA guidelines state that good quality care necessitates good communication with GPs and healthcare professionals involved in the management of comorbidities. (231) Therefore, access to other healthcare professionals, such as community pharmacists is becoming increasingly important to provide medicine-related support for older PLWH. However, studies in the UK have shown that PLWH are reluctant to share their HIV status with healthcare professionals outside of their usual specialist care (65,232). Moreover, as evidenced in the findings of chapter 4 and previous research, PLWH have expressed the need for GPs and community pharmacists to be more knowledgeable about HIV. (225)

Studies have shown that older PLWH experience social isolation more than younger PLWH. (233) As reported in the systematic review (chapter 2), older PLWH have highlighted a need for social support, which can be defined as emotional (being looked after, loved and sympathised with), informational (giving information and advice), and instrumental (providing tangible assistance) support received from significant others; partners, family members, friends, and work colleagues. (234-235) Peers can also help PLWH improve their coping skills and thus their psychosocial functioning by providing important experiential information and support, that supplements and complements those given by healthcare professionals. (236-237) Higher levels of social support can lead to improved health-related quality of life, lower levels of depression, increased adherence,

and subsequently a lower viral load. (234,238) Studies have reported that sharing of one's HIV status is an essential first step to gain HIV-specific social support. (239)

The aim of this chapter was therefore to identify medicine-related and other social support needs in older PLWH in the UK. A secondary aim was to test correlations between medicine burden (as measured by a shorter version of the LMQ) and social support (as measured by the MSPSS) with the hypothesis that higher medicine burden is associated with lower social support.

Objectives:

1. To measure the medicine-related burden in older and younger PLWH.
2. To identify the medicine support needs and current support available to older PLWH (≥ 50 years) and compare them to those of younger PLWH (18-49 years).
3. To identify differences in perceived social support in older (≥ 50 years) versus younger PLWH (18-49 years).
4. To assess correlations between medicine-related burden and social support.
5. To explore the current engagement of older (≥ 50 years) and younger (18-49 years) PLWH with primary care providers for HIV care, including the extent of sharing information about HIV status, and preferences for future care.

5.2 Summary of Methods

Data were collected using a cross-sectional survey conducted between September 2021 to January 2023. Figure 5.1 displays a summary of the methods that have been presented in further detail in chapter 3. This survey included the mini-LMQ, the MSPSS and additionally questions regarding participants engagement with primary care.

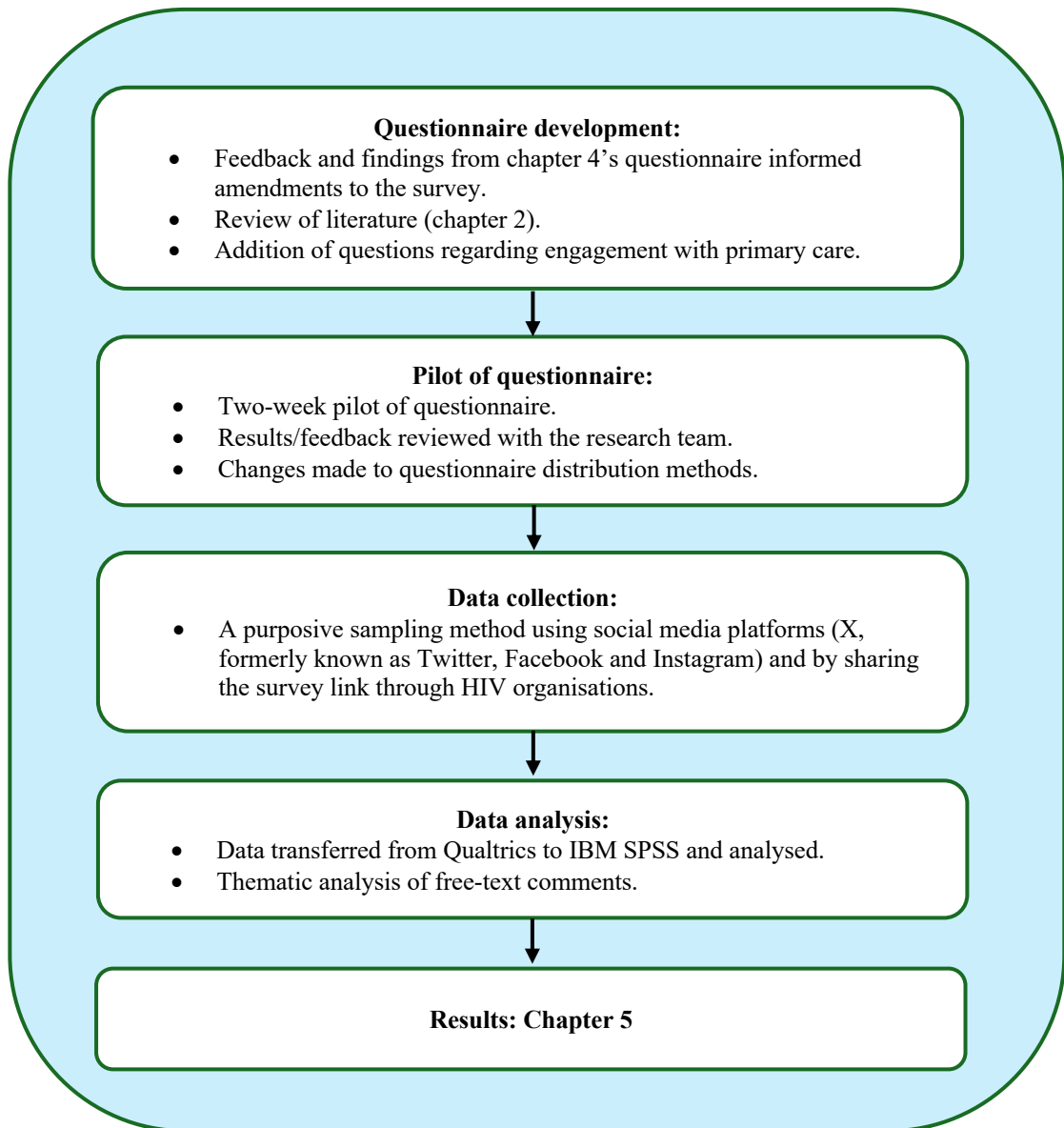


Figure 5.1 Summary of chapter 5 methods.

5.3 Results

5.3.1 Participant characteristics and response rate

Overall, 319 participants accessed the survey, and 256 consented, of which 173 participants were eligible to take part after answering all screening questions (Figure 5.2). One hundred and one (N=101) participants provided their age, of which 101 completed the mini-LMQ in full and one hundred (N=100) completed the MSPSS in full.

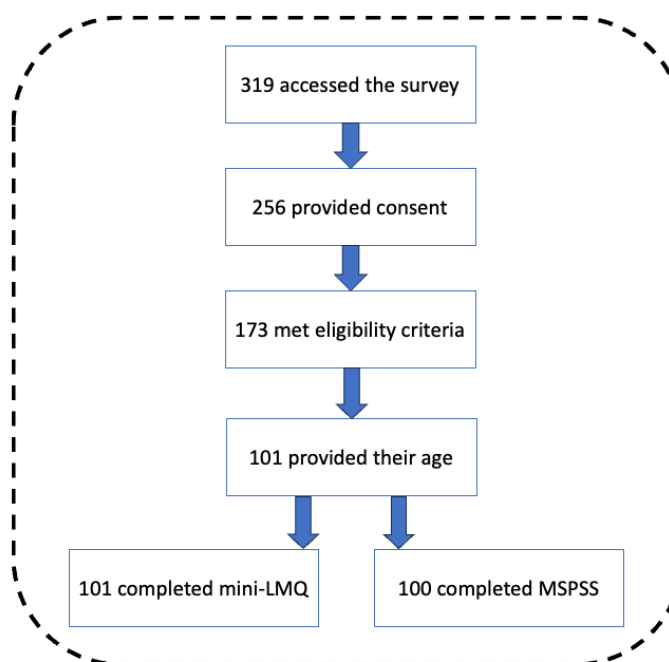


Figure 5.2 Participant survey response rate.

The mean age of participants was 48.7 (SD±12.5) and 50.5% (n=51/101) were aged 50 years and over. The mean age of the older group was 58.9 (SD±6.4). The majority of participants were male (77.5%, n=79/102), white (86.1%, n=87/101), gay or lesbian (60.8%, n=62/102), had university-level education (57.8%, n=59/103) and were employed (52.9%, n=54/102). Significantly more younger PLWH were employed ($p=0.001$). Participants' characteristics are presented in Table 5.1.

Table 5.1 Chapter 5 participant characteristics. *All variables are expressed as a number of participants (% total). Between group differences were determined using a Mann-Whitney U test for numerical variables and a Pearson's Chi-square test for categorical variables.*

Characteristic		PLWH <50	PLWH ≥50	p-value
		Frequency n (%)		
Gender		n=50	n=51	0.286
	Male	37 (74.0)	42 (82.4)	
	Female	11 (22.0)	9 (17.6)	
	Prefer not to say	2 (4.0)	-	
Sexuality		n=50	n=51	0.392
	Heterosexual	16 (32.0)	12 (23.5)	
	Gay/Lesbian	29 (58.0)	33 (64.7)	
	Bisexual	2 (4.0)	5 (9.8)	
	Other	1 (2.0)	1 (2.0)	
	Prefer not to say	2 (4.0)	-	
Age		n=50	n=51	-
	18-29	7 (14)	-	
	30-49	43 (86)	-	
	50-64	-	40 (78.4)	
	65 and over	-	11 (27.5)	
Education level		n=50	n=51	0.739
	School	6 (12.0)	9 (17.6)	
	Technical college/Apprenticeship	11 (22.0)	11 (21.6)	
	University	29 (58.0)	29 (56.9)	
	Other	4 (8.0)	2 (3.9)	
Employment status		n=50	n=51	0.001
	Employed	32 (64.0)	21 (41.2)	
	Unemployed	8 (16.0)	3 (5.9)	
	Retired	2 (4.0)	17 (33.3)	
	Student	1 (2.0)	-	
	Long-term sick leave	7 (14.0)	10 (19.6)	
Ethnicity		n=50	n=51	0.929
	White	42 (84.0)	45 (88.2)	
	Asian/Asian British	2 (4.0)	1 (2.0)	
	Black/African/Caribbean	5 (10.0)	3 (5.9)	
	Mixed	2 (2.0)	2 (3.9)	
*Number of comorbidities		n=50	n=50	0.045
	1	14 (28.0)	7 (14.0)	
	2	14 (28.0)	9 (18.0)	
	3	11 (22.0)	7 (14.0)	
	4	2 (4.0)	11 (22.0)	
	5	6 (12.0)	7 (14.0)	
	6	2 (4.0)	3 (6.0)	
	7	-	1 (2.0)	
	8	-	4 (8.0)	
	9	-	-	
	10	1 (2.0)	1 (2.0)	

Table 5.1 Continued. Participant characteristics.

Characteristic		PLWH <50	PLWH ≥50	p-value
		Frequency n (%)		
**Number of non-ARV medicines		n=49	n=49	0.008
	1-4	41 (83.7)	32 (65.32)	
	5-9	7 (14.3)	12 (24.5)	
	10 or more	1 (2.0)	5 (10.2)	
***Number of ARV medicines		n=50	n=51	0.550
	1	25 (50.0)	18 (35.3)	
	2	17 (34.0)	22 (43.1)	
	3	6 (12.0)	7 (13.7)	
	4	2 (4.0)	3 (5.9)	
	5	-	1 (2.0)	
Total number of medicines		n=49	n=49	0.001
	1-4	31 (63.3)	14 (28.6)	
	5-20	18 (36.7)	35 (71.4)	
Frequency of medicine use		n=50	n=51	0.168
	Once per day	27 (54.0)	26 (51.0)	
	Twice per day	20 (40.0)	16 (31.4)	
	Three times per day	3 (6.0)	3 (5.9)	
	More than three times per day	-	6 (11.8)	
Paying for non-HIV medicines		n=50	n=51	0.110
	Yes	19 (38.0)	19 (37.3)	
	No	27 (54.0)	32 (62.7)	
	Not Applicable (I live in Scotland/Wales)	4 (8.0)	-	
Time on ARVs		n=50	n=51	0.076
	Under 1 year	3 (6.0)	-	
	1 year or more	47 (94.0)	51 (100.0)	
Viral load		n=50	n=51	0.162
	Undetectable viral load (<50 copies/mL)	46 (92.0)	50 (98.0)	
	Detectable viral load (>50 copies/mL)	4 (8.0)	1 (2.0)	
Issues or side effects from medicines		n=50	n=51	0.264
	Yes	30 (60.0)	36 (70.6)	
	No	20 (40.0)	15 (29.4)	

*The number of comorbidities that participants used medicines for.

**Including inhalers, patches, etc.

***Combination formulations containing two or more active ingredients were counted as one pill.

Participants had a median of three comorbidities (range=1-10). The number of comorbidities PLWH had increased as their age increased ($r=0.282$, $p=0.004$). All participants were taking ARVs and the time since starting treatment ranged from three months to 32 years. All older PLWH (100%, $n=51/51$) and 94.0% ($n=47/50$) of younger PLWH included in this study had been on ARVs for a year or more.

Participants were using a median of 2.0 (range=1-5) ARV medicines and 3.0 (range=1-21) non-ARV medicines. The majority of participants were using their medicines once or twice per day, 54.9% ($n=62/113$) and 33.6% ($n=38/113$), respectively. Participants in the older group (PLWH ≥ 50) were taking a median of 2.0 (1-5) ARV medicines and 4.0 (range=1-18) non-ARV medicines. The number of non-ARV medicines taken by participants increased with age ($r=0.381$, $p<0.001$) (Figure 5.3). Polypharmacy (the use of 5 or more medicines), without including ARVs, was identified in 24.8% ($n=28/113$) of all participants and in 34.7% ($n=17/49$) of older PLWH. When including ARV medicines, polypharmacy was identified in 51.8% ($n=58/112$) of participants in the full dataset and was more prevalent in older PLWH at 71.4% ($n=35/49$) compared to 36.7% ($n=18/49$) in younger PLWH ($p=0.001$). The highest number of medicines used was 14 in the younger group and 20 in the older group. Moreover, polypharmacy was significantly associated with experiencing side effects ($p=0.018$ and $p=0.041$, with and without including ARVs, respectively).

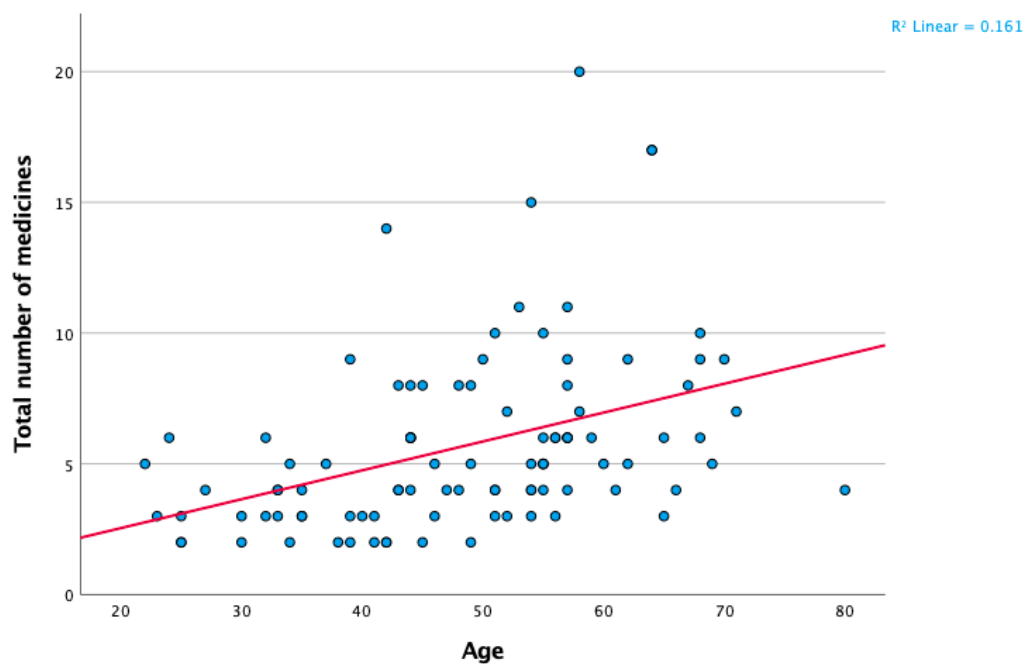


Figure 5.3 The relationship between age and the total number of medicines used, including ARVs, in PLWH.

The most common medicines taken among younger PLWH were for depression (40.0%, n=20/50) and anxiety (36.0%, n=18/50), and in older PLWH were for atrial fibrillation (51.0%, n=26/51) and heart failure (45.1%, n=23/51) (Table 5.2). A higher percentage of older PLWH (70.6%, n=36/51) had experienced side effects with their medicines compared to younger PLWH (60.0%, n=30/50), although the difference was not significant (p=0.264). The majority of both older and younger PLWH self-reported having undetectable viral loads (<50 copies/mL) at their most recent blood test, 98.0% (n=50/51) and 92.0% (n=46/50), respectively.

Table 5.2. The number of PLWH taking medicines for common conditions. *All variables are expressed as a number of participants (% total).*

Condition	PLWH <50	PLWH ≥50
	*n=50	*n=51
	Frequency n (%)	
Blood pressure	12 (24.0)	8 (15.7)
Anxiety	18 (36.0)	16 (31.4)
Cholesterol	1 (2.0)	-
Heart failure	6 (12.0)	23 (45.1)
Atrial Fibrillation	7 (14.0)	26 (51.0)
Chronic Obstructive Pulmonary Disease	-	8 (15.7)
Depression	20 (40.0)	12 (23.5)
Asthma	1 (2.0)	1 (2.0)
Pain	14 (28.0)	14 (27.5)
Stroke	1 (2.0)	2 (3.9)
Thyroid	3 (6.0)	2 (3.9)
Other	24 (48.0)	33 (64.7)

5.3.2 Prevalence of medicine-related burden

The first objective for this chapter was to measure the medicine-related burden in older (≥50 years) and younger (18-49 years) PLWH.

The mini-LMQ showed high medicine-related burden in both older and younger PLWH, 68.6% (n=35/51) and 58.0% (n=29/50), respectively (Table 5.3). Higher medicine-related burden was significantly associated with a university level education in older PLWH (p=0.021). Moreover, a higher medicine-related burden was evident in older PLWH who were employed and retired compared to unemployed individuals (p=0.038). In older PLWH, using fewer non-ARV medicines was significantly associated with higher medicine-related burden scores (r=-0.300 and p=0.036). A negative correlation was evident between the number of medicines used and medicine-related burden scores when including ARVs, however, this was not significant in older PLWH (r=-0.238 and p=0.099). In younger PLWH, using fewer medicines was significantly associated with high medicine-related burden (r=-0.411, p=0.003 and r=-0.355, p=0.012, with ARVs and without, respectively).

Table 5.3 Comparison of the mini-LMQ medicine-related burden scores between older and younger PLWH. All variables are expressed as a number of participants (% total). Between group differences were determined using a Pearson's Chi-square test.

Total mini-LMQ score	PLWH <50 (n=50) n (%)	PLWH ≥50 (n=51) n (%)	p-value
No or minimal burden	5 (10.0)	4 (7.8)	0.539
Moderate degree of burden	16 (32.0)	12 (23.5)	
High burden	29 (58.0)	35 (68.6)	

Moreover, younger PLWH with fewer comorbidities reported high medicine-related burden ($p=0.02$) (Table 5.4). In contrast, there were no significant differences in the medicine-related burden reported and the number of comorbidities in older PLWH. Older PLWH of white ethnicity reported high medicine-related burden ($p<0.001$).

Table 5.4 Mini-LMQ medicine related-burden scores according to the number of comorbidities reported in PLWH. All variables are expressed as a number of participants (n).

	Number of comorbidities		1	2	3	4	5	6	7	8	9	10
PLWH <50 (n=50) n	Mini-LMQ category	No or minimal burden	-	-	2	-	1	1	-	-	-	1
		Moderate degree of burden	4	3	4	2	2	1	-	-	-	-
		High burden	10	11	5	-	3	-	-	-	-	-
PLWH ≥50 (n=51) n		No or minimal burden	-	1	1	-	1	-	-	-	-	-
		Moderate degree of burden	-	-	1	3	2	3	-	2	-	1
		High burden	7	8	5	8	4	-	1	2	-	-

Domain-level analysis of the mini-LMQ data across the age groups was conducted (Table 5.5). A statistically significant difference was seen between scores of older and younger PLWH in the practical difficulties domain, with older PLWH reporting a higher burden score for this domain ($p=0.01$).

Table 5.5 Domain-level analysis of the mini-LMQ between PLWH<50 years and PLWH≥50 years. Between group differences were determined using a Pearson's Chi-square test.

Mini-LMQ domains	PLWH <50 (n=50)			PLWH ≥50 (n=51)			p-value
	Mean	Standard deviation	95% Confidence Interval (Lower, upper)	Mean	Standard deviation	95% Confidence Interval (Lower, upper)	
Practical difficulties	2.64	±1.21	(2.30, 2.98)	3.12	±1.48	(2.70, 3.53)	0.010
Relationships	3.60	±1.03	(2.70, 3.53)	3.78	±1.12	(3.47, 4.10)	0.626
Cost	3.30	±1.40	(2.90, 3.70)	3.71	±1.32	(3.34, 4.08)	0.671
Side Effects	3.16	±1.39	(2.76, 3.56)	2.88	±1.09	(2.58, 3.19)	0.126
Autonomy	2.24	±1.45	(1.83, 2.65)	2.37	±1.39	(1.98, 2.76)	0.430
Efficacy	3.60	±1.13	(3.28, 3.92)	3.90	±1.01	(3.62, 4.18)	0.254
Concerns	2.08	±1.10	(1.77, 2.39)	2.20	±0.98	(1.92, 2.47)	0.555
Interference with daily life	2.9	±1.52	(2.47, 3.33)	3.41	±1.28	(3.05, 3.77)	0.148

5.3.3 Medicine-related support

The second objective for this chapter was to identify the medicine-related support needs of older (≥ 50 years) and younger (18-49 years) PLWH and determine the current medicine support available to them.

Overall, more PLWH reported using their clinic healthcare professionals for medicine-related support compared to any other source (Table 5.3). The majority of both older (76.5%, $n=39/51$) and younger (66.0%, $n=33/50$) PLWH would use their clinic consultant/specialist doctor for support with their medicines and the second highest reported source of medicine-related support was their clinic pharmacist as reported by 49.0% ($n=25/51$) of older and 46.0% ($n=23/50$) of younger PLWH. More participants reported using their General Practitioner for medicine-related support compared to their Community Pharmacist (12.5%, $n=17/136$ and 2.9%, $n=4/136$, respectively). In comparison to other sources of medicine-related support, online support groups/forums were used the least, with no one from the older group using an online open support group/forum.

Table 5.6 Sources of medicine-related support among older and younger PLWH. *All variables are expressed as a number of participants (% total).*

Source of support	PLWH <50 ($n=50$) n (%)	PLWH ≥ 50 ($n=51$) n (%)
Clinic Pharmacist	23 (46.0)	25 (49.0)
Clinic Nurse	19 (38.0)	22 (43.1)
Clinic Consultant/Specialist Doctor	33 (66.0)	39 (76.5)
Non-HIV specialist at the hospital	-	2 (3.9)
Community Pharmacist	2 (4.0)	1 (2.0)
The General Practitioner	6 (12.0)	9 (17.6)
The Care home	-	-
Partner	16 (32.0)	8 (15.7)
Family and friends	12 (24.0)	8 (15.7)
Face-to-face support group	4 (8.0)	6 (11.8)
Online closed support group/forum	6 (12.0)	5 (9.8)
Online open support group/forum	3 (6.0)	-
Social media group (e.g. Facebook, Twitter, Instagram, WhatsApp group)	4 (8.0)	3 (5.9)
Online website	5 (10.0)	10 (19.6)

The majority of older PLWH (61.1%, $n=22/36$) reported getting the support they need when they have issues or problems with any of their medicines, whereas only 40% ($n=12/30$) younger PLWH reported the same (Table 5.4). A higher number of younger PLWH (40%, $n=12/30$) than older PLWH (27.8%, $n=10/36$), reported that they just put up with any medicine-related issues. Participants across all ages who reported that they get the support they need when they have an issue with any of their medicines were more likely to have a high medicine burden ($p<0.001$).

Table 5.7 How older and younger PLWH manage issues or problems with their medicines. *All variables are expressed as a number of participants (% total). Between group differences were determined using a Pearson's Chi-square test.*

When you have issues or problems with any of your medicines, which statement best describes what you do?	PLWH <50 (n=30) n (%)	PLWH ≥50 (n=36) n (%)	p-value
I just put up with them	12 (40.0)	10 (27.8)	0.238
I don't know what support is available	1 (3.3)	2 (5.6)	
I don't feel comfortable asking anyone for support	5 (16.7)	2 (5.6)	
I get the support I need	12 (40.0)	22 (61.1)	

Nearly two-thirds of older PLWH (64.7%, n=33/51) had their ARVs delivered to their home, whereas the majority of younger PLWH (56%, n=28/50) collected their ARVs from their specialist clinic/hospital (Table 5.5).

Table 5.8 Methods of obtaining medicines in older and younger PLWH and changes due to COVID-19. *All variables are expressed as a number of participants (% total). Between group differences were determined using a Pearson's Chi-square test.*

		PLWH <50 n (%)	PLWH ≥50 n (%)	p-value
		n=50	n=51	
Methods of obtaining medicines	Collection from Specialist clinic/hospital	28 (56.0)	18 (35.3)	-
	Home delivery	20 (40.0)	33 (64.7)	
	Collection from Community pharmacy	4 (8.0)	3 (5.9)	
	Other	2 (2.0)	1 (2.0)	
Did the method of obtaining your medicines change due to COVID-19?		n=50	n=51	0.535
	Yes	8 (16.0)	5 (9.8)	
	No	42 (84.0)	46 (90.2)	

The impact of Coronavirus disease (COVID-19) on PLWH's care

The majority of participants reported that how they obtained their medicines did not change due to COVID-19, however, 16% (n=8/50) and 9.8% (n=5/51) of younger and older PLWH, respectively, did report changes (Table 5.5). In the free-text comments, ten participants across both age groups stated that due to COVID-19 they now get their medicines delivered to their homes instead of collecting them from the local pharmacy or their specialist HIV clinic as they did previously.

The following free-text quotes demonstrate how the COVID-19 pandemic affected the experiences and care engagement of PLWH, with several participants describing difficulties getting appointments, appointments relating to their HIV being online or over-the-phone, and some even describing receiving more attentive care during the COVID-19 pandemic than ever before, whilst others stated there were no changes in their care or treatment.

'I had a shortage of medication. When I phoned my hospital to ask for a new prescription, they couldn't give me once unless I came in physically. This was impossible for me during the first few months of lockdown'

Male, age 30

'No impact on treatment, had to have phone consultation with my HIV consultant instead of face to face.

Personally, don't ever want to replace face to face with remote again'

Female, age 52

'I coped very poorly. Physically and mentally. And I live alone. Although I live close to my specialist clinic, I couldn't get the support I had depended on. I wish there had been some outreach or wellness check'

Male, age 68

'I've actually had more attention over the past two years than I can remember. That's the only upside to being clinically extremely vulnerable as far as I can see'

Male, age 67

5.3.4 Perceived social support

The third objective for this chapter was to identify any differences in perceived social support between older (≥ 50 years) and younger (18-49 years) PLWH.

Overall, the majority of PLWH reported high perceived social support in each subscale of MSPSS, except for the family subscale, where there were an equal number of participants in the total dataset reporting moderate and high support (Table 5.6). There were more older PLWH reporting moderate than high social support from family members (39.2%, $n=20/51$ and 33.3%, $n=17/51$, respectively), whereas more younger PLWH reported high support from family members (42.9%, $n=21/49$). In younger PLWH, there was a significant negative correlation between age and reported family social support scores ($r=-0.307$, $p=0.032$). The highest source of social support reported was from a significant other (58.8%, $n=30/51$ and 59.2%, $n=29/49$ in older and younger PLWH, respectively). In older PLWH, there was a significant association between the number of non-ARV medicines used and perceived social support from a significant other ($p=0.025$), however, the negative correlation was not significant ($r=-0.277$, $p=0.054$). Furthermore, older PLWH using fewer non-ARV medicines, had a higher total perceived social support score ($r=-0.286$, $p=0.046$). A negative correlation was also evident between the number of non-ARV medicines used and reported social support scores from friends in younger PLWH ($r=-0.326$, $p=0.024$).

Table 5.9 Comparison of the MSPSS perceived social support scores between older and younger PLWH. *All variables are expressed as a number of participants (% total). Between group differences were determined using a Pearson's Chi-square test.*

Subscale		PLWH <50 n (%)	PLWH ≥50 n (%)	p-value
Significant other		(n=49)	(n=51)	0.875
	Low support	7 (14.3)	9 (17.6)	
	Moderate support	13 (26.5)	12 (23.5)	
	High support	29 (59.2)	30 (58.8)	
Family		(n=49)	(n=51)	0.613
	Low support	12 (24.5)	14 (27.5)	
	Moderate support	16 (32.7)	20 (39.2)	
	High support	21 (42.9)	17 (33.3)	
Friends		(n=49)	(n=51)	0.588
	Low support	7 (14.3)	8 (15.7)	
	Moderate support	15 (30.6)	20 (39.2)	
	High support	27 (55.1)	23 (45.1)	
Total		(n=49)	(n=51)	0.810
	Low support	7 (14.3)	8 (15.6)	
	Moderate support	20 (40.8)	17 (33.3)	
	High support	22 (44.9)	26 (51.0)	

In the full dataset, age was significantly associated with perceived social support scores from a significant other ($p=0.011$) and from family ($p=0.028$), however, the negative correlations were not significant ($r=-0.023$, $p=0.818$ and $r=-0.129$, $p=0.201$, respectively). When comparing both age groups, a higher level of education was significantly associated with high perceived social support scores among older PLWH in the following subscales: significant other ($p=0.04$); friends ($p=0.002$); total perceived social support ($p=0.002$). These were not significant in younger PLWH. Ethnicity and social support from a significant other were significantly associated in younger PLWH ($p=0.037$).

Perceived social support scores were not significantly associated with employment, duration since starting ART, and viral load across both age groups.

5.3.5 Relationship between medicine burden and social support in older PLWH

The fourth objective for this chapter was to explore any correlation between medicine burden and social support.

There was a significant association between medicine burden and perceived social support ($r=0.353$, $p>0.001$) (Figure 5.4). High medicine-related burden was significantly associated with reports of higher social support from a significant other among older PLWH ($r=0.328$, $p=0.019$) (Table 5.7). Whilst younger PLWH with a higher medicine-related burden reported receiving more social support from their family ($r=0.355$, $p=0.012$).

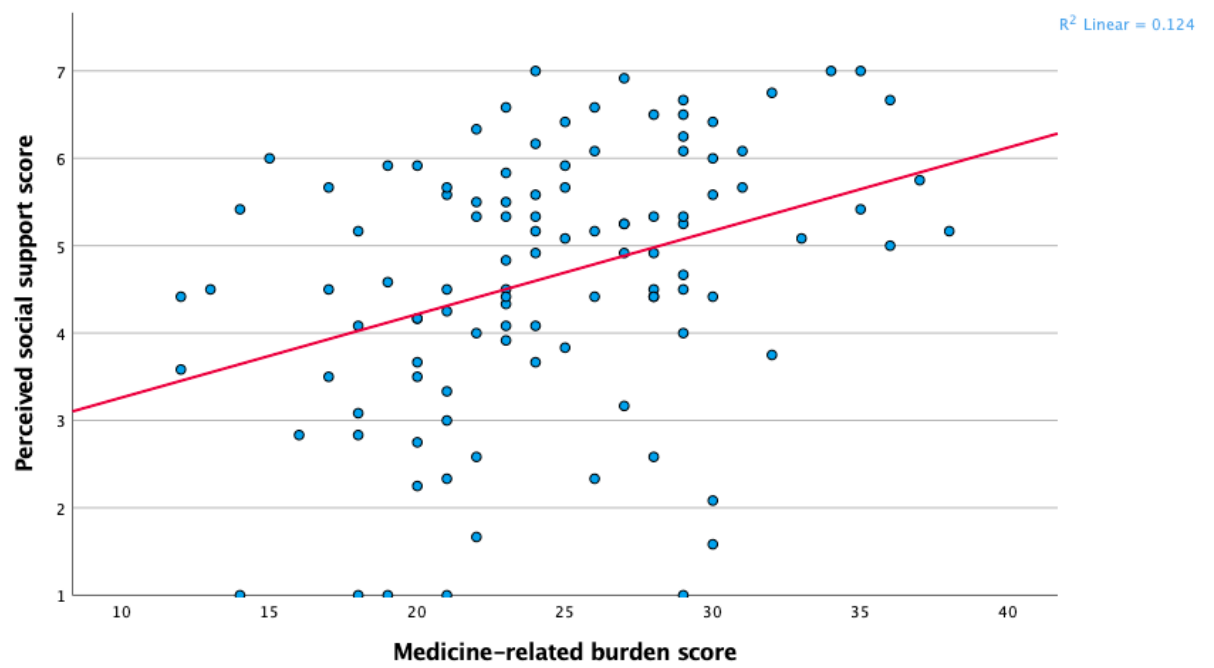


Figure 5.4 The association between perceived social support (MSPSS score) and medicine-related burden (mini-LMQ score) among PLWH.

Table 5.10 Comparison of medicine-related support (MSPSS) with medicine burden (mini-LMQ). *Between group differences were determined using a Pearson's Chi-square test.*

MSPSS category		Mini-LMQ burden category			p-value
		Low	Moderate	High	
Significant other	Low	2	10	7	0.064
	Moderate	3	7	17	
	High	5	12	44	
Family	Low	3	15	11	0.010
	Moderate	3	7	29	
	High	4	7	28	
Friends	Low	2	8	6	0.006
	Moderate	6	12	19	
	High	2	9	43	
Total	Low	2	9	5	0.011
	Moderate	5	12	23	
	High	3	8	39	

5.3.6 PLWH's engagement with primary care providers and preferences for future care

The fifth objective for this chapter was to explore the engagement of older and younger PLWH with their primary care providers for HIV care, including the extent of sharing their HIV serostatus and preferences for future care.

It was found that 64.7% (n=33/51) of older and 58.0% (n=29/50) of younger PLWH reported having all of their medicines reviewed, with the majority stating that it took place at their HIV clinic/hospital (75.8%, n=25/33 and 79.3%, n=23/29 of older and younger PLWH, respectively) (Table 5.8). Moreover, 69.7% (n=23/33) of older PLWH and 89.7% (n=26/29) of younger PLWH reported that their medicine review was less than 12 months ago with the remainder more than 12 months ago.

Table 5.11 Medicine reviews conducted in PLWH. *All variables are expressed as a number of participants (% total). Between group differences were determined using a Pearson's Chi-square test.*

		PLWH <50 n (%)	PLWH ≥50 n (%)	p-value
Has anyone ever reviewed all of your medicines?		n=50	n=51	0.640
	Yes	29 (58.0)	33 (64.7)	
	No	18 (36.0)	14 (27.5)	
	Can't remember	3 (6.0)	4 (7.8)	
Where did the medicine review take place?		n=29	n=33	0.777
	HIV clinic/hospital	23 (79.3)	25 (75.8)	
	GP surgery	5 (17.2)	7 (21.2)	
	Community pharmacy	1 (3.4)	1 (3.0)	
How long ago was your last medicine review?		n=29	n=33	0.054
	Under 12 months	26 (89.7)	23 (69.7)	
	12 months and over	3 (10.3)	10 (30.3)	

Sharing of HIV serostatus with healthcare professionals

Overall, fewer older PLWH reported being very uncomfortable sharing their HIV status with healthcare professionals compared to younger PLWH (Table 5.9).

More older PLWH reported to being very comfortable to share their serostatus with the GP ($p=0.016$) and non-HIV specialist at the hospital ($p=0.031$) compared to younger PLWH. Although the majority of both age groups were also very comfortable to share their HIV status with a community pharmacist (39.2%, $n=20/51$ and 30.0%, $n=15/50$ in older and younger PLWH, respectively), 25.5% ($n=13/51$) of older PLWH reported feeling neutral and 20% ($n=10/50$) of younger PLWH felt very uncomfortable. With regards to sharing their serostatus with care home staff, in the present or future, the majority of older PLWH reported being neutral (34.7%, $n=17/49$) on this issue and 26.5% ($n=13/49$) were uncomfortable. Similarly, most younger PLWH reported being neutral (33.3%, $n=16/48$) or uncomfortable (20.8%, $n=10/48$) to share their serostatus with care home staff.

In the free-text comments for the minority of participants ($n=6$) who have not shared their HIV status with their GP, expressed concerns around data privacy, a lack of trust and fears of stigmatisation.

Table 5.12 Sharing of HIV serostatus by older and younger PLWH. *All variables are expressed as a number of participants (% total). Between group differences were determined using a Pearson's Chi-square test.*

		PLWH <50 n (%)						PLWH ≥50 n (%)					p-value
		Very comfortable n (%)	Comfortable n (%)	Neutral n (%)	Uncomfortable n (%)	Very Uncomfortable n (%)		Very comfortable n (%)	Comfortable n (%)	Neutral n (%)	Uncomfortable n (%)	Very Uncomfortable n (%)	
General Practitioner (GP)	n=49	23 (46.9)	9 (18.4)	5 (10.2)	6 (12.2)	6 (12.2)	n=51	40 (78.4)	4 (7.8)	4 (7.8)	2 (3.9)	1 (2.0)	0.016
Community Pharmacist	n=50	15 (30.0)	9 (18.0)	8 (16.0)	8 (16.0)	10 (20.0)	n=51	20 (39.2)	7 (13.7)	13 (25.5)	8 (15.7)	3 (5.9)	0.206
Hospital non-HIV Specialist	n=49	18 (36.7)	8 (16.3)	8 (16.3)	9 (18.4)	6 (12.2)	n=51	27 (52.9)	12 (23.5)	9 (17.6)	2 (3.9)	1 (2.0)	0.031
Care home staff (present/future care)	n=48	10 (20.8)	7 (14.6)	16 (33.3)	10 (20.8)	5 (10.4)	n=49	10 (20.4)	7 (14.3)	17 (34.7)	13 (26.5)	2 (4.1)	0.791

PLWH's engagement with General Practitioners

Participants were asked a series of questions relating to their primary care engagement (Table 5.10). All older PLWH said they were registered and had shared their serostatus with a GP. In contrast, 94.0% (n=47/50) of younger PLWH reported being registered with a GP and 87.2% (n=41/47) had shared their serostatus with the GP. Significantly more older PLWH had shared their serostatus with a GP than younger PLWH (p=0.008). However, only two (3.9%, n=2/51) older PLWH and seven (14.9%, n=7/47) younger PLWH reported having booked an appointment with a GP specifically relating to their HIV.

The majority of younger PLWH reported that their GP was not involved in their HIV care (72.3%, n=34/47), compared to 43.1% (n=22/51) of older PLWH. The majority of older PLWH reported their GP to be somewhat involved with their HIV care (49.0%, n=25/51). Most older and younger PLWH had not opted out of summary care records (66.7%, n=34/51 and 55.3%, n=26/47). When participants were asked what would influence their decision to use their GP surgeries for all of their HIV services, the most frequent option chosen by older PLWH (54.9%, n=28/51) and younger PLWH (48.0%, n=24/50) was 'staff expertise'.

Table 5.13 PLWH's engagement with General Practitioners. *All variables are expressed as a number of participants (% total). Between group differences were determined using a Pearson's Chi-square test.*

		PLWH <50 n (%)	PLWH ≥50 n (%)	p-value
Registered with the GP		n=50	n=51	0.076
	Yes	47 (94.0)	51 (100)	
	No	3 (6.0)	-	
Shared HIV status with GP		n=47	n=51	0.008
	Yes	41 (87.2)	51 (100)	
	No	6 (12.8)	-	
Have you ever booked a GP/doctor appointment specifically relating to HIV?		n=47	n=51	0.168
	Yes	7 (14.9)	2 (3.9)	
	No	38 (80.9)	47 (92.2)	
	Don't remember	2 (4.3)	2 (3.9)	
How involved is your GP/doctor in your HIV care		n=47	n=51	0.011
	Not at all	34 (72.3)	22 (43.1)	
	Somewhat involved	10 (21.3)	25 (49.0)	
	Fully involved	3 (6.4)	4 (7.8)	
Have you opted out of Summary Care Records or decided not to share your medical information with other healthcare professionals?		n=47	n=51	0.498
	Yes	7 (14.9)	5 (9.8)	
	No	26 (55.3)	34 (66.7)	
	Not sure	14 (29.8)	12 (23.5)	
	Under 12 months	26 (89.7)	23 (69.7)	
	12 months and over	3 (10.3)	10 (30.3)	
What would influence your decision to use GP surgeries for all your HIV services?		n= 50*	n=51*	-
	Travel distance	19 (38.0)	21 (41.2)	
	Frequency of appointments	9 (18.0)	12 (23.5)	
	Need for faster review of any symptoms	18 (36.0)	22 (43.1)	
	Need for faster review of my medicines	16 (32.0)	18 (35.3)	
	Ease of access	18 (36.0)	24 (47.1)	
	Staff expertise	24 (48.0)	28 (54.9)	
	Stigma	17 (34.0)	9 (17.6)	
	Privacy	10 (20.0)	9 (17.6)	
	Someone to trust	15 (30.0)	8 (15.7)	

When asked if there were any other way participants thought their GP could help them, 19 participants across both age groups expressed concerns regarding a lack of knowledge or expertise among GP's regarding HIV. Example quotes can be seen below.

"I would be extremely nervous if I thought my HIV care was moving to my GP. I have no particular issue with my GP, but my HIV knowledge is probably more advanced than theirs is"

Age 42, male

"GPs don't have this knowledge and a 10-minute appointment would not be enough"

Age 65, Male

"GPs need to be more aware of the impact HIV can have on other areas...such as risk of cardiovascular disease; risk of cancers; need for earlier immunisations than the general population; drug interactions"

Age 68, Male

Two participants indicated experiences of homophobia and racism within their GP practice, with one participant stating they wanted their GPs to *"Stop being homophobic racists"* (age 48, gender not stated).

Several other participants highlighted the need for better communication between their GP and specialist HIV consultant.

"Better data sharing with the consultant regarding blood tests. Both asking for the same tests at the same time – craziness!"

Age 46, Male

One participant (male, aged 49) has highlighted the usefulness of Pharmacists within GP practices by stating, *"I've had a review with the pharmacist that was very detailed and good"*.

The impact of staff shortages within GP practices were evident in the free-text quotes, with one participant expressing that they do not want to have a different doctor each time they make an appointment.

"Not having to see a different doctor EVERY time I make an appointment"

Age 68, Male

An older participant (age 55, Female) stated they would like their GP to *"understand my specific needs"* whilst a younger participant (age 30, Male) wanted their GP to be *"reviewing my medications and explaining how they might interact with my other conditions"*.

Moreover, when asked if there was anything further GPs can do to help them, several participants mentioned helping to reduce stigma.

“My GP Practice won’t even have information about HIV available because, and I quote “we are a family practice and don’t want that on show here”

Female, age 52

PLWH’s engagement with pharmacists

Participants were asked several questions regarding their preferences for the involvement of community pharmacists with their HIV care (Table 5.11). Nearly half (49.0%, n=25/51) of older PLWH stated that they did not want their community pharmacist involved in their HIV care, with only 19.6% (n=10/51) stating that they would. In comparison, 40.0% (n=20/50) of younger PLWH stated that they would not want their community pharmacist involved with their HIV care, and 32.0% (n=16/50) said they would want this.

Table 5.14 PLWH’s preferences with community pharmacists’ involvement with their HIV care. *All variables are expressed as a number of participants (% total). Between group differences were determined using a Pearson’s Chi-square test.*

		PLWH <50 n (%)	PLWH ≥50 n (%)	p-value
Would you want your pharmacist involved in your HIV care?		n=50	n=51	0.356
	Yes	16 (32.0)	10 (19.6)	
	No	20 (40.0)	25 (49.0)	
	Not sure	14 (28.0)	16 (31.4)	
What would influence your decision to use pharmacists for all your HIV services?		n=50*	n=51*	-
	Travel distance	15 (30.0)	13 (25.5)	
	Frequency of appointments	15 (30.0)	4 (7.8)	
	Need for faster review of any symptoms	14 (28.0)	8 (15.7)	
	Need for faster review of my medicines	23 (46.0)	10 (19.6)	
	Ease of access	17 (34.0)	13 (25.5)	
	Staff expertise	22 (44.0)	24 (47.1)	
	Stigma	21 (42.0)	8 (15.7)	
	Privacy	17 (34.0)	9 (17.6)	
	Someone to trust	17 (34.0)	6 (11.8)	
	None of the above	4 (8.0)	15 (29.4)	
Would you tell a pharmacist about your HIV medicines when buying over the counter medicines		n=50	n=51	0.761
	Yes	23 (46.0)	25 (49.0)	
	No	27 (54.0)	26 (51.0)	
Would you tell a pharmacist about your HIV medicines during a private sit-down consultation		n= 50	n=51	0.077
	Yes	36 (72.0)	44 (86.3)	
	No	14 (28.0)	7 (13.7)	

When participants were asked what would influence their decision to use a community pharmacist for all of their HIV services, the most frequently chosen option was ‘staff expertise’ by older PLWH (47.1%, n=24/51) and ‘need for faster review of my medicines’ by younger PLWH (46.0%, n=23/50).

When participants were asked whether they would tell their community pharmacist about their HIV medicines when buying over-the-counter products, almost half of older PLWH (49.0%, n=25/51) reported that they would and slightly over half reported that they would not (51.0%, n=26/51); Similarly in younger PLWH, 46.0% (n=23/50) reported that they would tell their community pharmacist about their HIV medicines when buying over-the-counter products and 54% (n=27/50) reported that they would not.

Moreover, when asked if participants would tell a chemist about their HIV medicine if asked during a private sit-down consultation, 86.3% (n=44/51) and 72.0% (n=36/50) of older and younger PLWH, respectively, agreed that they would, and 13.7% (n=7/51) and 28.0% (n=14/50) of older and younger PLWH, respectively, stated that they would not.

Reasons for why PLWH would share information about their HIV medicines when buying over the counter were expressed in the free-text comment section, with 27 participants stating the reason being due to the possibility of interactions.

'Important to ensure there are no drug/drug interactions'

Male, age 57

'Due to side effects of other medications'

Male, age 32

Furthermore, the following free-text quotes show reasons why PLWH would consider telling their community pharmacists about their HIV medicines during private sit-down consultations.

'When I wasn't well with another drug which was affecting my symptoms, I had the confidence to speak with all the pharmacists who are fully knowledgeable about my meds'

Male, age 42

'Because they understand medication'

Female, age 59

'Would give me some control over who knew my HIV status. Also, gives me opportunity to judge what knowledge he/she has about HIV and how they treat HIV (or gay) patients'

Male, age 68

Reasons why PLWH would not tell their community pharmacist about their HIV medicines if asked when buying over-the-counter medicines were evident in the free-text quotes, with five participants mentioning a lack of trust, 14 participants explaining that they can check interactions checkers themselves, and 21 participants mentioning a lack of privacy, previous experiences of healthcare professionals disclosing their status to others without their permission, and confidentiality issues.

'I have the Liverpool HIV drugs interactions app, and don't trust the chemist/GP practices to keep my info confidential or treat me fairly if they know my status. Have already experienced a doctor disclosing my status to my colleagues. Will not allow again'

Age and gender not reported

'Lack of privacy, unsure of chemist reaction and understanding'

Male, age 42

'Stigma'

Female, age 55

Moreover, there were several reasons why PLWH would not consider telling their community pharmacist about their HIV medicines even in a private consultation, including concerns with privacy, confidentiality and experiences of stigma as can be seen in some of the free-text quotes below.

'Always feel embarrassed'

Female, age 25

'I don't trust that my confidentiality will be trusted. Plus, I have the Liverpool HIV drug-interactions app, and a degree in pharmacology, so I'm confident to manage my own drug regimen'

Gender not disclosed, age 48

'They can't be trusted and don't have the skills needed'

Male, age 40

Participants were asked if there were ways in which they thought their community pharmacist could help them in the future, responses were mixed with some participants stating they did not want their HIV care to be provided by primary care providers at all, whilst others expressed the need for more privacy within community pharmacies and training for pharmacists. Some participants mentioned wanting community pharmacies to provide free pre-exposure prophylaxis (PrEP), an option for online consultations with pharmacists, and for the community pharmacy to be a collection point for their ARVs.

'Normalise conversations about HIV but respect and understand some people might not be ready to talk in a public space about it'

Male, age 35

'It's already difficult keeping everyone involved in my care suitably aware and involved... HIV team/GP/other consultants...adding the chemist is another degree of complexity. I would much prefer a SINGLE point of contact who manages and coordinates my care holistically across all disciplines, including primary care and chemist'

Male, age 68

‘No and I certainly wouldn’t want my HIV care to be done by a chemist (or by my GP)’

Male, age 57

‘Training – having up to date info about HIV and U=U’

Male, age 57

5.4 Discussion

To understand older PLWH's medicine-related support needs, this chapter aimed to explore PLWH's experiences of and preferences for medicine-related support, social support, sharing of serostatus, engagement with primary care, and to investigate differences between older (≥ 50 years) and younger (18-49 years) PLWH. A secondary aim was to explore any relationship between medicine burden, assessed using the short form of the LMQ3, the mini-LMQ and social support, measured with the MSPSS.

Increased medicine-related and social support can provide many benefits to PLWH, such as increased adherence to treatments, lower incidences of depression, and a better quality of life. (240-242) All PLWH included in this study were using one or more medicines in addition to their ARVs. Over half of all participants and over 70% of older PLWH were using five or more medicines. As evident in literature (177,243) and chapters 2 and 4, the number of medicines taken and incidence of polypharmacy in PLWH increased with age in this study. Studies have shown that polypharmacy is associated with serious adverse drug events, drug-drug interactions and decreased adherence in PLWH. (177,243) This was evident among participants in this study, as polypharmacy was significantly associated with experiencing side effects. It is predicted that 54% of all PLWH will be prescribed co-medicines in 2030, with 20% using three or more medicines in addition to their ARVs. (244) It was found that medicines were most commonly taken for depression and anxiety in younger PLWH, and for atrial fibrillation and heart failure in older PLWH. This is similar to previous studies where depression, atrial fibrillation, and heart failure have been commonly seen among PLWH. (245–249) There are several factors that contribute to the increased incidence of depression in PLWH, for instance, the stress of living with a chronic condition, experiences of stigma, and challenges of getting the social support they need. (248) Depression can negatively impact adherence to treatment, selfcare, survival and risk behaviours in this population. (246,250)

Most older PLWH in this study reported seeking the support they need when they have issues with their medicines, whereas most younger PLWH stated that they just put up with these issues. HIV care in the UK is typically provided in secondary care clinics and findings showed that the majority of PLWH use their HIV clinic consultant/specialist doctors for medicine-related support, followed by their HIV clinic pharmacists and nurses. Primary care facilities such as GP practices and community pharmacies are well placed within the community to provide information and advice to PLWH. Community pharmacies have extended hours of operation and more convenient locations compared to other primary healthcare facilities. (241,251) Moreover, they already play effective roles in the management of other chronic conditions, such as cardiovascular disease and diabetes, where their involvement improved patient health outcomes and decreased medical care expenditure. (241) However, very few PLWH reported using their GP for medicine-related support and even less reported to using their community pharmacist.

Primary care engagement was investigated to understand reasons for participants using or not using their GP and community pharmacist. Free-text quotes highlighted older PLWH's concerns regarding a lack of expertise surrounding HIV among GPs and a lack of time during appointments to discuss their concerns. Some participants stated that they felt more knowledgeable about HIV than their GP, whilst others reported wanting consistency with the GP they are seeing and for them to understand their specific needs. Moreover, Participants

highlighted a need for GPs to be aware of the impact that HIV may have on their comorbidities and risk factors. One participant expressed their frustration and the need for better communication between their GP and HIV clinic when asked to do the same blood tests from both services. A lack of communication between the services in instances such as this could lead to increases in the treatment burden experienced by PLWH when having to travel to both sites, taking time and effort, whereas better communication and sharing of results would help both the patient and healthcare professionals. Participants described broader concerns surrounding the pressure on primary care, such as difficulties getting an appointment, lack of continuity and rushed consultations, which have been evident even prior to the COVID-19 pandemic. (65,252) These pressures are due to several factors, such as the increasing ageing population, higher numbers of people with complex conditions, rising expectations of the public, and initiatives to move care to the community from hospitals. (252) Participants listed staff expertise, travel distance, ease of access, and the need for faster review of symptoms or medicines as factors that would influence them to use GP surgeries for their HIV care. One participant commended their pharmacist within the GP practice, stating their medicine review was 'very detailed and good'.

A high percentage of PLWH reported being very comfortable to share their HIV status with their GP, this was also evident in literature. (226) It was found that more older PLWH were very comfortable to share their HIV status with their GP and non-HIV specialist compared to younger PLWH; Fewer participants in both groups felt very comfortable sharing their HIV status with a community pharmacist. Free-text comments showed that some older PLWH have not shared their HIV status with their GP due to a lack of trust, fears of stigmatisation and concerns around data privacy. Older PLWH were significantly more likely to share their HIV status with their GP than younger PLWH. However, despite having shared their HIV status with their GP, very few PLWH have ever booked an appointment relating specifically to HIV. Nearly half of older PLWH stated that their GP was somewhat involved with their HIV care, in contrast a large portion of younger PLWH reported that their GP was not involved at all. In the free-text comments, participants highlighted concerns that the 10-minute appointment slots with a GP would not be enough time to also cover their HIV care.

The majority of older PLWH expressed being either neutral or uncomfortable sharing their HIV status now or in the future with care home staff. Similarly, most younger PLWH felt neutral sharing their HIV status with care home staff. As PLWH are living longer, the number that may eventually need care in a care home will increase, therefore it is important to explore older PLWH's reasons for being neutral or uncomfortable with sharing their serostatus with care home staff.

Almost half of older and the majority of younger PLWH stated that they did not want their community pharmacist involved with their HIV care. Furthermore, participant responses were divided when asked whether they would share information about their HIV medicines with their community pharmacist, with more participants reporting that they would share this information during a private sit-down consultation compared to when buying over-the-counter products. Among those who reported they would be willing to share information regarding their ARVs with community pharmacists over the counter or in a private consultation, many stated it was to ensure there were no interactions between their medicines for HIV and other comorbidities. PLWH across the age groups expressed concerns around a lack of privacy, confidentiality and negative past experiences leading to them not sharing information on their HIV medicines with community pharmacists when buying over-the-counter products. Pharmacists have reported internal challenges in

previously published literature to providing medicine-related support to PLWH such as a lack of trained staff, time and insufficient experience with the psychological and mental health aspects of HIV. (241,251) Studies have shown that PLWH are highly involved with their own care, with many being the 'expert patient'. (222) Participants in this study described using interaction checkers themselves, such as the Liverpool HIV drug interactions app, and therefore not needing to speak to a community pharmacist about their HIV medicines. To improve future care for PLWH participants suggested increased knowledge surrounding HIV and proving improved privacy in community pharmacies. Community pharmacists are well placed to communicate and collaborate with other healthcare services to provide person-centred care by identifying, resolving, and presenting potential medicine-related problems. (241) Therefore, It is vital that all pharmacists are aware of important information sources to identify significant drug-drug interactions, such as the University of Liverpool HIV Drug Interaction website. (253-254)

When participants were asked whether there were any other way GPs can help them in the future, PLWH expressed the need for a reduction in stigma, homophobia and racism in primary care. As described in more detail in chapter 1, PLWH can experience several types of stigma, such as enacted, perceived, anticipated, and internalised stigma. (240) The stigma highlighted by participants in this study could be due to misunderstandings, judgmental attitudes, and a lack of knowledge surrounding HIV. (240) A recent systematic review highlighted that increased health-related stigma in PLWH can lead to decreased social support, increased anxiety and depression. (240) Moreover, stigma may lead PLWH to access care outside of their usual residency/locality and sometimes PLWH may not wish to access HIV-related services in primary care for several reasons including stigma. (226) It is essential to improve the quality of primary care and interaction between primary care and HIV specialist services to provide quality patient centred care. (33)

Social support has a key role in the psychological adjustment of individuals living with HIV. (240) Participants in this study showed high levels of perceived social support across both age groups, particularly from a significant other. The majority of older PLWH reported moderate support from family, whereas, most younger PLWH reported high levels of family support. Lower social support from family among older PLWH may be due to these individuals living through the early HIV pandemic, where stigma and negative portrayals of HIV led to lower rates of PLWH sharing their serostatus with others. (239) A higher level of education among older PLWH was associated with high perceived social support from a significant other, friends, and in total perceived social support scores.

Using fewer non-ARV medicines was associated with higher total perceived social support in older PLWH. Moreover, higher medicine-related burden scores were significantly associated with higher perceived social support scores. Older PLWH with a higher medicine-related burden reported receiving more social support from their significant other, whereas younger PLWH with high medicine-related burden received more social support from family members. This suggests that despite having a higher perceived social support level, PLWH's medicine-related burden has not reduced; these individuals may require further medicine-related support from other sources in addition to social support to decrease this burden, for instance from healthcare professionals outside of the HIV clinic. Current research indicates that greater levels of social support are associated with more positive effects than negative effects in PLWH. (255) Moreover, Studies have reported associations between increased social support and better adherence to ARVs in PLWH. (241)

Medicine optimisation interventions, such as medicine reviews or reconciliations, reduce the incidence of medicine-related problems. (177) The majority of older and younger PLWH reported having all of their medicines reviewed, predominantly occurring at their HIV clinic/hospital and within the last 12 months prior to completing the survey. A small group of older and younger PLWH reported that their medicine review occurred more than 12 months prior to completing the survey. It is recommended that PLWH's medicines are reviewed at least annually. (243) The administration of several medicines can affect adherence and in turn the efficacy of treatment if not managed and reviewed appropriately. (256) Very few PLWH reported having a medicine review with a GP and only one participant from each age group reported having a medicine review from a community pharmacy.

In contrast to the findings of chapter 4, a high medicine-related burden among PLWH was evident in this study, particularly among older PLWH, although the difference between the age groups was not significant. A high medicine-related burden in older PLWH was evident in those with a university level education. Unemployed older PLWH had lower medicine-related burden scores compared to those that were retired or employed. In contrast to the hypothesis, using fewer medicines was associated with a higher medicine-related burden among PLWH. Moreover, high medicine-related burden was evident among younger PLWH with fewer comorbidities and in older PLWH of white ethnicity. Findings demonstrated that PLWH who have a high medicine-related burden reported getting the support that they need when they have an issue with their medicines and were significantly more likely to have had a medicine review 3 to 6 months prior to completing the survey. Older PLWH reported higher medicine-related burden scores for the practical difficulties domain in the mini-LMQ compared to younger PLWH, whereas the highest burden scores were reported for attitudes/concerns about medicine use in chapter 4 with the LMQ-3 across both age groups and the second highest scores were for practical difficulties. Practical difficulties questioned in the LMQ-3 include difficulty using their medicines, getting prescriptions from a doctor, medicines from a pharmacist, the times medicines are taken, remembering to take medicines, and putting a lot of planning and thought into taking medicines; Practical difficulties in the mini-LMQ questioned whether PLWH are concerned they may forget to take their medicines. Medicine-related support from healthcare professionals can help reduce PLWH's concerns surrounding practical difficulties with their ARV and non-ARV medicines.

The impact of COVID-19 affected the engagement of PLWH with their primary care and specialist HIV clinic/hospital services within this study. Some PLWH found it even harder to get appointments with their GP and others reported experiencing more attention from healthcare professionals since the pandemic started than before. Many HIV clinics implemented effective telehealth or telemedicine measures to minimise face-to-face contact and maintain care during the pandemic. (257) Findings showed that healthcare appointments moving to over the phone or online were preferred by some PLWH, whilst others stated they 'don't ever want to replace face to face with remote again'. Furthermore, the effects of the pandemic were evident in the free-text quotes, with one participant describing how they did not cope well both mentally and physically; they lived alone and was not able to get the support they depended on. Social isolation and loneliness is an important social issue, particularly in older PLWH, that could result in poorer health outcomes. (195) Many studies have highlighted that PLWH experienced stress and anxiety not only due to the potential of contracting COVID-19 but also due to concerns surrounding the impact on their HIV treatment. (195) A recent systematic review found the

following eight key themes relating to PLWH and the social effect of the COVID-19 pandemic: stress and mental health, social isolation and loneliness, HIV care disruption and telehealth, food insecurity, impacts on income, education and employment, impacts on sexual behaviours, impacts on substance use, stigma, and racial and social inequality. (195) The differences in medicine-related burden seen between chapter 4 and 5 could also be due to the lack of or lowered medicine-related support received by PLWH due to COVID-19 disruptions, particularly with many describing difficulties obtaining a GP appointment. PLWH also experienced changes to appointment times and methods with their regular HIV clinics, with many seeing them less regularly or only over a telephone consultation for a year. Therefore, it is imperative that the aftermath of the pandemic's effects on these factors are researched in older PLWH and individuals who need extra support are targeted.

Limitations

A limitation to this study was the varying sample sizes across the analyses in this chapter, however, it was not possible to use listwise deletion as it would have significantly reduced the sample size. Due to this, the generalisability of the findings are reduced. It is important to note that the survey in chapter four, using the LMQ-3, was distributed both online and in-person, whereas the mini-LMQ was an online only survey; The difference in medicine-related burden reported using the LMQ-3 and mini-LMQ could be due social desirability bias by participants who answered the questionnaire in-person.

The low response rate may be due to a number of factors, such as, HIV being a hard-to-reach population, the questionnaire being too long, and as the survey was distributed online, this meant that only those with access to technology and internet services could participate. Moreover, the majority of participants in this study had an undetectable viral load, the study would need to be repeated among participants without an undetectable viral load to identify whether their experiences of medicine-related burden and social support differ.

5.5 Chapter summary

As PLWH are ageing, living with more comorbidities, and using more medicines, it is becoming increasingly important for healthcare professionals from a wide range of disciplines to work together to ensure continued high-quality care, improving the health-related outcomes of PLWH. PLWH are commonly using their GPs and community pharmacists for non-ARV medicines, however, this study demonstrated that the current engagement of PLWH with their primary care providers for their HIV care is low due to stigma, a need for increased training among staff, a lack of privacy/confidentiality, and negative past experiences.

High medicine-related burden was found among PLWH in this study. Moreover, using fewer medicines was associated with a higher burden. The effects of COVID-19 on older PLWH were evident within this study, with participants describing experiencing loneliness and difficulties seeking medicine-related support. Medicines optimisation interventions to reduce the number of medicines individuals are taking and signposting participants to social support groups may increase health-related experiences and outcomes in this population.

The use of free-text boxes clearly enabled PLWH to elaborate on their experiences, capturing the complexities and nuances that structured responses might overlook. This underscored the value of qualitative research in exploring the lives experiences of PLWH. Recognising this, chapters 6 and 7 employ qualitative semi-structured interviews to provide deeper insight into these experiences, offering a more comprehensive understanding of the challenges, perspectives, and unmet needs within this population.

CHAPTER SIX

Exploring the medicine support needs and medicine optimisation experiences of PLWH aged 50 years and older in areas of South East England

6.1 Introduction

The systematic review in chapter 2 and the findings in chapters 4 and 5 have provided evidence of the need to understand older PLWH's experiences, opinions, and concerns related to their medicines and care further. The qualitative work presented in this, and the following, chapter builds on the previous empirical chapters, to give a rich picture of the experience of ageing with HIV in this context, and in the following of providing HIV care to these people.

A high medicine burden was seen in a minority of PLWH in chapter 4 and in a majority of PLWH in chapter 5 across both age groups. Moreover, a higher medicine burden was associated with using fewer medications in chapter 5 and the effects of the COVID-19 pandemic on older PLWH was highlighted, with many experiencing difficulties seeking medicine-related support. These factors may contribute to the treatment burden felt by PLWH when managing their day-to-day life. (15) Treatment burden can be defined as the impact imposed on patient's and caregiver's well-being and functioning by the time and energy demands of treatment and self-care. (16,17) These include tasks such as health self-monitoring, attending clinic appointments, diet, and exercise, and managing everyday medicines use. (17) The burden experienced by patients may lead to non-adherence of prescribed treatments, an increase in hospitalisations, poor quality of life, and higher mortality. (15,18-19) Poor patient outcomes have often resulted in physicians intensifying treatment, further adding to already burdened patients. (15) Assessing treatment burden may alert healthcare professionals to patient or caregiver distress and enable treatment strategies that are less burdensome for patients. (16) Therefore, this chapter aims to explore older PLWH's experiences with HIV care and medications using semi-structured interviews.

Objectives:

1. To understand the needs and experiences of older PLWH with their medications and HIV care.
2. To examine the extent to which medicine burden and treatment burden affects older PLWH.
3. To explore medicine support needs of older PLWH

6.2 Summary of Methods

Semi-structured interviews were used to interview older PLWH to understand their medicine-use experiences and needs in further detail. Figure 6.1 displays a summary of the methods that have been presented in further detail in chapter 3.

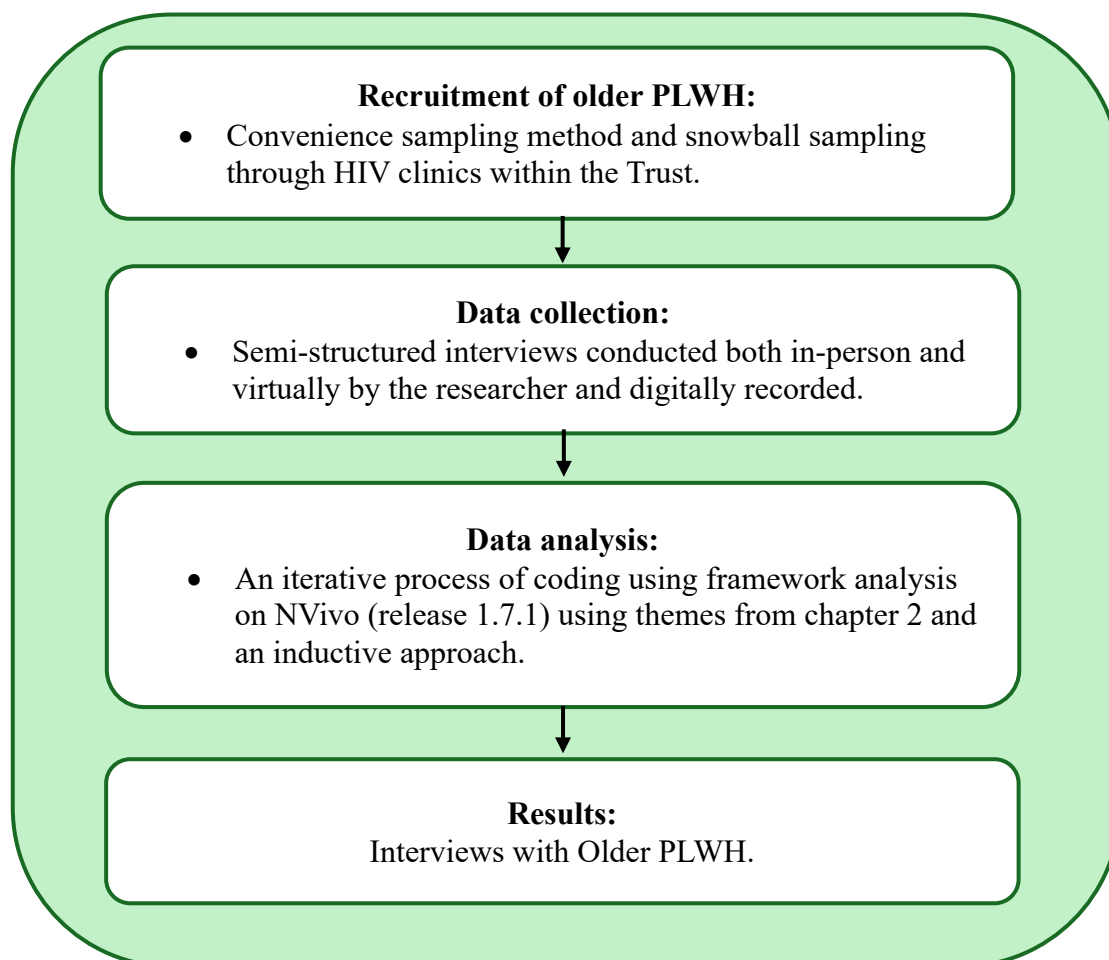


Figure 6.1 Summary of chapter 6 methods (interviews with older PLWH).

6.3 Results

To understand older PLWH's medicine optimisation needs, it is important to recognise the factors that affect their daily lives, whilst considering the role that factors such as side effects, comorbidities, and stigma play in their overall treatment. Therefore, a series of questions (Appendix 10) were discussed with participants, which has been discussed under themes within this chapter. The themes identified in the systematic review presented in chapter 2 were used as a basis to identify further themes as can be seen in Table 6.1 below. Example participant quotes have been displayed under themes in Table 6.2.

Table 6.1 Themes identified in chapters two and six.

	Chapter 2	Chapter 6
Themes	<ul style="list-style-type: none"> • Adverse drug reactions • Adherence • Comorbidities • Drug interactions • Health-related quality of life • Medicine burden • Polypharmacy • Patient and provider relationships • Stigma • Treatment burden 	<ul style="list-style-type: none"> • Ageing - Care home - Uncertainty • Adverse Drug Reactions • Adherence • Comorbidities • Covid-19 • Clinic Services • Health-related quality of life • NHS England Switches • Medicine reviews • Medicine burden • Polypharmacy • Provider relationship • Stigma • Sharing of serostatus • Social support • Treatment burden

Table 6.2 Example participant quotes under themes identified.

Theme	Sub-themes	Participant quotes
Comorbidities	Impact on daily life	“Everything’s ongoing... I have to keep going back to Chelsea and Westminster and I have to keep going back to St Thomas’ and, if I don’t keep a record of everything, then I get in a muddle as to where I’m supposed to be.” (Interview 12)
	Routine monitoring of comorbidities	“They picked up that my blood pressure was quite high...and recommended I go see my GP.” (Interview 16)
	Concerns with comorbidities	“HIV doesn’t worry me, being overweight does... my dad was diabetic, so it scares me.” (Interview 6)
Health related quality of life	Lifestyle adjustments due to antiretrovirals	“I was told to take my antiviral drugs in the morning because people were forgetting them at night because they were so busy going to nightclubs.” (Interview 12)
	Persistent side effects	“With HIV, you never feel 100%... I always felt like I was sort of under the weather all the time.” (Interview 4)
	Mental health challenges	“I’m under the community mental health team now because of suicidal thoughts... a product of isolation and being lonely.” (Interview 15)
Adherence	Use of adherence aids	“I take them at night. It’s a daily strip... and I just pop one out... so that’s pretty easy.” (Interview 14)
	High adherence	“I’m so conscious I’ve got to take that tablet at ten... I have to take that HIV tablet religiously and that’s how I’ve always been with it.” (Interview 22)
	Challenges to adherence due to lifestyle disruptions	“In the pandemic I forgot twice in the first week, you know, there were all sorts of other things going on.” (Interview 11)
Treatment burden	Managing clinic appointments	“The main thing for me is trying to fit it in with my, with my work... sometimes I have to leave work early and that can be a little bit stressful... if it’s a busy day at work it’s sometimes quite difficult for me to get away.” (Interview 1)
	Travel and logistical challenges	“Parking at the health centre is a bloody nightmare. There is no parking at all, and it’s all permit controlled around it.” (Interview 11)
Medicine burden	Managing multiple medications	“When I first started taking tablets there were dozens, you had so many pills to take. Now they’re – you know, within one pill basically... Before it was more difficult.” (Interview 13)
	Planning around medication use	“The evening one was always more problematic... if I’m on my way to a party or the cinema.” (Interview 1)
Polypharmacy	Preference for fewer tablets	“I prefer just taking one tablet than taking two tablets.” (Interview 16)
	Complexity of managing multiple drugs	“I just down them all in one go... years of practice.” (Interview 23)
Adverse drug reactions	Physical and mental side effects	“Atripla... The mental effects of the drug were quite alarming and really quite frightening... I became very disorientated and had trouble doing my job or driving.” (Interview 1)
	Adjustment to side effects over time	“I’ve never been so ill in all my life. But I persevered.” (Interview 14)
Medicine review	Monitoring prescribed medications	“The doctor should review my medication... Because they keep giving me tablets, nobody checks up to see whether they’re actually doing the job they’re supposed to do or whether you’ve got any side effects.” (Interview 6)
NHS England switches	Changes due to cost-saving policies	“They swapped me out into the two tablets, which I wasn’t too happy about, ‘cos I prefer just taking one... but it was cheaper for the NHS... but it’s more inconvenient for me... They’re like horse pills... it’s a bit frustrating that way and I think that’s the only thing that really annoys me about it is I don’t have a choice in what’s sent to me.” (Interview 16)

Table 6.2 continued.

Social support	Importance of social networks	"I'm not a very well person so he [husband] will need time to take me for appointments and everything." (Interview 19)
	Mixed feelings about support groups	"I don't want to sit around and just listen to a load of people going on about them and promoting HIV awareness. No, I don't. I want to get on with my own life." (Interview 10)
	Fear of serostatus being shared within support settings	"I still don't want people to know. Um, yeah, I'm embarrassed and ashamed, really, that I've got myself in a pickle." (Interview 11)
Stigma and sharing of serostatus	Experiences of stigma	"You had to hide everything and... live a lie to survive." (Interview 13)
	Sharing of HIV serostatus	"Health professionals, as far as I'm concerned, they can be told. I've told them on the phone, but not across the counter, 'cos someone else might hear." (Interview 17)
HIV clinic services	Satisfaction with clinic care	"I like going in, really, because they're like friends to me now, we have a laugh." (Interview 22)
	Communication and appointments	"I mean it's a silly thing but the telephone at first felt like it wasn't a very personal service... But when you think about it unless there's something serious it takes five minutes to have a chat on the phone... What is the point of me coming all the way here from home and waiting to see the doctor." (Interview 6)
Provider relationships	Trust in HIV clinic staff	"I trust my HIV doctor, I'm not sure I trust my GP in the same way." (Interview 1)
	Limited trust in community healthcare	"I think some GPs, they don't understand HIV especially in a rural area like where I live." (Interview 1)
The COVID-19 pandemic	Fears around mortality	"It was totally down to probably anxiety, you know, what happens if I catch Covid, you know, am I going to die, etc." (Interview 25)
	Accessing healthcare during the pandemic	"The other frustration I've had with care since covid hit is trying to see my GP." (Interview 16)
Ageing and uncertainty	Fear of future health decline	"I just think that my health is going to pack up one way or the other before I ever have to get into the fact of what am I going to do when I get older." (Interview 14)
	Uncertainty about long-term antiretroviral effects	"I've always believed that I'm going to die younger because I've got HIV, and probably because of the meds I take." (Interview 15)
	Living beyond expected	"The thought of getting older, if we're talking HIV-wise, no, I haven't because I was supposed to live five years and I've lived forty beyond my death sentence... so if I die tomorrow so be it, I am very lucky." (Interview 13)
Care home	Fear of discrimination in care homes	"I've heard stories of where HIV patients have gone into, not so much private ones but, you know, NHS care homes and have been treated really badly because of their status... That worries me." (Interview 13)
	Desire for privacy and control	"The only thing that would concern me is maintaining the privacy of who would know... going into something like a care home or an assisted living accommodation, I think that control has gone, because you're having to have it marked on your records, which then anyone who comes and works at that place has access to." (Interview 16)

6.3.1 Participant characteristics and response rate

A total of twenty-six interviews were completed with older PLWH. Overall, the recorded duration of interviews was 1,128.44 minutes, with interview lengths ranging from 11.47 minutes to 158.13 minutes (median=37.28 minutes). The majority of participants were white males, despite increased efforts made to recruit different demographics. Interviews were conducted both in person and virtually. The option of telephone interviews increased the number of individuals agreeing to take part from minority ethnic groups.

6.3.2 Comorbidities

It was evident that comorbidities affected the daily lives of older PLWH. For many it impacted them more than HIV, for instance, one participant reported losing their ability to drive due to having a stroke, and another individual mentioned having disturbed sleep due to urinary incontinence causing them to go to the toilet five or six times a night. Although, some older PLWH have stated concerns that HIV was the cause of or has worsened their comorbidities. One participant described concerns of HIV leading to them getting cancer or having a heart attack in the future, and another stated that they think that HIV will kill them as it will cause something that will make them unwell, such as neurosyphilis, and so despite taking ARVs they feel that they still have to be careful.

It emerged from several older PLWH that many of their comorbidities were discovered during routine bi-annual or annual appointments. Participants highlighted the advantage of these routine appointments, emphasising that without their HIV diagnosis, the timely detection and diagnosis of their comorbidities might not have occurred. Furthermore, participants felt that their comorbidities were monitored more carefully as they were living with HIV.

“I started suffering with some really bad headaches and blurred vision. And it was actually when I went to see my HIV nurse and they check all my blood pressure when I was doing my normal six-monthly check, they picked up that my blood pressure was quite high, and she recommended I go and see my GP”.

Interview 16

“Other health situations being monitored a little bit more carefully than perhaps they otherwise would be, which is a good thing in a way because I'm in my fifties now”.

Interview 25

It was clear that some older PLWH were more fearful of their comorbidities causing mortality than HIV. For instance, one participant mentioned that they believe they are more likely to die due to their blood pressure rather than their HIV. Similarly, another participant stated, “HIV doesn’t worry me, being overweight does, I’ve seen what it does to people...my dad was diabetic, you know, because of it so it scares me” (Interview 6). One participant was worried about having comorbidities as their consultant had always told them that as they are immunosuppressed, it would have to be taken more seriously when treating them, for instance, they were told that “a cold isn’t just a cold for you, a cold sore isn’t just a cold sore for you” (Interview 18). Moreover, another participant expressed concerns regarding discussions with their HIV consultant about their cardiovascular risk score (QRISK score), which informs whether you are at a low, moderate, or high risk of a

cardiovascular event in the next 10 years, as despite being on tablets for their cholesterol and not having any unhealthy habits, this individual's cholesterol and subsequently their QRISK score had not reduced over the years.

Many older PLWH interviewed with several comorbidities stated that they were organised with their information regarding HIV and their comorbidities, because they felt that they had to be in the past, with one participant having a folder for each of their conditions.

"Because, you know, everything's ongoing. You know, I have to keep going back to Chelsea and Westminster and I have to keep going back to St Thomas' and, if I don't keep a record of everything, then I get in a muddle as to where I'm supposed to be".

Interview 12

6.3.3 Health-related quality of life

Despite older PLWH in this study stating that they did not have to make many lifestyle changes due to their ARVs, when recollecting when they first started taking ARVs, many mentioned adjustments or changes they had to make or were advised to make due to their medicines. One participant recounted going out and drinking alcohol more when they were first put on ARVs but being advised to be careful with drinking alcohol. Others described the difficulty of taking multiple tablets throughout the day when they first started ARVs, and several mentioned a feeling of being drunk after taking ARVs that wore off after a while. Some long-term survivors stated changing their lifestyle and sexual encounters either after being diagnosed or when those around them were dying, for example, one participant said "when this disease came along, yeah, you had to change your lifestyle. When you saw your friends dying, you know, you had to change your lifestyle because we were all so worried about it" (interview 13). One participant reported that the lifestyle changes that they have had to make were not because of HIV but were due to old age and the effects of chemotherapy on the nerve endings of their fingers.

"I was told to take my antiviral drugs in the morning because so many people were forgetting to take them at night because they were so busy going to nightclubs and having a good time."

Interview 12

"Before it was more difficult. It was every like – I think when I first started taking tablets it was like every so many hours you had to take another one and then another one. It was like a combination of loads to begin with and throughout the day."

Interview 13

One participant reported that you never feel completely fine when living with HIV, and it was evident that some older PLWH fit their lifestyle around the side effects of their medicines. Some older PLWH reported making lifestyle changes to reduce weight gain.

“Well to be quite honest I’ve never - with HIV you never feel 100%.... I always felt like I was sort of like under the weather all the time.”

Interview 4

“I started putting on weight and I have never been a woman of weight...I’m trying to control and take it back where it used to be...I’m trying to fast and do whatever is right for my body.”

Interview 3

Participants also described how the side effects of treatment for comorbidities, for example, chemotherapy affects daily life, but they have learnt to live with the side effects.

“The only lifestyle changes I’ve had to make have been due to old age and the effects of chemotherapy on my nerve endings in my fingers and feet...it’s made my walking quite painful and slow...I have trouble doing up buttons...But, you know, you learn to live with it”

Interview 12

A shift physically and mentally was evident between PLWH being told that they will only live a few years to then being told that they will live a near to normal life expectancy. Many older PLWH cashed out their life insurances, sold or lost their homes due to their positive serostatus, or made funeral arrangements but have lived many years after this. Participants stated that the experience of living with HIV has led them to be grateful for each day. Moreover, several participants reported only finding out recently that having an undetectable viral load meant that they could not transmit HIV and wishing they found out about this sooner.

“If you’ve been through what I’ve been through you’re grateful for every extra day you can get”.

Interview 12

“I’d only married my husband five years ago and when we first were together, we were using condoms because I thought that it was transmittable, and it was only in that time that I’ve found out that it’s not transmittable because it’s undetectable in my blood stream. So, it’s within the last five years”.

Interview 22

One participant described their long-term struggle with drug misuse, addiction and mental health difficulties, they stated how this affected their work and led to them being suspended, causing more stress. They stated that these issues were a product of loneliness and childhood trauma, which were triggered by isolation due to COVID-19.

“I’m under the community mental health team now because of suicidal thoughts and all that kind of stuff that’s gone on, and that is definitely a product of isolation and being lonely, and yeah, just childhood trauma, all of that that came back when I was on my own through the covid experience”.

Interview 15

Moreover, a few participants have mentioned having suicidal thoughts in the past.

“I did think about at one point taking the whole lot in one go but I thought no I won’t do that. Because having worked for the ambulance service I know what that can do, you know, literally destroy every organ in your body, and especially if you live then – which is even worse.”

Interview 4

In contrast, there were several participants that stated that as their HIV is managed, it does not impact their daily life much. One participant stated, “HIV doesn’t affect my life, the medication seems to do its job, I don’t worry about it”. Another participant said that their family and they themselves always forget that they are living with HIV.

“I think I’m leading my life pretty much exactly as I would have done, had I been negative. Other than that, I’m taking some tablets and I have to go to the clinic twice a year”.

Interview 25

6.3.4 Adherence

Overall, most older PLWH reported a high adherence to their medicines. Many described using adherence aids, such as Dossett boxes, to help them remember to take their medicines, particularly when using multiple medicines, whilst others attributed their good adherence to being on the tablets for a long time.

“I take them at night. It’s a daily strip. It’s like having a strip of tablets, and I just pop one out and that’s me until the next day, so that’s pretty easy, really.”

Interview 14

“I was like, “I need to remember how to do this,” ‘cos I know I’m hopeless when it comes to things like antibiotics and things, and when did I last take my antibiotic, you know. When you’ve got to take them three times a day, it’s very confusing. So, I’ve always been conscious, more so with the HIV medication than anything else. I know I have to take it every day, and if I don’t take it every day, it’s going to cause me problems, so that’s why I sought out a way of making sure I did it when I needed to do it.”

Interview 16

Several older PLWH described high adherence being due to them viewing their ARVs as imperative to being alive and feeling “lucky” that they have the medicines. One participant described having to get over the feeling of ‘if I don’t take this pill, I’m going to die’ when first starting ART. It was evident that some participants viewed their HIV medicines as more important than medicines for their comorbidities.

“I think to me the medication is prescribed for a purpose and that purpose is usually to keep you alive and, if you ignore it because you’ve forgotten or it’s not important, then I can’t see that there’s any hope for you.”

Interview 12

“I’m so conscious of it, I’m so conscious I’ve got to take that tablet at ten – whether I take any of the others, I don’t care, I have to take that HIV tablet religiously and that’s how I’ve always been with it.”

Interview 22

Participants described creating a routine as a significant factor for maintaining adherence. When asked what they would recommend to those struggling to remember to take their medicines, many older PLWH suggested associating taking their medicines with a certain time of the day or task. Others attributed their adherence to support from family and friends.

“I’ll tell you what, because my husband is a nurse and so he is always there to see that the tablets are in the packet.”

Interview 19

One participant recollected struggling to remember to take their medicines when they were first put on ARVs as they did not have their Dossett box, meaning they often missed a pill. Similarly, other participants stated missing tablets when their routine had been disturbed. One participant who struggled with drug use, reported not taking their medicine for up to two weeks when they were going through a relapse as they could not remember the last time that they took their ARVs, which led them to share their serostatus with a friend at work who would send a text reminder every day at 10pm.

“In all the years I’ve been diagnosed, I forgot once in the first week, I just forgot to take it ... And then in the pandemic I forgot twice in the first week, you know, there were all sorts of other things going on and I – but ever since then it’s the first thing in the morning as soon as I get up.”

Interview 11

“Occasionally, I’ve been late or forgotten, you know, it’s mainly when you’re on holiday and therefore the routine is slightly changed or if I’m in a meeting or something.”

Interview 25

However, one participant described “chemsex” as a possible reason for why gay men may not take or not stick to their ART regimen. Two participants reported forgetting to take their medicines when using drugs, with one participant reporting having to put a plan in place for when this happens.

“When I do use, I obviously forget to take my medication... I just can’t remember when I last took it... And I’m so confused about what day it is. I’ve now got something in place

where a friend of mine, she will text me at 10pm – if she knows that I'm using, she'll text me at 10pm and say, "Have you taken your meds?" And it's like – 'cos I thought, I need to put something in place just in case. So, if it went five, six, seven days – and then I'm usually depressed for a good ten days after, you know, an episode like that, so you're talking nearly two weeks where I may not be taking my medication."

Interview 15

One individual described forgetting to take their acid reflux medicine as they knew they were “not going to die” from the missed pill. A female participant reported failing to use medicines that are not supplied in a Dossett box.

"I keep forgetting to do this Vagifem thing, I think, did I do it or didn't I do it? I don't know if I've done it or not because you can't put that in a Dossett box."

Interview 22

When asked if they had any advice to help PLWH take their medicines, participants mentioned a good support network and those who had partners also living with HIV, reported that this was very useful as they support them with their treatment and remind them to take their medicines.

"It depends if you've got a good support network as well, I mean, it's not the kind of horror story it was when I – you know, when I was in my twenties and stuff, so yeah, I did work in kind of that area, HIV, AIDS, met lots of people and they became very ill and stuff like that. So I've got some, you know, memories of that time that were quite bad. But it just seems to work now, so – which is fantastic, I mean, you know, who would have thought, you know, what was kind of a death sentence has just, you know, changed completely and so quickly."

Interview 21

6.3.5 Treatment burden

Some participants stated that they do not have difficulty fitting clinic appointments around their lifestyle as they have been retired for a while, whilst others who were employed stated that their workplace were accommodating with their clinic appointments. Many participants spoke positively regarding yearly appointments, however, one participant highlighted how reducing the frequency of clinic appointments could worry PLWH as they may feel that they are not being looked after as well.

"It would be lovely to see the doctor twice a year, it's just – it's like a safety blanket, because I've lived through this whole thing and it's still like that safety blanket slightly being taken away, but you don't need it anymore, you know, we're healthy."

Interview 13

In contrast, one participant reported clinic appointments during the week being difficult to manage with work and another participant reported that the afternoon appointments were a nuisance with transport as they were blind and had to rely on a transport service. This participant also mentioned incidents where they had waited

for over five hours without any food or water for the transport service to pick them up from the clinic, or times when they did not come to pick him up from his home. Furthermore, one participant described struggling to attend appointments for their comorbidity as it was weekly warfarin monitoring. Some participants also described difficulties travelling to different hospitals for treatment of their other conditions.

“The main thing for me is trying to fit it in with my, with my work, you know, sometimes I have to leave work early and that can be a little bit stressful Because obviously the clinics don’t take place at weekend. So, I’m, you know, if it’s a busy day at work it’s sometimes quite difficult for me to get away.”

Interview 1

“It is time consuming, especially going up to London. The journey last week when I went up for the PET scan was fairly horrid.”

Interview 12

It was evident that some older PLWH who have been living with HIV for several years have worked through difficult emotions in the past regarding their HIV clinic appointments and now enjoy visiting the clinic.

“I used to really hate going to the clinic, I used to get anxious, I used to get upset. I used to – you know, it was awful back in the day, get grumpy and get angry, and my partner used to know that I was – there was an appointment due, but that was back in the day. But now I quite like going, have a little laugh with them.”

Interview 18

Many participants reported not having any concerns about travel costs to the HIV clinic, with several participants mentioning that the clinics are quite close to where they live. One participant stated they pay £2.60 for the car park near their HIV clinic, and another pays £1.20. Although, one participant described struggling to find parking when attending their clinic appointments.

“It’s not an issue where exactly it is, other than the fact that parking at the health centre is a bloody nightmare. There is no parking at all, and it’s all permit controlled around it. There’s a parking area at the clinic, but it’s just staff only.”

Interview 16

Participants did not have any concerns with paying for prescriptions, many were receiving free prescriptions or paying for an NHS prescription prepayment certificate. However, one participant mentioned frustration that NHS prescriptions for blood pressure medication must be paid for, but prescriptions for thyroid medications are free. This participant questioned why there was this difference as both conditions are equally as important to the individual. One participant reported getting their comorbidity medication online as it was a lot cheaper than an NHS prescription.

HIV medications can either be delivered to older PLWH's homes, pharmacies or be collected in person at the clinic. The majority of older PLWH have their medications from the HIV clinic delivered to their homes; They receive a phone call from the delivery company to organise a suitable date and time for delivery of their medications or they are able to choose a delivery slot from the company's website. One participant, who gets their HIV medications delivered to their home, stated that they usually have to call the delivery company back to arrange a delivery time to make sure it does not clash with their shifts. Participants stated that the medication arrives in a plain box with a 'private and confidential' yellow label. For those that collect their medications from the clinic, reasons included people at home not knowing their serostatus and concerns of others seeing the medication boxes. Another individual chooses to collect from the clinic instead of having to wait around and sign the home delivery. One participant described how difficult it was for them to collect their non-HIV medication from their local community pharmacy, leading them to now get their medications delivered. Older PLWH reported being very nervous when their medications aren't delivered early, with one participant describing becoming worried when they only had a weeks' supply left, but after speaking to the clinic and delivery company, they received their medication within three days.

"I'm finding it more and more difficult to walk and it's all uphill... I have to stop about three times for a rest, I'm always short of breath and my legs – so and it's – there's nowhere to park up there, so I just get them delivered."

Interview 11

Several participants described that their HIV clinic have been very accommodating with their appointments and have rearranged it to more suitable times when needed, this meant that some participants did not need to share their HIV status with others.

"I was quite lucky because on the GUM people, doctors, and nurses, were very good, you know, they always tried to squeeze me in super early in the morning or super late of a night. So, I didn't actually have to tell anybody that I was, you know."

Interview 4

6.3.6 Medicine burden

When discussing the burden of medications, older PLWH compared their current ARV regimens to their experiences of when they were first diagnosed, reporting that the medications and their side effects are much better than before.

"When I first started taking tablets there were dozens, you had so many pills to take. Now they're – you know, within one pill basically... Before it was more difficult. It was every like – I think when I first started taking tablets it was like every so many hours you had to take another one and then another one."

Interview 13

Despite currently using multiple medicines, many older PLWH denied experiencing difficulties as it was now a part of their routine. For instance, one participant who has been using up to eleven medications for several years stated that it was not difficult as it is part of their routine, but they stated they could do without it and are hopeful for a day where research leads to them having to take less tablets or an injection instead.

In contrast, there were several participants that described daily difficulties associated with taking tablets. The sizes of tablets caused problems for some older PLWH, with one participant described their ARV to be the size of a “house brick”. Moreover, one participant described mastering the art of being able to swallow five tablets in one go with just their saliva so that they can take them in the car. One participant recounted that the hardest part to come to terms with when diagnosed with HIV was that once they took the first tablet, there was no going back and they will have to continue to take one tablet a day for the rest of their life. As described under adverse drug reactions, older PLWH recounted issues with nausea, vomiting and struggling to drive or work when first taking ARVs. One participant described struggling mentally when they first had to start taking ARVs but as their partner was also starting tablets, they were able to do it together with each other’s support.

“Sometimes they get stuck in my gap in my tooth and I spend about an hour trying to get it out, you know, the small ones they’re so tiny.”

Interview 4

“No, no. If that’s – well, in one go, there’s probably five or six of them. I just down them all in one go...Years of practice”

Interview 23

“I’ve never been so ill in all my life. But I persevered. Well, you’ve got no choice, have you? And I mean, they say you have, but you haven’t. I mean, the way I looked at that was you either take the tablets and your body gets used to taking them, and hopefully you live a life taking them, or you don’t take them, and you don’t live much of a life ‘cos you don’t know how long you’ve got.”

Interview 14

One participant reported difficulties taking their medication around evening social plans, such as attending parties or the cinema. Furthermore, older PLWH described having to do extra planning when leaving the house for several days or going on holiday to ensure they have enough medication in the event there are any delays with their travel. Participants described decanting their ARVs into containers without labels and carrying them in their hand luggage to prevent any chance of them going missing.

“The evening one was always more problematic because remembering to take a drug in the evening when you might be on your way to, you know, a party or a cinema or a dinner, going out with friends was always difficult.”

Interview 1

6.3.7 Polypharmacy, Adverse Drug Reactions, and Medicine reviews

Polypharmacy

Overall, older PLWH did not complain about the number of medications they had to take. The majority of participants were taking five or more medications. Common medications other than ARVs taken by older PLWH included those for blood pressure, cholesterol, diabetes, acid reflux, thyroid, and depression. Older PLWH reported frequently buying Gaviscon, vitamin D, multivitamins, antihistamines, and paracetamol over the counter.

Participants stated they would prefer to take their ARVs in one tablet instead of two or three. As described under medicine burden, some older PLWH were hopeful for a day when they can take fewer tablets or use the injectable ARVs.

“I was started originally on the one tablet that had all three of them combined, and then they swapped me out after my sort of levels settled, and they swapped me out into the two tablets, which I wasn’t too happy about, ‘cos I prefer just taking one tablet than taking two tablets, but it was cheaper for the NHS, and that’s why they said they were doing it.”

Interview 16

Adverse Drug Reactions

Despite several older PLWH stating that HIV and their medications did not affect their quality of life, when questioned further, a history of experiencing side effects from various medications was revealed. Although, there were several participants that labelled themselves as being “lucky” for not experiencing any side effects from their ARVs. Moreover, one participant also described themselves as being lucky because there is nothing wrong with their heart.

Participants described experiences of adverse drug reactions from previous ARVs leading to them being prescribed new ARVs, which had then caused a different side effect. Some participants mentioned their ARVs being changed due to side effects such as causing ‘weak, brittle bones’.

“I took something called Atripla...The mental effects of the drug were quite alarming and really quite frightening...I became very disorientated and had trouble doing my job or driving...When I went from Atripla to a second HIV medicine, it caused me to put on a lot of weight around my stomach and this again was a common, unwanted product of this particular regime”

Interview 1

A long-term survivor of HIV described their history of taking various ARVs and the negative effects these drugs had, such as night sweats, nightmares, effects on nerve endings, paralysis, renal toxicity and stated how now there are safer and more tolerable drugs. Many other older PLWH had similar experiences, as well as reports of nausea, vomiting, diarrhoea, bone thinning, a rash, general pain, weight gain, and issues with kidney

or liver failure. Several male participants reported experiences of erectile dysfunction, and their acceptance to live with it. One female participant described feelings of depression due to the weight gain caused by her ARV.

Some participants described their side effects going away over time as they got used to the medicine and others described using trial and error to find when or how they should take their medicines to reduce the side effects they feel. Some participants reported not expressing concerns with the side effects they were experiencing for several years. One participant recollected going on years before changing their ARV as they did not realise that it was the cause of the diarrhoea they were experiencing. Moreover, due to the side effect this participant had to carefully plan if there were going to be toilets wherever they go, describing this as ‘quite difficult’ but stated that changing to a new ARV without this side effect transformed their life. This participant also blamed themselves for not having asked their doctor if it was their medication causing the side effect sooner, but stated “I’m taking these tablets, they’re keeping me alive, so, you know, why should I complain about them”, interview 21. Moreover, long-term survivors living with HIV recounted refraining from expressing complaints about any present side effects, noting that they are significantly more manageable in comparison to the severity of the side effects that they endured when first using ARVs in the 1990s and early 2000s.

“So to start with you were taking these very toxic drugs and they made you fell ill, basically, to survive, because it was either you develop full-blown AIDS and you died, or you suffered side effects and stayed relatively healthy... on the earlier ones, it would keep you just about safe so you put up with the side effects. There were a lot but nobody complained about it, I mean, some people wouldn’t take them because of the side effects but then they died, I mean to me there was no choice.”

Interview 13

In contrast, there were also several participants who did not experience any side effects from their medicines.

Medicine review

Some participants stated they have not had a medicine review by a pharmacist, others reported having a medicine review with their GP and a few reported never having had a medicine review. Participants described being asked at every clinic appointment what medications they take and if they are still on the same medications. Several participants reiterated not having a medicine review from their GP as they have found it very difficult to even get an appointment. One participant showed frustration over their GP not reviewing their medications and not being asked if they are experiencing any side effects. Another participant stated that they would not recommend medicine reviews from a GP due to a lack of knowledge.

“The doctor should review my medication every eighteen months or every two years, or maybe every year I don’t know. Because they keep giving me tablets, nobody checks up to see whether they’re actually doing the job they’re supposed to do or whether you’ve got any side effects, they just give you the medication.”

Interview 6

Older PLWH reported positively to wanting medicine reviews with pharmacists to learn more about the medications they are taking.

“It would be nice to sit down with a pharmacist, who could say, “This is why you’re still on it. This is what it does.”

Interview 15

6.3.8 NHS England switches

At the time of this study, PLWH within the clinics were having their ARV medications changed due to the NHS England switches that were being implemented. These switches were reported to be due to the NHS having a five-year cycle where changes are made due to prioritisation around budgets and maximising medication cost efficiency. NHS procurement bulk procures HIV medication for NHS patients and the contracts are negotiated where it is not cost effective to provide certain medication. Within HIV care, a lot of medication are co-formulated into single tablet regimens, where they could contain two or more drugs in one tablet, reducing the number of tablets an individual must take. However, if these single tablets are not cost effective then the drugs must be prescribed as two or more separate tablets as appropriate, which could mean that some individuals are going from taking one tablet to up to four instead.

Several older PLWH had shown frustration around the NHS England medication switches, where many have been changed from taking one tablet to now taking two or more. Despite expressing their frustrations, the majority of older PLWH stated that they would continue to take the tablets and it should not be too much of an issue, as taking their medications is a part of their routine.

“They swapped me out into the two tablets, which I wasn’t too happy about, ‘cos I prefer just taking one tablet than taking two tablets, but it was cheaper for the NHS, and that’s why they said they were doing it... it may well be cheaper for the NHS, but it’s more inconvenient for me, you know, because they’re not small tablets. They’re like horse pills, you know, so taking two of them every day rather than just one, just because it’s cheaper for the NHS to pay for it... it’s a bit frustrating that way and I think that’s the only thing that really annoys me about it is I don’t have a choice in what’s sent to me”.

Interview 16

“In a way, it was going to be more inconvenient because there’s two tablets, but at the end of the day, they’re both going to be taken at the same time of the day, they’re going to be taken in the same way as I took the other one. So really, it shouldn’t make any difference at all”.

Interview 25

A few older PLWH described experiencing side effects, such as nausea and dizziness, when starting to take the new tablets they were prescribed. Some older PLWH stated that taking their tablets at night instead of during the day helped to reduce these side effects. It was reported that the side effects reduced after a few weeks of being on the tablets.

6.3.9 Social support

Older PLWH described several benefits of having social support, such as help with adherence, depression, and advice about side effects from partners, friends, and social support groups. A few participants discussed episodes of low mood and depression in the past but stated that they got through this with either support from a partner or therapy sessions. It was evident that some older PLWH rely on their family and friends to support them with attending clinic appointments. Some participants described how their partners would ask how they are and how their clinic appointment was, whereas another participant stated that their family who knew of their serostatus would never talk or ask about HIV.

“I’m not a very well person so he [husband] will need time to take me for appointments and everything”.

Interview 19

Participants who were attending support groups with other PLWH reported enjoying socialising with others and discussing their experiences of living with HIV. Some participants also stated searching for a support group when they were first diagnosed but there were not any set up in their area.

“I most certainly would [recommend support groups] because it gives you a chance to bounce things off each other and, you know, your experiences and who you’ve told about your situation, who you haven’t... It would have helped in my early diagnosis, like 2015, to have known about a support group. I mean, I looked online and there was nothing in [their county] and now there is. And I was desperate to talk to other people about my condition and there was no one”.

Interview 12

“In London more so, everything’s there for you, they had support groups and all this sort of thing. Where I lived, starting in [Location], there wasn’t anything, really... The set up in London was completely different...I was amazed, all these support groups all over the place, like Terrence Higgins and all this, and Lighthouse”.

Interview 13

The more problematic negotiation of disclosure and exposure/stigma was also raised in relation to seeking support from others.

“If it [support group] was out of town, maybe but in town, you know, I don’t want people – even after all these years, it’s not – it hasn’t got the stigma it used to have but I still don’t want people to know. Um, yeah, I’m embarrassed and ashamed, really, that I’ve got myself in a pickle”.

Interview 11

However, several participants described not wanting to join or continue going to support groups as they do not want to think about HIV outside their clinic appointments. Similarly, one participant who attends a support group started missing some sessions as they did not want to discuss HIV all the time. The participant above

(11) did not want to join a support group if it was in their town as they did not want people to find out that they are living with HIV due to fear of stigmatisation, with others feeling similar discomfort.

"I didn't like going [to support groups]. They were asking me how I was, you know, I just hated it, I hated putting so much attention on the fact that I had it [HIV]".

Interview 18

"I don't feel the need for a support group. And also, you know, I don't particularly want to identify as an HIV positive person, you know. To me it's one of the least important aspects of my existence, you know. Because it's just a few tablets I take once a day it's really, it's really of no consequence to me".

Interview 1

"I joined one online one once. But I, no sorry [laughs]. I deal with my own issues. I don't want to sit around and just listen to a load of people going on about them and promoting HIV awareness. No, I don't. I want to get on with my own life, I'm not a flag waver".

Interview 10

A long-term survivor of HIV reported not needing a support group now as they have been living with HIV for forty years and live a 'normal' life. Some long-term survivors were describing how they have lived through a lot of their friends passing away from HIV over the years, particularly during the 1990's and early 2000s, leading to some loneliness.

"I'm forty years ago now... I'd access it [support group] myself if I needed it. I live a very normal if you like, just an integrated life, you know. It's great to be married and have the same rights as heterosexual people and live with heterosexual people ... It's absolutely brilliant, things have changed so much, unbelievable".

Interview 13

When older PLWH were asked if their concerns around support groups would be reduced if it was age specific, some strongly disagreed, stating they don't want further separation, and despite being over 50 years old themselves, stated that "people in their fifties, they're so boring". Another participant suggested instead of an age-specific support group, they would prefer a male and female group so that they could be more open about their experiences, which they believe would not relate to women.

"No, you've got to mix with young people, otherwise you'll never feel young yourself. Oh, no, I don't want to mix with old people".

Interview 12

"It would be like a male group or a female group, so that you can be more open with each other, rather than a mixed group. Because I think sometimes you can't – I wouldn't know where to even start with a woman... I wouldn't be able to give them any recommendations or advice or anything,

because, you know, what I'd be thinking about is me as a man, you know. So, I think if I was to do a group, it would probably be for me more beneficial to be in an all-male group".

Interview 16

Participants reported feeling lucky to have great support from the clinic. However, a few older PLWH reported their HIV clinics not suggesting or informing them of any available support groups and several participants who have been living with HIV for a number of years stated they would join support groups to help others and answer their questions. One participant reported that they have never mentioned that they needed support to the clinic staff as they keep that part of their life to themselves and "just get on with" it. Another participant mentioned previously joining a support group, but the funding was cancelled for it.

"I consider myself really lucky, I have great support here, you know, looking after my health. I'm very happy in my relationship, lovely home, great friends".

Interview 13

"I've not actually had anything sent to me, like, "Oh, there's this group running that runs every Wednesday in this location. You might want to go and see – you know, you might want to join it. It's a group of individuals with the same problem," type of thing, none of that. I don't know any groups that are running... I think I would probably use it, if nothing else, to provide support to other people... and someone who's maybe been newly diagnosed can come and see, well, you know, I am a fifty-year-old bloke who's got it and I've had it for twelve years. Just because you've been diagnosed with it, it's not a death sentence.".

Interview 16

One participant reported that they do not use a HIV support group as where they come from, support is not available, and they had to train their mind to find the information they needed themselves.

"Where I come from in Africa somebody can even be quiet and quiet and quiet, you don't have nobody to support you. You have to train your mind, to train your brain to go on social media, to read what you read and to get what you need. To find yourself, you are your life".

Interview 3

When asked what they would like to get from a support group, one participant mentioned social interaction, knowing others are living life the same way that you are and that they are managing to survive. Another individual liked the idea of meeting people, dating, and seeing others who are also living with HIV and described hoping that once their son moved out, they could have someone move in with them who knew their serostatus. This participant reported finding a dating site for PLWH when they were first diagnosed but it was expensive to join, they stated it would be nice to have a free dating service for PLWH only.

6.3.10 Stigma

Many participants recalled having to hide and lie about their HIV status for many years due to fear of being stigmatised, with several PLWH not sharing their status with families, friends and, in a few instances, partners. Participants described not being able to get life insurance for many years due their HIV diagnosis. Some older PLWH reported having to lie to health insurance companies as they would not be able to get insurance if they shared their HIV serostatus and others reported having to lie to keep their jobs.

“You had to hide everything and that wasn't nice, living a lie and you had to live a lie to survive”.

Interview 13

“When you get into a new relationship, when is the best point to tell them and are they going to do a runner as soon as you tell them? Because of I suppose the ignorance of what it is, because as far as I can see, I mean, it's come a long way since the first times when it like first came out, all the treatments, etc, but the stigma and the people that talk about it, although there are a couple of celebrities now that come out and say, “I've got this and I've got that,” it's very much under wraps, as far as I can see”.

Interview 17

Stigma around HIV is also linked to ART, and the experience of taking medicines. Moreover, some participants reported hiding their ARVs and taking them in private, even around family members. Another participant described encounters where people have said “Oh, you don't look ill. Why are you taking tablets?”.

“I don't like to make a big thing of taking my tablet in front of groups of people. So for instance, if I'm having a lunch with the family, what I don't want to be doing is proudly taking out my tablets and taking them. So I normally have to be more surreptitious, either by going to the toilet or whatever and sort of having it with water in there or, you know, waiting later because I know it works on the digestion system, so you have it with your meal, but I suppose you can have it after your meal provided it's within a certain amount of time. They're the only inconveniences really, nothing else.”

Interview 25

One participant stated that where you live can also affect the level of stigma experienced.

“Where you live, they have a different outlook on life... But London, it's more tolerable, sexuality, HIV, anything like that, it's part of life and they accept – more accepted. Down here, it's like, oh, oh, you're so different”.

Interview 13

Long-term survivors described how there is more awareness surrounding HIV and how it is transmitted now, compared to when they were first diagnosed. One participant who was diagnosed later in life expressed having bad memories of HIV and AIDS from their twenties when they worked in the field and met people that became very ill, however, they thought it was fantastic that what was a death sentence is now completely changed. One long-time survivor mentioned sharing their HIV status with their family in the past and how their family struggled with the news as they saw everyone with HIV die at the time, and out of fear of transmission would use separate cutlery, this participant stated that these experiences made them more acceptable to people.

“There’s more awareness these days that you can’t get HIV by shaking someone’s hand or kissing them or whatever, you know. So, people are a little bit more clued up now than they were when I was first diagnosed”.

Interview 1

“My mum was heartbroken... because everybody died then, nobody survived... To start with it was like, I had my own cutlery at meals... I remember my mum saying, “When you become ill, we’ll tell everybody you’ve got cancer. You’re not to tell them, it’s a disgrace” ... you had to live through a lot. It changes you but, yeah. It makes you more tolerable to people”.

Interview 13

It was evident that clinic spaces shaped the fear/stigma felt by older PLWH. One participant described feelings of anticipated stigma due to their age when HIV and sexual health services are amalgamated in one building, with the same waiting room. Another participant reported transferring to a different HIV clinic as initially it was in the hospital that they worked in, and they kept seeing people they knew who would ask what they were doing there or what was wrong, which was very difficult for them.

“Again, the stigma because at the end of the day I do sometimes think – I walk into that clinic and obviously there’s a lot of young people there because it’s also where you get all your contraception and all this sort of thing. And they look at you as if to say, what are you doing coming here for contraception? So, they know I’m not there for contraception so they’re second guessing as to what you’re there for and that can be a little off-putting at times as well, is who’s already sitting in the clinic when you get there.”

Interview 2

Many older PLWH stated that there is still stigma attached with HIV and people are still scared of it. It was stated that although people may be more educated about it, they still hold prejudice and stereotypical views about those living with it, with many still viewing HIV as a death sentence. Although, one participant did state that “people are a little bit more clued up now” and know that HIV cannot be transmitted by a handshake or kissing. One participant recalled when they shared their HIV status with their workplace as they had to go to hospital several times and wanted to be honest with them but sadly the establishment tried to fire them due to this. It was evident that stigma was not just from the public but also healthcare professionals and PLWH believe more education on HIV is needed. Several participants shared experiences of healthcare professionals being

insufficiently informed on HIV, with one participant reporting a nurse asking them if they need to be double gloved and another nurse refusing to take their bloods. Moreover, one participant who works as a nurse reported to having stigmatising views about HIV themselves before they were diagnosed. However, some participants have stated that the U=U campaign has been great and has helped to reduce some of the stigma surrounding HIV.

“There is still a stigma attached to it... I don't think a lot of people realise that although it's still a serious illness, it's no longer what it used to be and I think they get scared and frightened”.

Interview 9

“I think people are gracious about... but I – like today, you know, in the healthcare setting, you don't have to look very far, just watch their faces. I think it's the same, I think people are educated but, in their minds think thank God it's not me kind of stuff”.

Interview 18

“Education is definitely needed even in the health care profession because even though we are health care workers you'd be surprised how ignorant some of those people are as well... If only they could understand the impact it has on somebody who has this condition, you know, they might be treated a little bit better”.

Interview 2

6.3.11 Sharing of Serostatus

Many older PLWH reported sharing their serostatus with only a select few people, for instance, many shared it with their sexual partners but did not share it with their children. Reasons why they did not share their serostatus became evident when participants discussed the upsetting situations they have been in when someone had discovered their HIV serostatus, with one individual recollecting when their friend stopped talking to them and stopped allowing their children to see them. Other reasons for not sharing their serostatus included the fear or previous experience of people gossiping and telling others. Participants who had shared their serostatus with their workplace, stated being treated differently and that there was a lack of knowledge around HIV by seniors. Moreover, one participant reported losing friends after sharing their HIV status as their friends had previously lost someone who had HIV and did not want to experience it again. A few older PLWH simply stated that it was nobody's business but their own, so did not feel the need to share their serostatus with others. Participants stated they stopped sharing their serostatus with friends and family as the few they did tell became really upset and burst into tears. Moreover, one participant described the difficulty of being in an ethical conundrum when they had a new sexual partner but had to decide whether to share their serostatus with them, in the end they decided not to as they were undetectable and thought there was no need if they weren't at risk of passing on the virus.

“I think the only reason that I don't tell people generally is in case I get the reaction I don't want. I feel that it is still quite stigmatised if you have HIV. And they assume the reason you've got it which

isn't always the case and people can feel a bit uncomfortable and change the way they perceive you."

Interview 2

"Yeah, 'cos when you get into a new relationship, when is the best point to tell them, and are they going to do a runner as soon as you tell them, because of I suppose the ignorance of what it is."

Interview 17

Older PLWH that have shared their serostatus with healthcare professionals provided the following reasons for doing so: one participant stated that they shared their HIV status with their GP as they were not sure if when they got ill it was because they have HIV or due to a low immune system; another participant informed them for their own protection, despite being undetectable, as they believe it is only fair to let them know; and others have shared their serostatus to ensure there are no interactions with other medications. Being treated differently and a fear of others hearing was a factor in why older PLWH would not share their serostatus with healthcare professionals. Furthermore, one participant stated that they would only tell those that need to know, such as doctors and dentists, and stated that pharmacists do not need to know as they do not think it is necessary for them to know as their clinic consultant and GP deal with their medications and should know if there are any drug-drug interactions.

"Health professionals, as far as I'm concerned, they can be told. I've told them on the phone, but not across the counter, 'cos someone else might hear."

Interview 17

Several participants stated living a "double life" one when they attend their clinic appointments and discuss HIV and another life outside of the clinic where they do not talk about it and no one knows they are living with HIV.

"Yeah, it is part of my life. It's not a thing that I think about all day long, oh I've got this wrong with me, you know, I've never – never, ever and I never talk about it, it's not because I don't want to, but I don't particularly need to".

Interview 22

6.3.12 HIV clinic services

Participants spoke highly of the service provided by the HIV clinic, with many describing the team as a family and appreciating the convenient communication channels available, such as texting nurses and pharmacists. One participant stated that being able to see the same healthcare professionals at the clinic makes their experience of the clinic services much better as they have built good rapport with the doctors and nurses. Some participants highlighted that despite the HIV service having difficulties with staffing and resources, their experiences have still been satisfactory. Moreover, participants reported that the clinic were always able to fit appointments in for them at short notice or around their availability.

“They are a very good team where they are, and I know they’ve been under a lot of pressure and a lot of resource issues have happened with them recently, and the changing of stuff that’s been going on in the business. And I just hope it doesn’t change too much, because they are a fantastic team of people”.

Interview 16

“I like going in, really, because they’re like friends to me now, we have a laugh”.

Interview 22

One participant described how they struggled with telephone consultations initially but then liked that they saved time and travel.

“I’ve got used to it now, you know, it felt like at – I mean it’s a silly thing but the telephone at first felt like it wasn’t a very personal service, you know. But when you think about it unless there’s something serious it takes five minutes to have a chat on the phone to say, you know, your results are fine and there’s not underlying issues and things. What is the point of me coming all the way here from home and waiting to see the doctor because he wasn’t very punctual”.

Interview 6

One participant stated that they would appreciate if the HIV clinic could notify them of any check-ups or vaccinations they would need. Moreover, a few participants have said the COVID-19 vaccination guidance from the government has been quite confusing.

“That’s something I think that sort of the HIV department could be saying to people is saying, “Well, you should be having this check ‘cos you’re in the age group that needs to have that done... the covid vaccinations have been quite confusing for people with HIV... so the whole thing around the covid and the HIV side of it has been very muddy, and it really could have done with being cleared up and being more visible to us as a community”.

Interview 16

6.3.13 Provider relationships

It was evident that older PLWH held strong relationships and trust with healthcare professionals working within the HIV clinic, and many stated described staff to be like their family. Older PLWH described not having the same relationship with their GP or community pharmacist. Participants spoke extremely highly of the service they received from the HIV clinics that they currently attend. Staff were reported to be caring, patient and did not make older PLWH feel rushed during appointments. Moreover, participants appreciated that clinic staff gave them eye contact during appointments and allowed them to speak freely without guessing their answers. Older PLWH appreciated being able to contact staff via text message and noted that they would usually get a same day response.

“You’ve got to be honest with your doctor at the very least. I do trust [name], I trust my HIV doctor. I’m not sure I trust my GP in the same way but er, so I don’t tell my GP about my recreational drug use.”

“I get on so well with them though, I love them to bits.”

Interview 20

General Practitioner

Older PLWH recounted instances where they felt they had been treated differently by a GP due to their serostatus. Several participants also felt that GPs may not be completely confident nor competent with managing the care of older PLWH. One participant stated they would rather speak to a nurse, pharmacist, or HIV consultant about their medication than their GP.

“She was questioning me in quite an aggressive way I felt and, you know, I hadn’t gone to the GP to discuss my [inaudible], I had gone to discuss another aspect of my health. I think some GPs, they don’t understand HIV especially in a rural area like where I live. Maybe if I was in the centre of London or Brighton it would be different, but a lot of GPs don’t understand HIV and therefore they feel perhaps slightly apprehensive about dealing with someone who is HIV positive.”

Interview 1

Pharmacist

Older PLWH stated that they were given the contact details of the HIV specialist pharmacist when they joined the clinic. One participant stated that it was useful having a HIV specialist pharmacist sit in their clinic appointment to discuss their concerns and side effects about their ARVs. However, some participants stated that they haven’t had much contact with the pharmacy team as they are not taking many other medications, other than multivitamins, for which they sought advice from the pharmacist before starting them.

Several older PLWH described preferring to use their community pharmacist over their GP for advice with their medications, but many stated that they would speak to their community pharmacist about their non-HIV medications but not their ARVs. One participant stated that they would use the internet or ask their HIV clinic if they were starting a new medicine or vitamin to see if it interacted with their ARVs. Moreover, many older PLWH said they would feel uncomfortable discussing HIV in a community pharmacy as they feel there is not enough privacy, and everyone can overhear their conversation. Some older PLWH stated they would be worried to ask the pharmacist if they could go into the private consultation room as they live in a small town and everyone in the pharmacy would know and wonder what was wrong. A few participants said that they do not need to speak to their community pharmacist as everything is sorted in their HIV clinic.

“I usually go through my local pharmacy... I get more sense out of the pharmacy than I do a doctor.”

Interview 12

6.3.14 The COVID-19 Pandemic

Some participants described feeling the need to be extra careful when the COVID-19 pandemic started due to them living with HIV and their age, one participant explained that they did not go out, even for shopping but

had it delivered instead. Although, there were several participants that reported never having caught COVID-19 at the time of interviews, with some speculating whether this was due to their ARVs protecting them.

“It did affect us, yeah, because, you know, because of our age and that we were being ultra-careful and because I’ve got what I’ve got, I didn’t want to go out and catch anything else on top of it”.

Interview 22

Several participants reported experiencing more anxiety and loneliness during the COVID-19 pandemic. One participant described not seeing any family members for 18 months but were able to video-call their family, which helped. However, there were some participants that enjoyed the lockdowns, not having to see many people, and working from home during this time.

“So, it was totally down to probably anxiety, you know, what happens if I catch Covid, you know, am I going to die, etc.”

Interview 25

“I found Zoom and House Party and all these other ways of engaging with people – it was much worse for me to do that, because, you know, one minute you’ve got five or six friends on a screen, and as soon as you shut that laptop down, you’re back on your own in the house, and it’s just like, I’d rather not see them and have to feel like that afterwards. So, talking on the phone was okay and stuff like that, but yeah, I really struggled.”

Interview 15

“Socially it means I don’t have to see so many annoying people...I loved lockdown”.

Interview 10

During the COVID-19 lockdowns, routine HIV clinic appointments were moved to over the phone or via a videocall. However, participants reported that they still had to go in person to get their blood tests done prior to the appointments with their HIV consultant. Many older PLWH reported that prior to the COVID-19 pandemic, there will be a lot of patients in the waiting area who were at the clinic for other reasons, however this changed due to the pandemic, with people only entering at their appointment time. One participant described being frustrated by having to wait outside the clinic to be let in prior to appointments.

“You couldn’t go into the health centre until somebody let you in, which then – you were stood outside, you know, waiting for someone to come down from the second floor to let you in, which was frustrating”.

Interview 16

Older PLWH have described that COVID-19 vaccinations have been quite confusing between government guidance, advice from their HIV clinic and then being denied vaccinations for COVID-19 by vaccination clinic

staff, many described staff questioning them on why they would be eligible for the vaccine or asking for a letter from the doctor stating the reasons.

“They [vaccination clinic staff] said, “No, you’re not allowed...No, unless you’ve got a letter from your consultant describing why you’re vulnerable, or your medication”. I said, “Well, I don’t really want to announce to you what my condition – what’s wrong with me. Why would I get a letter from my consultant?”

Interview 15

Many participants reported difficulties obtaining a GP appointment, with some stating they have not managed to see the GP in several years and others stating it has been due to the pandemic. One participant stated having to seek private healthcare as they were so desperate to see a doctor and having to pay a lot of money for their services. Furthermore, participants described difficulties collecting their non-HIV medications from local pharmacies because of staff shortages due to COVID-19.

“The other frustration I’ve had with care since covid hit is trying to see my GP”.

Interview 16

6.3.15 Ageing

Many older PLWH reported not thinking about getting older or not wanting to think about it as either they were only given a certain number of years to live and did not expect to live longer or some felt that it was better to ignore the thought as it could make them feel worse worrying about getting older. Many older PLWH have had to live through the consequences of selling or losing their homes due to their positive serostatus and rebuild their lives after living past the short life expectancy they were first given. As mentioned previously in this chapter under comorbidities, participants described concerns of how HIV has and could increase the risk and level of harm of other comorbidities or accelerate it. One participant stated that when they are sixty, they will not be surprised if they were diagnosed with a condition and were told that HIV caused it, however, this participant stated they do not think they will make it to ‘old bones’ due to HIV.

“I personally think if you start worrying (about getting older), I do feel myself slowing down...I do feel myself getting older but worrying about what’s going to happen when I’m sort of 70 or 80, I certainly feel the worry ages you. Both mentally and I feel it can have certain physical effects as well if you worry about stuff so much...I don’t ignore it, but it’s just I don’t let things play on my mind”.

Interview 10

“The thought of getting older, if we’re talking HIV-wise, no, I haven’t because I was supposed to live five years and I’ve lived forty beyond my death sentence... so if I die tomorrow so be it, I am very lucky”.

Interview 13

“I’ve always believed that I’m going to die younger because I’ve got HIV, and probably because of the meds I take”.

Interview 15

“I just think that my health is going to pack up one way or the other before I ever have to get into the fact of what am I going to do when I get older”.

Interview 14

One individual mentioned the importance of being aware that as you get older, you have more health problems and should get the check-ups required, they suggested that it would be helpful for HIV clinics to remind people of check-ups that they are eligible for or would require, for example, a prostate examination at their GP. One participant stated that although they would not expect older individuals to have HIV, they know of PLWH in their seventies, and due to this preconception, they can imagine that healthcare professionals would make the same assumption.

Older PLWH expressed concerns of ageing with HIV, such as worries that if they become less mobile then they wouldn’t be able to travel and thus go to clinic appointments and get their bloods done. Others showed concerns regarding living or dying alone and forgetting to take their medications due to the development of dementia in the future. Participants described losing friends and family as they have gotten older, whilst another participant expressed fears of hearing stories of people dying and not being found for weeks. One participant was worried of HIV turning into AIDS when they get older but was reassured by their doctor that as long as they take their medication, they should be fine.

“As you get older, all your contemporaries start dying off and your relatives start dying off, um, you know, it’s inevitable. You know, my list of dead people’s getting longer and longer”.

Interview 12

6.3.16 Care Home

Several PLWH expressed their reluctance and concerns regarding potentially moving into a care home in the future, with one participant stating that they would prefer going into an assisted living facility rather than a care home so that they could get the help when they needed and be left alone otherwise. Other participants suggested that they would rather pass away before they have to be taken into a care home and some did not think they will live long enough to go into a care home due to their comorbidities.

“To be honest, I’m not looking forward to going into a care home anyway. I might be lucky and, you know, like her majesty, die at home...a lot of people do have to go into care homes... I’m aware they’re not always the nicest of places”.

Interview 1

“I have thought about it, but I’ve kind of – this sounds a bit morbid, but I hope I die before that happens to me, to be honest. I don’t want to go into a care home”.

Several participants expressed their concerns around sharing their HIV status in a care home. It was evident that older PLWH are used to having control over who they share their serostatus with and fear that they would lose this control within a care home. Moreover, PLWH mentioned hearing horror stories of homophobia and being treated badly by care home staff due to one's positive serostatus. A few participants hoped that care home staff would see HIV as just another illness and give them their medicine without any discrimination or prejudice towards them.

"The only thing that would concern me is maintaining the privacy of who would know. I think that's the only thing that would be sort of the downside to me...the few people that I've told, I know that they are trustworthy...going into something like a care home or an assisted living accommodation, I think that control has gone, because you're having to have it marked on your records, which then anyone who comes and works at that place has access to"

Interview 16

"I've heard stories of where HIV patients have gone into, not so much private ones but, you know, NHS care homes and have been treated really badly because of their status and that's a fact. That worries me".

Interview 13

Some older PLWH mentioned they would prefer a HIV specific care home, whilst others stated they would rather be in a care home because they are old not because they have HIV. When one participant was asked why they wouldn't want a care home for PLWH, they expressed that they felt as though they do not deserve it.

"Because I got this, I deserve it, I put myself in the frontline to get this, I didn't use a condom, I trusted someone when I shouldn't have done, and why should I – why should I then rely on special care, even at that age, do you know, for people looking after me, with HIV. I don't think I deserve that".

Interview 2

It was evident that many older PLWH have not thought about care homes or do not want to, one participant stated that it had not even crossed their mind. A few participants were impartial to the idea of moving into a care home.

"It's not really worth worrying about, is it?... If I need to go into a care home, I will".

Interview 10

"I know I'm getting older but hopefully that's a long way off, or not at all".

Interview 13

Uncertainty

It was evident that many older PLWH felt a lot of uncertainty about their futures, particularly regarding the effects of living with HIV and using ARVs. Some participants do not want to think about the future as they cannot imagine what it would look like and thus live each day as it comes.

“How many years of my life, may I have knocked off by waiting to get diagnosed? Have I weakened things that I don’t know yet, that will come back to bite me later on?”.

Interview 25

“I’m aware I’m taking very strong antiretrovirals every day and, you know, no one knows because these medicines have not been around for generations, no one knows what the long-term health implications are. It might be that my life is shorter as a result of this”.

Interview 1

“I live with it day-to-day, but I don’t think about it. It’s just – it’s not worth it. It’s really not worth it and medication is really, really good.”.

Interview 26

6.4 Discussion

In this study, the older population living with HIV can be further understood by considering two distinct groups. The first group comprises of individuals who have navigated the challenges of HIV and adhered to ART over an extended period, often spanning years or even decades. Their experiences are marked by resilience, adaptation, and a deep understanding of the nuances of living with HIV. In contrast, the second group consists of individuals who received their HIV diagnosis later in life, potentially facing a different set of circumstances and emotional responses. For them the journey with HIV is relatively newer, and they may still be adjusting to the implications of their diagnosis and the intricacies of ARV treatment. It was evident that participants vividly recalled the emergence of the HIV epidemic and the narratives that surrounded it. By recognising these variations in lived experiences, we gain insight into the diverse trajectories within the ageing HIV population.

Comorbidities

Many older PLWH conveyed that their comorbidities posed greater challenges to their daily lives than HIV, although some suggested that HIV either caused or exacerbated their existing health conditions. Participants expressed fears of comorbidities leading to fatal outcomes, such as heart attacks or cancer. Literature shows the long-term effects that both the HIV infection and the toxicities of ARVs can have in increasing kidney and liver dysfunctions, cardiovascular disease, and reducing bone mineral density. (258) Many participants felt compelled to remain cautious due to their HIV status, despite being in overall good health. Additionally, older PLWH voiced concerns about elevated Q-risk scores, blood pressure and weight. Although some older PLWH claimed not to dwell on their HIV status, their behaviours suggested that it still significantly influences their daily lives, with many taking extra precautions to avoid exacerbating their condition. The refusal to dwell on their HIV diagnosis may be due to a desire to avoid the difficult emotions associated with the long-term “shadow” cast by HIV. (259)

It became apparent that statements from consultants such as “a cold isn’t just a cold for you, a cold sore isn’t just a cold sore for you” during the early stages of diagnosis instilled fear in long-term survivors of HIV regarding the impact of comorbidities over time due to HIV. It was evident in literature that experiences from the early HIV epidemic have led to death anxiety in some, where individuals have a fear of death or dying. (260) This should be taken into consideration when healthcare professionals are discussing comorbidities with older PLWH to ensure they are not increasing anxieties among this group.

Long-term survivors managing multiple comorbidities demonstrated high levels of organisation with their health records. One participant mentioned the necessity of this organisation due to ongoing comorbidities requiring frequent visits to different hospitals. Moreover, older PLWH found the regularity of HIV clinic appointments beneficial, as they felt it ensured better care and facilitated the timely detection of comorbidities.

Health related quality of life

The discourse surrounding the influence of HIV medications on the quality of life of older PLWH unveiled a spectrum of experiences and coping mechanisms. The transformation experienced by older PLWH, from being told they had only a few years to live to being informed of near-normal life expectancies was evident. Many had to rebuild their lives after selling or losing their homes, jobs, and friends. Older PLWH expressed gratitude for each day, a sentiment born from the experience of living with HIV.

While older PLWH asserted that their lifestyles remain largely unaffected, it became evident that they had indeed made adjustments to accommodate the demands and side effects associated with ARV therapy. Many have tailored their daily routines and developed strategies to manage medication side effects linked to HIV and/or comorbidities. One participant underscored the perpetual challenge of never feeling entirely healthy whilst living with HIV. Older PLWH's high resilience was palpable in their capacity to adapt and persevere amidst these challenges, which has also been noted in literature. (261) Moreover, long-term survivors of HIV noted that witnessing friends or acquaintances succumb to the virus influenced their behaviour and lifestyle choices. In contrast, others stressed that their HIV is effectively managed, and they perceive its impact on their daily lives to be minimal as ARVs fulfil their intended purpose.

The impact of mental health on the HRQOL of some older PLWH was evident, with individuals recounting past struggles with suicidal thoughts. Studies have shown that anxiety, depression, and loneliness can negatively impact HRQOL. (138,142,262) Moreover, one participant shared that isolation during the COVID-19 pandemic, coupled with loneliness and childhood trauma, contributed to mental health challenges and substance misuse.

Some participants revealed that they had only recently learned about U=U and wished they had known earlier that having an undetectable viral load meant that they could not sexually transmit HIV to others. Literature has shown the importance of proactively discussing U=U with PLWH routinely, which can lead to significantly better health outcomes and empowering individuals to have more open conversations about sexual health. (263)

Adherence

The majority of older PLWH stated high adherence to their medications. Some participants used adherence aids, such as Dosette boxes and others stated good adherence due to being on the tablets for a long time. Participants described creating a routine as a significant factor for maintaining adherence. For example, associating taking your medication with a certain time of day or task could be helpful. Some PLWH stated support from family and friends helped their adherence. Participants reported missing tablets when their routine was disturbed, some participants attributed a lack of adherence at times due to drug use.

Interestingly, it was evident that older PLWH view their medications with varying importance. For instance, the majority view their ARVs as a lifeline and feel 'lucky' to have them, therefore maintain a high adherence towards these medications, but they view their medications for their comorbidities as less important. Thus, although older PLWH have a high adherence with their ARVs, it is important to increase their knowledge on the importance of their other medications and understand their views about them. The 'Necessity-Concerns Framework (NCF)' can offer clinicians a model to understand and address key beliefs that influence an individual's attitudes and decisions regarding their treatment, providing a basis for tailored interventions to improve adherence. (264) Kamal et al., reported PLWH having higher necessity and lower concern scores for their ART in comparison to their comedications. (265)

Treatment burden

As elaborated in chapter 2, treatment burden refers to the ‘work’ of being a patient, which demands significant time, effort, attention, and cognitive energy. (266) This includes managing medications, self-monitoring health, travelling to and attending appointments, undergoing blood tests, making lifestyle and dietary changes, and handling administrative tasks related to accessing and coordinating care. (164)

Older PLWH’s perspectives on managing their clinic appointments with their lifestyles and employment varied. While retirees expressed ease in fitting clinic visits into their schedules, some employed individuals found support from accommodating workplaces. Annual appointments were generally viewed positively, yet concerns arose regarding the anxiety stemming from reduced appointment frequencies, as some participants feared a decrease in attentive care. Conversely, challenges emerged for those juggling work commitments, with one participant highlighting the clash between weekday appointments and employment responsibilities. Although, flexibility and accommodation by staff at HIV clinics with appointment scheduling were highly valued by older PLWH. However, one participant with visual impairment, faced logistical hurdles with transportation services for the clinic visits, enduring prolonged waits without sustenance or occasional absences of the transport service altogether. Additionally, individuals managing multiple comorbidities faced difficulties in accessing care at different hospitals for each condition. These varied experiences underscore the importance of considering individual circumstances and accessibility in optimising healthcare delivery for older PLWH.

The experiences of older PLWH shed light on the evolution of attitudes towards clinic appointments and the practicalities of managing healthcare needs. Over time, many older PLWH have navigated complex emotions surrounding clinic visits, transitioning to a place of comfort and even enjoyment with their ‘clinic family’ that know of their diagnosis. Concerns about travel costs to clinics were generally minimal, with proximity and affordable parking cited as facilitating factors, although some struggled with availability of parking. Access to medications varied widely, with some benefiting from free prescriptions or others utilising the NHS prescription prepayment certificate; Some individuals were frustrated that only certain conditions received medical exemptions from prescription charges.

The convenience of ARV medication delivery to homes emerged as a prevalent preference among the majority of older PLWH, balancing privacy concerns and logistical ease, though occasional challenges in coordinating delivery times were noted.

Medicine burden

As detailed in chapter 2, medicine burden is linked to the complexity of the regimen, the number, size, and taste of daily pills, and their side effects they may have. (266)

The discourse surrounding medicine burden among older PLWH revealed a spectrum of experiences and coping mechanisms. Many participants expressed gratitude for the advancements in ARVs, highlighting improvements in medication efficacy and reduced side effects compared to their first regimens after being diagnosed.

Despite managing multiple medications daily, a considerable portion of older PLWH reported integrating this routine into their daily lives, viewing it as a necessary aspect of their health maintenance. However, others recounted daily challenges associated with medication intake, ranging from the physical discomfort of swallowing large tablets to the psychological adjustment of committing to lifelong treatment. Adverse drug reactions, including nausea and vomiting, were cited as initial hurdles, but support from partners and peers were reported as invaluable encouragement during that period. It was evident that social engagements and travel plans necessitated extra planning and discreet medication management strategies for participants. These accounts underscore the nuanced experiences of older PLWH navigating medication burden in their daily lives and is in agreement with findings in literature. (137,267)

Polypharmacy

Although most older PLWH were using five or more medications, which is defined as polypharmacy (266), they did not express any grievances regarding the number of medications they needed to take. Common medications reported were those for blood pressure, cholesterol, diabetes, acid reflux, thyroid, and depression. Additionally, it was commonplace among the participants to purchase over-the-counter medication, such as Gaviscon, vitamin D supplements, multivitamins, antihistamines, and paracetamol. Despite their overall acceptance of medication regimens, older PLWH expressed a preference for simplified ARV dosing, indicating a desire for single-tablet regimens or injectable alternatives in the hopes of reducing the overall pill burden. This collective perspective underscores the importance of considering medication complexity and individual preferences in optimising HIV treatment and overall health outcomes for older PLWH. Studies have shown switching or simplifying ART can reduce ARV-related toxicities, drug-drug interactions and pill burden, and increase adherence. (268-269)

Adverse drug reactions

Whilst some participants initially claimed that HIV and its treatments had minimal effect on their wellbeing, deeper inquiry showcased a history of encountering side effects from various medications. Despite this, a subset of participants considered themselves fortunate for their lack of adverse reactions, with one individual expressing gratitude for the absence of cardiac issues. Accounts of switching ARVs in the past due to intolerable side effects were common, with participants detailing a range of adverse drug reactions such as bone fragility, night sweats, and gastrointestinal disturbances. These side effects have been commonly reported in literature. (270-271) Despite enduring these challenges, some participants noted an improvement over time as they acclimated to their medication regimens or experimented with dosing schedules to mitigate side effects. However, instances of prolonged tolerance of side effects underscored the importance of proactive communication with healthcare providers and self-advocacy in optimising treatment outcomes. Strategies such as seeking information from healthcare providers and online resources emerged as crucial tools in navigating medication interactions and potential side effects. Additionally, long-term survivors reflected on the transformative advancements in medication tolerability since the early days of HIV treatment.

Medicine reviews

Some participants disclosed a lack of medication reviews, citing challenges in accessing GP appointments and frustration over perceived oversight in medication management, others emphasised the importance of regular reviews to monitor for side effects and optimise treatments. Critically, participants expressed a desire for

pharmacist-led medication reviews and reported a perceived knowledge gap among some general practitioners with medication reviews, which has also been noted in literature previously. (225,272) This suggests the need for tailored approaches to medication management, with pharmacist involvement potentially offering valuable educational opportunities and enhancing medication adherence among older PLWH. Studies have shown that medicine reviews can reduce polypharmacy, potential drug-drug interactions and improve health outcomes. (106,114-115)

NHS England switches

The implementation of NHS England medication switches among PLWH within clinics, driven by the NHS budget priorities and efforts to maximise cost efficiency, have led to alterations in ARV regimens. Some individuals have transitioned from single-tablet formulations to multiple-tablet regimens. While the primary aim is to optimise procurement practices, the consequences for older PLWH include an increased pill burden and potential side effects. Despite expressing frustrations over these changes, the majority of older PLWH displayed resilience. However, some individuals reported experiencing side effects, such as nausea and dizziness, upon initiation of the new medications, with strategies like adjusting dosing times offering relief over time.

Social support

Discussions on the role of social support among older PLWH revealed a diverse array of experiences and attitudes towards support networks. Many participants highlighted the invaluable assistance provided by partners, friends, and support groups in navigating challenges associated with HIV, including medication adherence, depression, and coping with side effects. However, while some found solace and camaraderie in support group settings, others expressed reluctance or disinterest in joining or continuing participation due to concerns about HIV-related stigma or a desire to maintain separation from HIV outside of clinic appointments. Long-term survivors reflected on their journey with HIV, recounting the loss of friends and periods of loneliness, yet some expressed contentment with their current support systems or a preference for alternative forms of support, such as online resources. Studies have shown higher levels of loneliness in older PLWH and the negative affects it could have on health outcomes for these individuals. (273)

Despite varying perspectives on the necessity and utility of support groups, there was a consensus among participants regarding the importance of social interaction, shared experiences, and the potential for meaningful connections within supportive communities. Additionally, suggestions for tailored support options such as gender-specific or age-inclusive groups, underscored the need for flexibility and accessibility in meeting the diverse needs of older PLWH. (110,172) Moreover, the discussion illuminated gaps in communication and awareness within HIV clinics regarding available support resources, highlighting the importance of proactive outreach and comprehensive support services in enhancing the wellbeing of older PLWH.

Stigma

The conversation on stigma among older PLWH highlights the ongoing hurdles and shifting attitudes surrounding the condition. Many participants recounted years of concealing their HIV status out of fear of stigmatisation, leading to a life of secrecy within familial, social, and professional spheres. From facing obstacles in obtaining life insurance to navigating workplace discrimination, the pervasive stigma surrounding

HIV has infiltrated various aspects of participants' lives, shaping behaviours and interactions. However, long-term survivors noted a shift in societal awareness and attitudes towards HIV over time, acknowledging strides in understanding and acceptance. Although, despite this progress it was stated that instances of stigma persist, perpetuating misconceptions and discriminatory attitudes towards PLWH.

Clinic environments also played a role in shaping participants' experiences of stigma, with concerns raised about age-related stigma and encounters with familiar faces in healthcare settings. While education and awareness initiatives like the U=U campaign have contributed to reducing stigma, participants emphasised the need for ongoing efforts to combat misinformation and prejudice surrounding HIV, particularly within healthcare settings where misconceptions and stigmatising attitudes persist. (274)

Sharing of serostatus

The reluctance among older PLWH to disclose their serostatus reflects the complex and often distressing consequences of stigma and fear of discrimination. Participants recounted instances of social ostracization and strained relationships following disclosure, leading to a sense of isolation and the maintenance of secrecy surrounding their HIV status. Concerns about potential gossip, differences in the way they are treated, and emotional reactions from friends and families further fuelled this reluctance to share their serostatus openly. Despite the importance of disclosure in certain contexts, such as healthcare settings for medication management and safety considerations, participants grappled with ethical dilemmas and concerns about privacy and potential repercussions. The notion of living a "double life", where discussions of HIV are confined to clinic settings, underscored the profound impact of stigma on lived experiences of older PLWH. Highlighting the ongoing need for supportive environments and comprehensive education to challenge misconceptions and foster acceptance. Studies have shown that sharing one's serostatus may be an important step to care engagement and better adherence. (275-276)

HIV clinic services

The positive feedback from participants regarding the HIV clinic services underscores the vital role these healthcare facilities play in providing comprehensive care and support for individuals living with HIV. Participants lauded the clinic staff for their professionalism, emphasising the strong sense of camaraderie and trust established through ongoing interactions. Regardless of challenges such as staffing shortages and resource constraints, participants expressed satisfaction with the quality of care received, noting the clinic's flexibility in accommodating their scheduling needs and providing timely appointments. Additionally, the adoption of convenient communication channels, including texting nurses and pharmacists, was praised for enhancing accessibility and streamlining healthcare interactions. While some participants initially grappled with telephone consultations, many appreciated the time-saving aspect and eventually adapted to this mode of communication. Suggestions for improvement, such as proactive notifications for check-ups and vaccinations, highlight the importance of ongoing communication and patient engagement in optimising healthcare delivery. Moreover, concerns regarding the clarity of COVID-19 vaccination guidance underscored the need for clear and accessible information to support informed decision-making and promotes vaccine uptake among PLWH. Overall, participants' positive experiences and constructive feedback underscore the pivotal role of HIV clinics in providing holistic and patient-centred care for individuals living with HIV.

Provider relationships

The profound sense of trust and camaraderie between older PLWH and healthcare professionals within HIV clinics emerged as a recurring theme in the interviews. Participants expressed a deep sense of connection and familiarity with clinic staff, likening them to family members and highlighting the unique bond forged through ongoing interactions. High praise was reserved for the caring and patient-centred approach of clinic staff, who were commended for their attentive listening, non-judgemental demeanour, and commitment to ensuring older PLWH felt heard and valued during appointments. In contrast, participants noted a lack of similar rapport with their GPs or community pharmacists.

General practitioners

Participants reported concerns regarding the attitudes and competency of GPs in managing their healthcare needs. Thus, leading to older PLWH reporting a preference for seeking medical-related advice from specialist HIV healthcare providers within their clinics. This was also evident among participants in chapter 5. (277) Older PLWH recounted experiences of feeling stigmatised and treated differently by GPs due to their serostatus, highlighting the misconceptions and discriminatory attitudes within primary care settings. This has also been noted in literature. (226) These findings shed light on the need for targeted education and training initiatives to improve awareness and further competency for HIV care, as well as the importance of fostering collaborative relationships between primary care and specialist HIV services to ensure comprehensive and patient-centred care for older PLWH. (253)

Pharmacists

The role of HIV specialist pharmacist emerged as a valuable resource for older individuals living with HIV in managing their medication regimens. Participants highlighted the convenience and effectiveness of having a dedicated HIV specialist pharmacist available during clinic appointments to address concerns and side effects related to antiretroviral therapy. However, while some participants reported utilising the service extensively, others noted limited interaction with the pharmacy team due to their relatively straightforward medication needs, particularly if they were only taking ARVs. Interestingly, although older people living with HIV expressed a preference for consulting the community pharmacist over their GP for non-HIV medications, there was reluctance to discuss HIV-related concerns in a community pharmacy setting due to privacy concerns and fears of stigma. The apprehension around discussing HIV openly in a community pharmacy underscores the need for enhanced privacy measures and sensitivity training to ensure that PLWH feel comfortable accessing support and advice from community pharmacists. Overall, the availability of HIV specialist pharmacists within clinic settings offers a valuable avenue for tailored medication management and support for older people living with HIV complementing the broader healthcare landscape and contributing to improved patient outcomes. Studies have indicated that the involvement of HIV pharmacists with the care of PLWH has led to better health outcomes, including increased adherence, reduced medication errors, pill burden and dosing frequency. (278)

The COVID-19 pandemic

The onset of the COVID-19 pandemic brought unique challenges and concerns for older PLWH, who felt the need to exercise extra caution due to their HIV serostatus and age. While some participants took stringent measures such as avoiding public outings and opting for home deliveries, others speculated on the potential protective effects of their ART against COVID-19. However, alongside these precautions, many participants

experienced heightened anxiety and loneliness during the pandemic, exacerbating by prolonged periods of isolation from family and friends. While video calls provided a lifeline for some, others found solace in the enforced solitude of lockdowns and remote working arrangements. The pandemic also prompted changes in HIV clinic procedures, with routine appointments transitioning to telemedicine formats, albeit with the necessity of in-person blood tests. This shift altered the clinic experience, with fewer patients in waiting areas and frustrations arising from logistical changes. Additionally, participants encountered confusion and challenges regarding COVID-19 vaccinations, facing discrepancies between government guidance, HIV clinic advice, and vaccination clinics. Access to primary healthcare services further compounded these issues, with difficulties in obtaining GP appointments and collecting non-HIV medications from local pharmacies due to staff shortages and pandemic-related disruptions.

Literature shows that the COVID-19 pandemic led to several challenges aside from health services interruption but also increased difficulty with social support, psychological disorders, substance abuse, experienced stigma and discrimination. (279-280)

Ageing

The narratives shared by older PLWH underscore the complex emotional and practical considerations surrounding ageing with HIV. Many participants grappled with the paradox of not wanting to confront the realities of ageing, either due to past prognoses limiting their expectations of longevity or as a coping mechanism to avoid worsening anxiety about the future. Moreover, the lived experiences of selling or losing homes due to their serostatus and rebuilding their lives beyond initial life expectancies highlight the resilience and adaptability among older PLWH. Concerns regarding comorbidities further compounded anxieties, with participants expressing apprehension about potential health complications associated with HIV and ageing, including the heightened risk of other conditions. Some participants emphasised the importance of proactive healthcare management as they age, advocating for HIV clinics to facilitate reminders for necessary check-ups and screenings. Additionally, fears surrounding mobility, social isolation, medication adherence, and the progression of HIV-related complications such as dementia underpins the multifaceted challenges faced by older PLWH. Despite these concerns, participants also shared instances of reassurance from healthcare professionals and strategies for coping with anxieties, highlighting the significance of holistic support in navigating the complexities of ageing with HIV.

Care Home

The reluctance and apprehensions expressed by several older PLWH regarding the prospect of moving into a care home illuminates the nuanced considerations surrounding ageing and long-term care within this demographic. Some participants articulated preferences for assisted living facilities over traditional care homes, citing a desire for autonomy balanced with access to necessary support. Concerns about sharing HIV status in a care home underpinned broader anxieties about potential discrimination, with participants expressing fears based on past experiences and stigma surrounding HIV. While some participants expressed hope for understanding and non-discriminatory treatment from care home staff, others pondered the feasibility and desirability of HIV-specific care homes versus non-specific care homes. Additionally, the topic of deservingness emerged, reflecting complex emotions and self-perceptions among older PLWH contemplating future care arrangements. Overall, these discussions highlight the need for nuanced approaches to long-term

care planning that consider the unique needs and preferences of older PLWH, while addressing concerns related to HIV disclosure, stigma, and equitable access to supportive services.

Uncertainty

The future appeared uncertain for many older PLWH, highlighting the intricate landscape of living with HIV, relying on ARVs, and ageing. Participants expressed a reluctance to ponder what lied ahead, opting instead to concentrate on managing each day as it unfolds. This hesitancy to look forward reflects the profound impact that living with HIV has had, where the unpredictability of health outcomes had led to feelings of apprehension and unease. In confronting this uncertainty, the importance of holistic support systems becomes paramount, encompassing not only medical interventions but also emotional and psychological care.

Strengths and limitations

The research study conducted within this chapter, which involved semi-structured interviews with older PLWH has a number of strengths and limitations.

One of the major strengths of this research is that it directly addresses the gap in literature, providing insights into the perspectives of older PLWH in relation to their medications and care services. These results have highlighted the multifaceted approach needed in the care of the ageing HIV population to increase positive health outcomes. Semi-structured interviews, both in-person and virtually, provided the ability to gather rich and nuanced data from older PLWH. The strengths of this approach lie in its flexibility and depth, with semi-structured interviews allowing for the exploration of complex and sensitive topics, providing participants with the opportunity to express their experiences and perspectives in their own words. The inclusion of both in-person and virtual interviews enhanced the accessibility of the study, accommodating participants with varying levels of mobility and geographical constraints, thereby broadening the diversity of the sample, particularly after the COVID-19 pandemic, some participants felt safer conducting the interview virtually.

However, limitations to the study must be acknowledged. The dual mode of interview delivery may introduce variability in the data, as non-verbal cues and the rapport-building process can differ between in-person and virtually. Additionally, the reliance on self-reported data may introduce biases, such as recall bias or social desirability bias, which could affect the accuracy and authenticity of the responses. Moreover, the study sample was predominantly comprised of participants from a white ethnic background, which may limit the generalisability of the study findings. The lack of ethnic diversity may mean that the experiences, challenges, and healthcare interactions of minority groups living with HIV are underrepresented. Furthermore, the PLWH who chose to participate in this study may have been more willing or comfortable discussing their experiences, which could skew the data toward those with stronger opinions or more positive interactions with healthcare. Thus, those experiencing facing different difficulties or those disengaged from care may be underrepresented. Despite these limitations, the insights gained from this approach were invaluable for understanding the experiences of older PLWH.

6.5 Chapter Summary

This chapter utilised semi-structured interviews to explore the needs and experiences of older PLWH with their HIV care and medications. This deeper understanding of their lived experiences captured the subtleties of their interactions with healthcare systems, social support networks, and their personal coping mechanisms.

Two distinct groups of older people living with HIV became apparent: long-term survivors who have managed HIV for years, demonstrating resilience and adaptation, and those diagnosed later in life, facing new challenges and adjustments. Comorbidities emerged as a significant concern among participants, often posing greater daily challenges than HIV itself, with fears of fatal outcomes like heart attacks or cancer. Participants described a high level of organisation in managing their health records and valued regular HIV clinic appointments for better overall care. Despite acknowledging the impact of HIV on their quality of life, many older people living with HIV expressed gratitude for their extended lifespans and showcased adapted routines to accommodate ARV side effects. Mental health challenges and loneliness, exacerbated by isolation during the COVID-19 pandemic, highlighted the need for proactive mental health and social support. High medication adherence to ARVs was noted among participants, however, the importance of ARVs were emphasised more than other comedications, suggesting a need for better education on overall medication adherence. Despite describing difficulties with medicine and treatment burden, older PLWH reported daily coping strategies, with many emphasising that they are 'lucky' to be alive. This perception can help us understand why older PLWH may not complain about side effects or view themselves as having a high medicine or treatment burden. It was evident that social support plays a crucial role in the lives of older PLWH, though experiences of stigma and fear of disclosure persisted, affecting their daily interactions with others. Positive feedback on HIV clinic services underscored the importance of professional empathetic care, although the relationships with GPs were less favourable due to perceived stigma and lack of expertise. While ageing brought concerns about comorbidities and future care, participants held a preference for autonomy and non-discriminatory support in potential care home settings in the future. The findings emphasise the need for holistic, tailored strategies that address the multifaceted challenges faced by older PLWH.

CHAPTER SEVEN

Views and experiences of healthcare professionals on medicine optimisation needs of older PLWH

7.1 Introduction

Building upon the in-depth exploration of older PLWH and their multifaceted experiences with their medicine and care detailed in chapter 6, this chapter shifts focus to the perspectives of healthcare professionals working within HIV clinics. The aim, by delving into their experiences was to enrich the understanding of the complexities surrounding HIV care for older PLWH.

HIV services within the UK are typically delivered through specialised HIV clinics located within larger hospitals or community health centres. These clinics are staffed by a diverse team of healthcare professionals, including Genitourinary medicine and HIV consultants, nurses, pharmacists, pharmacy technicians, healthcare assistants, etc., who collaborate to deliver holistic care. With the National Health Service (NHS) these services are free at point of use, facilitating access to medications, routine monitoring, and preventive measures. With the increase in the comorbidities among older PLWH, the management and treatment of these long-term conditions come under the jurisdiction of primary care services. However, studies have shown several barriers to primary care for older PLWH with poor communication between primacy and specialist care being a concern, which is explored with clinic staff in this chapter. (226)

In this chapter, the findings from semi-structured interviews conducted with healthcare professionals working within a HIV specialist clinic will be presented. Their first-hand experiences offer critical insights into the system and interpersonal dynamics that shape HIV care for older PLWH.

Objectives:

1. To explore how medicine optimisation interventions are currently implemented in practice, examining their uptake by older PLWH and effectiveness in supporting medicine use from the perspective of healthcare professionals.
2. To understand the relationship between the specialist HIV clinic staff and other healthcare professionals in providing care for older PLWH

7.2 Summary of Methods

Semi-structured interviews were used to interview staff to explore the views and experiences of healthcare professionals on medicine optimisation needs of older people living with HIV. Figure 7.1 displays a summary of the methods that have been presented in further detail in chapter 3.

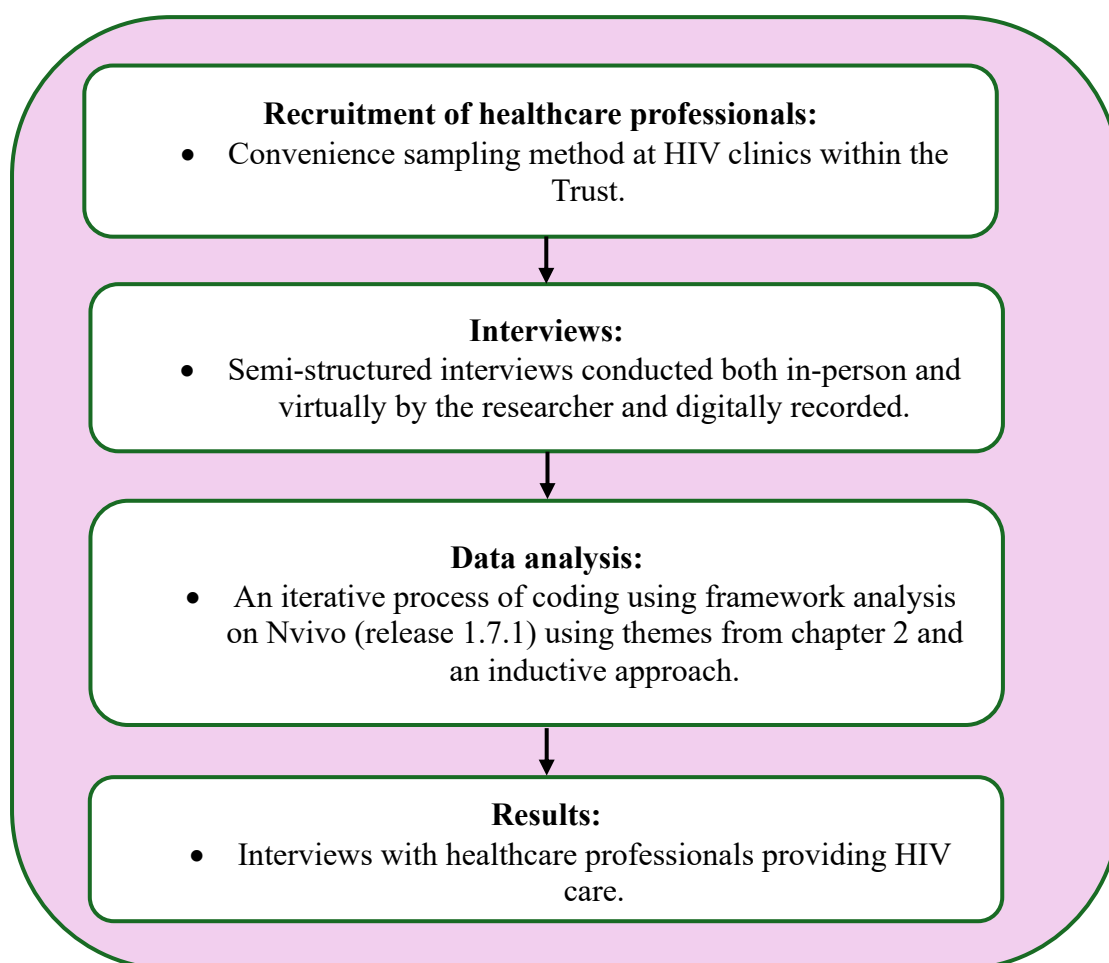


Figure 7.1 Summary of chapter 7 methods (interviews with healthcare professionals).

7.3 Results

7.3.1 Participant characteristics and response rate

A total of eleven interviews were completed with healthcare professionals who were working within the HIV clinics and managing the care of PLWH. Overall, the recorded duration of interviews was 471.73 minutes, with interview lengths ranging from 19.19 minutes to 65.25 minutes (median=39.45 minutes). All interviews were convened at times according to the preferences of individual staff members and were conducted either in person or via video call on Microsoft Teams, in a private area where staff felt comfortable to discuss the interview questions. Four participants were HIV and Genitourinary medicine consultants, three were nurses, one was a pharmacist, one was a pharmacy technician, and two were healthcare assistants. One consultant and one nurse did not take part in the study due to difficulties with staff shortages at the time.

7.3.2 Themes

The themes identified from chapters two and six were used as a guide to analyse the interview data within this chapter. All of the themes identified, including those in this chapter, are listed below within Table 7.1. Further details on the interview and analysis methods can be found in chapter 3.

Table 7.1 Themes identified in chapters two, six and seven.

	Chapter 2	Chapter 6	Chapter 7
Themes	<ul style="list-style-type: none"> • Adverse drug reactions • Adherence • Comorbidities • Drug interactions • Health-related quality of life • Medicine burden • Polypharmacy • Patient and provider relationships • Stigma • Treatment burden 	<ul style="list-style-type: none"> • Ageing - Care home - Uncertainty • Adverse Drug Reactions • Adherence • Comorbidities • Covid-19 • Clinic Services • Health-related quality of life • NHS England Switches • Medicine reviews • Medicine burden • Polypharmacy • Provider relationship • Stigma • Sharing of serostatus • Social support • Treatment burden 	<ul style="list-style-type: none"> • Ageing - Care home • Adverse Drug Reactions • Adherence • Comorbidities • Covid-19 • Clinic Services - Clinic setting • NHS England Switches • Medicine reviews • Medicine burden • Polypharmacy • Stigma • Social support • Treatment burden

7.3.3 Comorbidities

Staff observed a rising incidence of hypertension, heart disease, and diabetes among older PLWH, resulting in more medicines being prescribed and polypharmacy. It was reported that some older PLWH do not go to their GP despite having high blood pressure and an increased risk of heart attacks.

“You sort of think, oh they should be on a statin, but they never seem to – the patients never – you know I think it may just be them, they just will never go to the GP and sort it out. They’d rather just say – complain, oh my GP’s useless”.

Interview 30

Staff reported commonly conducting FRAX (Fracture Risk Assessment Tool) score and mental health assessments on older PLWH. (281) One staff member stated that when some older PLWH saw their depression score, it was a revelation as to why they felt bad and led to them getting the help they needed. It was stated that clinic assessments should be conducted when deemed appropriate and to not bombard older PLWH in an appointment with multiple scores as this could be overwhelming. Moreover, the difficulty of conducting these assessments within the thirty-minute clinic appointments was reiterated by staff. Staff have reported asking GPs to conduct cognitive assessments and dementia assessments on some older PLWH, when noticing signs of memory loss and non-adherence.

“A FRAX is to look at the risk of potential bone injury and long-term damage. So, the FRAX scores that we do, we often pick up osteomalacia where we can, and we’ll contact the GP but then we are reliant on the GP to start bone protection. So, we can’t do that, we can’t do the bisphosphonates ourselves...We also do mental health wellbeing checks, so we’ve done the depression scores, that we’ve done for some people, especially if they come in and if you have known them for years and you’ve noticed a change in their mood”.

Interview 31

Several staff reported older females living with HIV experiencing difficulties with menopause. One consultant mentioned seeing a lot of African women who are not keen on hormone replacement therapy (HRT) and would prefer herbal medicines. It was reported that a lot of women think their symptoms are due to HIV or ARVs and do not consider menopause. Staff reiterated the importance of asking questions surrounding periods and contraception routinely as older PLWH have told them retrospectively that this has been missed at their GP and they have been suffering with menopause symptoms for a while. A few staff members have stated that further education around women’s health, such as menopause, is needed among GPs and older PLWH. Furthermore, it was noted that older women living with HIV were encouraged to get breast screenings and smear tests, which should be conducted yearly, but many women push it to around every two years.

“Most people you have to go asking, they may not think it’s relevant to you, they may not think that there is a problem. So sometimes you’ve got to ask them and when you ask them in a particular way then the penny drops for them. So ah, so it could be due to that, that’s why I’m getting this, you know, the penny drops and then you talk about the perimenopause and menopause. Because they are

probably associating a lot of these things with their HIV or their HIV medication when actually they, like any non-HIV positive individual, will be experiencing the same sort of problems so it is really about asking”.

Interview 28

A staff member stated that some older PLWH are not taking their comorbidities as seriously as their HIV, when they are just as harmful to their health if not managed properly. Moreover, the importance of smoking cessation in older PLWH, including the monetary and health benefits, was highlighted.

“I find it really hard – we’ve got a couple of patients who are really good with their HIV care but are chaotic with their diabetic care. And I find that really weird because I think how can you pick and choose one? Like they’re both killers, you know, so why are you looking after yourself in this side but not that side?”

Interview 37

7.3.4 Adherence

As stated by staff, in the pursuit of ensuring optimal health outcomes for older PLWH, high adherence rates to ARVs are crucial. To bolster adherence, various aids and practical steps are suggested, such as Dosette boxes, reminder alarms, incorporation into daily routines, and support from family and friends. One suggestion from a staff member involved the use of daily smarties or peppermints for newly diagnosed PLWH, fostering the habit of daily medication intake. Dosette boxes are commonly supplied to older PLWH with or who have early signs of dementia. However, challenges in the provision of free adherence aids within the clinics have been observed, with the discontinuation of Dosette boxes and diaries from drug companies. This cessation predates the COVID-19 pandemic, with staff speculating reduced funding as a potential factor. Although, it was noted that PLWH do not like taking away products or information with HIV or ARVs written on it.

“I’m also a big fan of making people add reminders to their phones... You can put whatever you want. Some people don’t want to put pill, some people put medicines, some people put – you know, take the garbage out at eight, which isn’t the garbage, it’s their tablet, depending on who they live with, you can change them, so you don’t have to make it overtly obvious, you know, take the green pill at 8pm, you can change the name of the alarm to something to remind you for”.

Interview 31

It was reported that some older PLWH state that they are adherent to their medications, but their blood tests contradict this, with a viral load higher than expected. Potential reasons behind this variation, as stated by staff, include forgetfulness or non-adherence due to experiencing side effects. Moreover, the issue of non-adherence by older PLWH during time away from home or on holidays was highlighted, with one person living with HIV reportedly going without their ARVs for extended periods. Another way the clinic keeps track of adherence is by keeping track of how many medicines older PLWH have in stock and when they will be due their next batch, if there is a discrepancy in the numbers then they will investigate further into potential non-adherence or if there is another cause. For instance, it was found that one individual was accidentally taking a medicine

twice daily instead of once daily, which meant they ran out of their medicines in three months instead of six. This then led the pharmacy team to have follow-up appointments with the individual to ensure they are taking their medicines correctly.

“Sometimes patients will swear blindly that they’re taking it [ARVs] 100% but the results tell us otherwise, but then that could be because they may be taking it properly but it’s not being absorbed, they are vomiting, they are having severe diarrhoea or there’s drug-drug interaction. So, we do have to look at the bigger picture.”

Interview 28

“There’s one patient that goes without pills for months when he’s away in Africa... he’s been away, comes back, obviously wasn’t taking his treatment while he was away because he was away for a long time. Comes back and he must have restarted the treatment before he came to see us, but he was undetectable. So, they take us by surprise”.

Interview 28

Moreover, the psychological aspects of adherence were explored. Staff acknowledged the challenge of adhering to daily medication regimens, especially when individuals feel well in themselves, recognising that it can act as a constant reminder of their diagnosis. Furthermore, staff observed manifestations of survivor’s guilt, fatigue stemming from long-term medication use, and the integration of ARVs into daily routines among long-term HIV survivors.

“For some the longer they’re living with HIV and having to take tablets there is an element certainty for those that have lived through the '80s. Like the mid-80's and there is sort of, I don't know, an element of survival guilt, an element of being tired of taking medication long-term. Because at present it is for life, we don't know if it's going to be in the future because whoever knew that injectable would be an option for people. So yeah, some people just say it's just part of their routine and they don't even think about it”.

Interview 29

“One old chap I had, he was on a few medications, and he was just very blasé well, you know, I just take them when I remember, I’m not that bothered ... he was sort of like, you know I’ve sort of had enough, I’m very old, I’ve had a good life and if I die soon that’s fine”.

Interview 30

Religious beliefs emerged as a factor influencing adherence, with staff recognising its impact on the medication-taking behaviour of some older PLWH. Moreover, some resistance to taking medications stemmed from individual concerns regarding side effects and toxicity. One staff member sympathised and understood why some people do not want to take medicines that are causing them side effects such as dizziness. It was

reported that staff usually warn PLWH of potential side effects that they may experience, and state that this anticipation of feeling different could be overwhelming for PLWH when newly diagnosed.

“One lady I’ve got whose – so she must be about fifty-six or something but she’s very religious. So, she prays to God a lot to cure her of HIV but anyway she kept going on and off treatment, and it turned out the reason why was because the only way she would know whether God had answered her prayers was to just come off her treatment to see whether her viral load stays undetectable because she’d been cured”.

Interview 30

“He gave me a call the other day just sort of saying that he felt like stopping his HIV medication because he sort of felt it was almost poisoning him”.

Interview 34

Interestingly, despite being adherent with ARVs, it was reported that some older PLWH do not want to take or even discuss the medications for their comorbidities.

“He’s happy to take his HIV medication but I don’t want to be taking any more, I can’t be bothered doing any more medication, so he won’t even talk to us about it, he won’t even acknowledge it. Takes his HIV, he knows he needs that to stay well but obviously he needs the others to stay well but no, he won’t take them”.

Interview 36

7.3.5 Treatment burden

Some individuals who are stable will have appointments every six to twelve months, whereas others may have appointments more regularly, such as two to three monthly. Staff stated that stable older PLWH usually also attend the clinic every six to twelve months for blood tests, and they check if GP practices have carried out urea and electrolyte or HbA1c blood tests so that they can reduce the number of tests taken on PLWH. Staff sympathised with older PLWH living with several comorbidities as they have to keep track of all of their conditions, treatment and appointments.

Older PLWH were able to choose to have some appointments over-the-phone or a video call, or if some individuals forgot about their appointment and did not turn up, they received a call instead. Staff stated that virtual appointments had been very useful for some individuals, such as one older male who is blind and another older female who is bed bound. Older PLWH attending the clinics could text, call, or email staff members to discuss any issues or upcoming appointments. They were sent appointment reminders via text message; the clinic ensured that messages does not contain any information that may cause accidental sharing of the individuals serostatus.

It was reported that PLWH can have their medicines delivered to any address they prefer, such as their home or a community pharmacy. It arrives in a discreet box and label, if delivered to a pharmacy, should not be opened, but one staff member stated that this can be an issue in some community pharmacies where staff may open the box without realising, leading to accidental disclosures. Staff have reported that only a minority of older PLWH have had issues with the delivery company for their ARVs to their home. A few older PLWH preferred to collect their medications from the clinic themselves.

“A patient if they want to can elect it to go to a pharmacy as their alternative address... It's not really a good idea because you know what it's like when you go into a pharmacy, box arrives, let's open and see what's inside. So, that doesn't happen with Boots because it must come on a separate, you know – these are Homecare parcels, and the Homecare parcels, those Boots staff don't know whether it's cancer treatment, whether it's IVF treatment, anti-TNFs, HIV, so it's a bit of a strange one because the pharmacist doesn't know what they're handing over to that patient. They haven't got the responsibility for that and what they do is just check the ID and so on”.

Interview 27

7.3.6 Medicine burden

Staff stated that older PLWH who were using Dosette boxes, were given two; One for their ARVs from the HIV clinic and another for their other medicines from the GP. The older PLWH using a Dosette box had challenges with medicine taking due to blindness, confusion, or difficulty after having a stroke.

It was reported that most older PLWH were stable on their ARVs. One staff member stated that many older PLWH have shown interest in the injectable ARVs, but they do not know all the requirements involved, such as the need to come into clinic every two months for lengthy appointments.

One staff member described older PLWH getting panicked when there are any changes to their supply of ARVs, including the number of months supplied at one time, as their medication is very important to them. Some issues relating to different packaging causing confusion for PLWH were raised. For example, one staff member reported that an older male living with HIV was taking two tablets instead of one for two weeks because the pharmacy who supplied the medicine had given two bottles that looked different but were the same drug. The older gentleman was used to a particular bottle and when he saw two different bottles, he assumed that he had to take one from each, which led to him feeling very unwell and calling into the HIV clinic. As mentioned earlier in this chapter, staff also described the difficulties older PLWH experience due to polypharmacy and managing side effects experienced from both ARVs and medications for their comorbidities.

“At the moment there is a bit of confusion because like changing of contracts, people are panicking because they're only getting two months' supply instead of their whole six months. And, you know, those drugs are so special to patients”.

Interview 37

7.3.7 Polypharmacy

Staff reported polypharmacy being a major concern for older PLWH. As mentioned throughout this chapter, staff reiterated that more comorbidities were seen in older PLWH as they got older and with this, an increase in comorbidities and polypharmacy was observed. Challenges arose for older PLWH when having medications prescribed separately from the HIV clinic and GPs, where in some instances the GP may not know that the individual is taking ARVs or where the HIV clinic does not have a full list of what medications the individual is using.

“Hypertension, heart disease, diabetes, all of that. So, it's all there and yeah, as they get older, yes and, you know polypharmacy is a big issue”.

Interview 28

7.3.8 Adverse drug reactions

Interviews with staff members highlighted the challenges older PLWH can experience due to adverse drug reactions. The narrative presented suggests that older PLWH might inadvertently dismiss symptoms, attributing them to ageing or overlooking the possibility of feeling better than their current state. This indicates that they may not accurately recognise or communicate these side effects with their care providers, either due to a lack of awareness or an acceptance of certain symptoms as normal. Additionally, the fear associated with any changes to their stable treatment regimen, particularly if their viral load and CD4 counts are satisfactory, may contribute to a reluctance in exploring alternative ARVs. Staff reported instances where older PLWH are being prescribed medications from their GP that has an interaction with their ARVs, which can lead to undesirable adverse drug reactions. One staff member reported commonly noticing older PLWH experiencing slight nausea and fatigue when switching to a different ARV in the first few weeks, which later disappears.

“Every time you may ask people or you think you do at the time whether they're alright and they've got no side effects and they're like, “oh no I'm fine”, and then doing that sort of again ... just because you can give them something else, and some of them, “oh I do feel a bit dizzy headed” and then when he went off it he said he felt like absolutely a completely different person. With hindsight he just didn't sort of – he thought that was normal and he'd just been on it so long that he couldn't remember how he felt before he was ever on it... So, it makes you sort of think oh, you know, maybe other people are sort of like that but they don't even really know they could be feeling better than they're feeling... Whether they just think it's their old age... or there's a fear as well if they've been on something and their viral load's suppressed, CD4 count's good, it's a bit stressful for them isn't it to come off it and to try something new”.

Interview 30

7.3.9 Medicine reviews

In the context of medicine reviews to optimise older PLWH treatment regimens, the requirement of a multifaceted approach emerged from interviews with healthcare professionals. Consultants emphasised the importance of rationalising prescribed medications used by older PLWH, recommending the discontinuation of those deemed unnecessary whilst expressing the need for primary care support for those medicine initiated by them. Moreover, the importance of viewing older PLWHs treatment holistically was reiterated,

particularly the need to consider their comorbidities. One consultant stated that they are actively looking out for and managing the long-term effects of ARVs in older PLWH. The importance of monitoring and switching ARVs due to their effects on renal function, cardiovascular risks, bone density in older PLWH was emphasized by staff. A staff member proposed the possibility of simplifying older PLWH's treatment regimens as they get older. However, they stated that this was more likely to be possible at larger teaching hospitals, where clinics collaborate with other departments who managed the comorbidities of these individuals. Another staff member envisioned a future where stable older PLWH would receive HIV care in the community by their GPs. They questioned the longevity of specialist HIV services for this demographic, suggesting that, given effective treatment, HIV management might become a relatively minor concern in comparison to other age-related health issues.

"If we can ask medicines to be rationalised, we do try. So, you know, "Why are you on this? You haven't got folate deficiency, let's get rid of the folic acid. It's only a tiny tablet but let's get rid of it." You know, "Why are you on this? ... we would need support of primary care because some of it has been instigated outside of our purview and then, you know, if we've prescribed anything, actually, you don't need your Cotrimoxazole, your CD score's 400, right, we'll stop that. You know, we can kind of review that and kind of try, where we can, just to kind of rationalise what we prescribe".

Interview 31

The pharmacy team reported conducting medicine reviews for older PLWH who were recently discharged from hospital and when screening each ARV prescription, utilising the information they have on the clinic's system and the national care records service with medications provided by the GP practice. Resources used included the Liverpool HIV Drug Interaction checker, Stockley's Interactions, British HIV Association guidelines, and NAM aidsmap. However, challenges were experienced when the GP records are incomplete or outdated. Staff stated that current medications are noted at each clinic appointment to keep an up-to-date list on the system, but sometimes older PLWH forget to mention some medicines until later. To improve this, it was suggested that better communication is needed between older PLWH, GPs and the HIV clinic. It was reported that having a pro-forma with questions to prompt staff when carrying out medicine optimisation interventions would be useful.

"It's just finding a way to get people to communicate better, bring the pieces of the jigsaw together rather than have everyone else, because we try and go through every time, you know, "Have you got all the medicines? Can we just double check?" And they might say yes, but they might have forgotten there's something else on the bottom and then they'll go, "Hang on, I forgot to tell you." And send a text message, "I forgot to tell you, the GP started me on this for my sleep." Okay, add it on. So, it becomes a disjointed thing. So, trying to optimise medicines, if we can, is to try and get everyone to communicate and see everything clearly. Summary care record goes a certain way to that but not everything is updated, necessarily, in real time, it might be six, eight weeks later that something gets updated".

Interview 31

One staff member described the importance of all decisions around treatment being made in partnership with older PLWH and taking into consideration their needs and lifestyle. It was reported that older PLWHs lifestyles and concerns are taken into account when prescribing ARVs. For instance, if they are working night shifts and are not able to eat but are prescribed ARVs that must be taken with food, their ARV will be changed to one that does not need to be taken with food.

"I always say to the patients that this is a partnership, it's a deal between you and us in order to keep you well, because there's no point prescribing you something that you have to take with food in the morning if you don't eat breakfast".

Interview 29

Desired outcomes from medicine optimisation interventions included enhancing safety and satisfaction, reducing toxicity, and improving patient understanding of prescribed medications. It was reported that some individuals have been given medicines without explanation of what they are and what they have been prescribed for. Improving education for older PLWH about the importance of adherence, resistance, how to take medicines (i.e. if it is with or after food, once or twice daily), and discussing possible side effects were suggested. Common queries received by the pharmacy team included the use of herbal medicines, drug-drug interactions, and travel health, such as which vaccines are required and malaria prophylaxis.

However, barriers to implementing medicine optimisation interventions included time constraints, staff shortages, resource limitations, and availability of clinics rooms. Consultants expressed concerns regarding adding medicine optimisation interventions during clinic appointments that are already tight for time, suggesting potential solutions, such as dedicating more time for older PLWH with the pharmacy team. Staff mentioned difficulties conducting visits to care homes for medicine reviews again due to staff shortages and a lack of resources. Moreover, despite the routine completion of QRISK, FRAX, and frailty scores, it was revealed that there is a lack of specific medicine optimisation interventions conducted for older PLWH within the clinics.

"When you've only got half an hour but yet your priority is to look at their HIV care or their wellbeing or, etc., the last thing – and if it's not, per se, relevant, you might not be sitting there doing a FRAX score on them. But we can potentially – if you've got all the measurements, you can do an outside but then that would mean it's additional time for us to do. And then potentially we could call them back afterwards, saying, "Actually, after your last consultation we followed up on some results, calculated your FRAX score, your bones are a bit thin. You now need to go and see your GP." So, we can do that afterwards as well, it doesn't have to be all in real time because, as you say, half an hour isn't enough".

Interview 31

One staff member explained that medicine reviews and changes are made either because they have found a better medication for that individual or because that individual has come to them with concerns, which has then

led to a change occurring. An increase in medicine reviews has been noted due to the rise in direct oral anti-coagulants (DOACs) prescribed in older PLWH for atrial fibrillation or post-embolic events; DOACs may interact with certain ARVs, therefore an alternative anticoagulant or ARV must be prescribed. Moreover, Tenofovir disoproxil fumarate being changed to the newer Tenofovir alafenamide was reported as being common in older PLWH with declining renal function. PLWH are monitored four weeks after any changes to their ARVs to ensure safety and efficacy of the medications.

"It's both because it a two-way conversation as well. Sometimes it's because we are being proactive or reactive depending on what we find but other times it's because they are saying actually, I really don't get on with this medication. I really can't take it. This is far too many pills or it's too big and it's really causing issues for me. So, there may be lots of reasons from their point of view other than side effects as well".

Interview 28

The pharmacy team had planned to conduct specific medicine optimisation interventions in older PLWH, however, this had to be put on hold due to staff shortages. In the short time that it did occur, staff reported that older PLWH highlighted issues such as trouble obtaining repeat prescriptions from their GP and the medications not being ready on the same date as each other; it was reported that older PLWH found this frustrating. Staff stated that the future plan was to have a pharmacy presence in each clinic site once a month to focus on medicine optimisation interventions in older PLWH.

7.3.10 NHS England switches

Staff reported changes to current ARV medication for PLWH within the clinics due to the NHS England medicine switches as described in chapter six, where several PLWH have had to go from taking one tablet to up to four tablets. It was described that these changes can be a backwards step for some older PLWH, increasing the number of tablets they are taking overall. The pharmacy team arranged two-week post-switch follow up calls to see how individuals were getting on, highlighting the importance of adherence, and discussing any potential side effects.

"People do get quite frightened about changing a tablet and then they kind of go, "But you've given me this whenever we started it. You told me to take this, you told me this will work. This has worked. Why do we now need to change this? You know, can I kind of pay you for this? Can I pay for my old tablet? Can I pay for the one, because it's the one you started me on?" And you're trying to kind of reinforce then, that the NHS, fortunately, doesn't procure medications that don't work, they've all been tested, they've been validated and confirmed that they do work, whether it is as a two-pill combination or a three-pill combination. So, trying to reassure them it's okay and sometimes we can change from single tablet regimens to individual components, sometimes we can't and there's certain criteria around where talking with the patient and kind of looking at their background as to whether we won't switch them to that single tablet regimen".

Interview 31

It was reported by staff that a significant challenge to the NHS England switches in older PLWH were primarily due to the longstanding use of their current ARV. The apprehension arises from their familiarity and confidence in the effectiveness of their current regimen, leading to concerns that the proposed switch may not yield comparable results or may introduce unwanted side effects. This hesitancy was exemplified in a case where a couple, both living with HIV, adamantly refused to participate in the medication switches. In response, their autonomy was respected, and they were granted the space to reconsider their decision, with the matter set to be revisited during a subsequent appointment. In contrast, some staff members conveyed that they have not yet encountered an individual refusing the medication switches. Nonetheless, they expressed an awareness of the potential challenges that may arise for certain individuals when confronted with the requirement to switch.

"We've had a couple who've said no and then we've tried to work with them. So, at that point, obviously you don't change anything at that point because the last thing you want them to do is to stop their treatment but you can say, "Look, please think about it again." You might give them a slightly shorter prescription, not see them six months, maybe see them four, have a think, talk about it again and see where we go and some of those people haven't reached that return state yet, so maybe over time they'll have got to think about it".

Interview 31

7.3.11 Social support

Staff observed that some older PLWH experience significant loneliness and struggle to reach out to others due to their serostatus. The importance of social and medicine-related support with adherence was reiterated by several staff members. Staff emphasised the positive impact of the locally organised social support group on older PLWH.

"There is a social support group that has been set up for patients by patients, which is good. I think we need more of it because people are – I certainly remember one lady saying to me recently from the African community, she says, "I don't have anyone around here that I can talk to." And so, she had that support in London".

Interview 28

Staff stated that despite needing social support, some older PLWH do not want to join the local support group due to fear of people finding out about their serostatus and sharing this with others or seeing someone they know in the group who did not previously know their diagnosis. A staff member described having a list of vulnerable individuals who do not go to any groups, despite needing the support. They periodically reach out to them via phone calls to provide check-ins and engage in casual conversations, fostering a sense of connection and support. It was reported that during COVID-19, staff would call those who were particularly suffering with loneliness and mental health difficulties every week if necessary. Staff observed older PLWH responded positively to these phone calls.

7.3.12 Stigma

Staff described several scenarios of seeing or hearing stories of stigma towards PLWH. The stigma faced by older PLWH has been noted to emanate not only from individuals in the community but also from healthcare professionals themselves. This has led to many older PLWH who are healthcare professionals themselves, and yet have not shared their serostatus with their workplace due to fear of stigmatisation.

"I think the one thing that hasn't changed since I've been working in HIV since '96, the one thing that hasn't progressed at the same pace as how you treat HIV is the stigma, is people's views and thoughts, and that's people, that's not always out looking in, that's people themselves that, you know. I can remember being on a ward at the [Hospital name] and the ward sister saying if you don't inject drugs, if you don't sleep around HIV is never going to be an issue for you. When in reality all you have to do is have unprotected sex with somebody that you love, and sex is the most natural thing in the world. So, it's very strange".

Interview 29

"A lot of our patients are professionals, and they wouldn't dream of disclosing to their workplace, and you think we're talking like doctors and nurses, and they wouldn't share, and you think you should be able to".

Interview 36

One staff member stated that it is usually those who have not shared their HIV status who have the most trouble with their medication as they do not want people to see them taking any medication or they decant their ARVs into another bottle to hide the packaging. It was also reported that some older PLWH do not take their ARVs with them when travelling due to the fear of others seeing the medication.

"They don't want to take pills around people because they don't want them to say, what do you keep taking all those tablets for, are you ill? We have patients, so when they come into collect their medication, I quite often give them their medication and we have to open it in front of them. And I'll say do you want to take the box or do you want to put it in your bag? And they start decanting it, so they're taking it out of the packaging and putting the bottles into their bag because they don't even want the packaging, they're so worried about people seeing it. We have patients that are missing doses because they didn't want to take them on holiday, because they don't want to be stopped going through the airport to see why they've got all this medication with them or they haven't disclosed to their friends, so they don't want their friends to see it".

Interview 36

Staff stated that some older PLWH attended the clinic under a pseudonym, which makes it difficult to view their GP records and it could potentially lead to issues if these individuals go into hospital, as their NHS numbers would be under their real names.

7.3.13 Clinic services

Staff stated that it is important that PLWH who are registered to the clinics are able to contact HIV staff at any time if there are any issues and they do see individuals doing so, these calls are usually handled by specialist nurses and the pharmacy team. Staff reported starting an urgent clinic once a month for PLWH who needed urgent attention as prior to this appointment slots were booked for months ahead which made it difficult to manage urgent requests.

It was reported that due to funding, the clinics no longer have a team of specialist care managers, who would help with queries surrounding housing, benefits and looking for jobs. One staff member reported that the funding they receive is a contract with the council for several years, which means the budget is fixed and does not respond flexibly with increasing numbers of PLWH and care demands. Moreover, a lack of funding was also reported as an issue when trying to provide support services to older PLWH. Moreover, it was stated that the removal of a social care team has impacted older PLWH, particularly with mental health support. Staff reported wanting to mirror the service model provided in Brighton but noted that Brighton had a much bigger population of older PLWH and more funding for services.

“With the social care, with psychology, we have not got our own in house psychologist, mental psychiatrist. You know, if we had some kind of link with mental health services, someone that came and linked up and then we could work better together because people with HIV have got greater mental health needs than someone without HIV”.

Interview 28

Joint clinics, with geriatricians and cardiologists for example, was suggested by staff to improve care for the ageing HIV population. It was specified that there were not enough PLWH within the trust to do this on a regular basis but even once quarterly was suggested to be useful. Staff stated that they can seek advice from a weekly virtual clinic at Chelsea and Westminster if they have any problems with resistance or drug issues.

Staff described several difficulties with the electronic health record system used across the trust for sexual health and HIV services, such as it being time consuming to use and unreliable. One staff member stated that they would be wary of adding any new medicine optimisation tools to the current system as it is already so temperamental. Another staff member said it can be stressful when the system suddenly closes whilst they are in the middle of a consultation. Staff stated that a more reliable system that can manage all aspects of PLWH's care and prescribing would make the service smoother and easier.

When asked how the care of older PLWH can be improved, one staff member stated that having monthly meetings attended by the HIV consultant, pharmacy team, nurses, and the GP would aid closer monitoring and reduce polypharmacy and drug-drug interactions; They stated that they had heard of this occurring within the HIV services in Brighton and were presented to be very useful. Overall, staff believe that they really support older PLWH attending their clinics. One staff member stated that older PLWH who have transferred their care from London, say that their consultants didn't know them very well and it felt like a conveyer belt, whereas now their care is more personable from a smaller team. Furthermore, it was reported that staff feel lucky to have the pharmacy team within the clinics who respond quickly to queries.

Clinic setting

It was reported that some clinics have different days for sexual health and HIV clinic appointments, whereas other clinics share the same space for both appointment types. For some clinics, since the COVID-19 pandemic, PLWH come at their appointment time and ring the bell, after which a healthcare professional will let them in. It was stated that pre-pandemic, PLWH would walk in and wait in the waiting room before appointments.

7.3.14 Provider relationships

Staff Interviews showed that the relationship between healthcare providers and older PLWH can have an effect on their care experiences and treatment. A pharmacy staff member stated that four or five years ago they knew all of the PLWH attending the clinic well and vice versa, but this has changed in recent years with growing numbers being diagnosed and newly attending the clinic. Moreover, it was noted that a lot of queries to the pharmacy team were from older PLWH who had been attending the clinic for a long time, and thus awareness around the specialist pharmacist team needs to be pushed to new attendees.

“Something that we need to do is to push the awareness that the service does have a specialist pharmacy team that are there, and you know, there's a lot of things for people to take on board when they're newly diagnosed or move into area or something but that can sometimes get missed a bit”.

Interview 27

Staff stated that most older PLWH have shared their serostatus with their GP, however, there are some older PLWH who have refused, which can make it difficult to help them manage their comorbidities as they have to convince and remind these individuals to go to their GP for these conditions, such as high cholesterol, as they would not be able to send the GP a letter themselves. This is also a difficulty for some individuals who have an uncertain immigration status in the UK and thus are not registered with a GP. One staff member reported that after a while of communicating back and forth between the GP and HIV clinic, older PLWH would rather the clinic communicates with the GP directly.

“Can you show these to your GP? Can you talk to your GP about managing your blood pressure? Can you let us know what medication they prescribe?” And usually that starts to open a dialogue with the fact that the patient doesn't want to be the guinea pig, “Actually, why do I have to keep going back and we're always having the same conversation twice?” Actually, let the doctors do it. So sometimes that breaks the barriers down”.

Interview 31

Staff indicated that an issue sometimes is that older PLWH are on a drug with an interaction that the GP does not know about. Staff reported that they get very little correspondence back from GPs and other healthcare professionals after sending clinic letters. However, one staff member stated that this lack of correspondence back does not stop them from sending information to other healthcare professionals as they want to keep a channel of communication open and want the opportunity for others to be able to contact them.

“I think the other issue you feel when you write to the GP is it just feels like, I don’t know really what goes wrong, but it feels like the letter’s just scanned in and that’s it, no-one ever reads it. Because nothing ever – they come back six months later, and nothing’s ever changed”.

Interview 30

It was reported that some older PLWH would like their HIV care and GP care to be together.

“A few patients would want us to be their GP in terms of, you know, and I fully appreciate that trying to get a GPs appointment is really difficult in the current climate, but I guess that's down to the commissioners and how different people find it for different things”.

Interview 29

7.3.15 The COVID-19 Pandemic

Staff described several ways in which they saw older PLWH struggle during and since the COVID-19 pandemic, such as loneliness, mental health issues, difficulties getting medicines and making appointments to see healthcare professionals. One staff member mentioned their colleagues noticing higher viral loads among PLWH during the COVID-19 lockdown periods. Moreover, there has been a lot of new transfers into the clinic since the COVID-19 pandemic started due to travel restrictions resulting in them being unable to travel to London or Brighton.

Staff stated that older PLWH were quite anxious about contracting COVID-19. However, it was reported that the majority of older PLWH within this service, did not get COVID-19, and when some did it was not severe. It was reported that COVID-19 has impacted the services in both negative and positive ways, a negative was that there is less face-to-face contact with older PLWH but a positive was that for those who are stable, they do not need to be seen in person every time, so it has increase individual choice to have virtual appointments instead. The pandemic also led to less blood tests being taken from older PLWH, particularly if they have been stable for a number of years, their six-monthly blood tests were changed to yearly. Several staff members echoed the importance of still having some face-to-face appointments as there are certain things that can only be seen/detected in person. Staff have suggested that the COVID-19 pandemic could be a cause for the lower rates of HIV diagnoses that they have seen as people have not been able to get tested.

“I think it’s still important to see people face to face at least once a year just to make sure that they okay. They may say they’re okay, but we might see something, which we wouldn’t do if on the phone. Also, I think people with mental health issues and so on over the phone you can’t see their facial expressions and so on. So, it’s very difficult to gauge what’s really going on and it’s a more impersonal way of communication. Until you see them you don’t really know what’s going”.

Interview 28

Staff stated that older PLWH missed visiting the clinic during COVID-19 lockdowns as attending the clinic was a part of their yearly routine and they cared about the wellbeing of staff. Staff described older PLWH seeing them like a family.

“I think some of them missed the stimulation of seeing people, even though it’s a healthcare professional and a healthcare setting, they did miss that. And because a lot of us have been part of their lives for so many years, we’re kind of part of their kind of yearly routine for some of them, it’s like – and I think they wanted to check we were okay”.

Interview 31

One staff member compared how PLWH felt in the early days when HIV emerged to the beginning of the COVID-19 pandemic.

“I often think there are elements of when Covid hit that correlate when HIV was first because, you know, I got redeployed to hospital and although it was mainly elderly people... but fancy being a patient. You know, some zombie is coming towards you with all this get up, never mind trying to work in it, and that must have been how the poor HIV patients felt when there wasn’t much known about it and they were just approached by these people, and often in rooms on their own isolated because nobody knew what the virus was up to”.

Interview 29

One staff member reported seeing signs of domestic violence and alcoholism when in-person appointments resumed. Another staff member speculated whether the cancer cases they saw after the COVID-19 pandemic could have been picked up earlier if appointments had not been moved over the phone. Staff explained that some older PLWH faced problems when the clinic services were disrupted, but they did not seek help and instead sat on their concerns until they saw clinic staff again.

“When we started to resume face-to-face, because of Covid, because of long, protracted lockdowns, people perhaps being stuck with people they wouldn’t spend so much time with all the time, we started to pick up things like domestic violence and alcoholism coming through, which you can’t hear on the telephone”.

Interview 31

“When we came out of lockdown and it was – you know, we were dying to see our patients. It’s not the way we worked, you know, so it was quite hard. Because they see me first before they see a consultant, I have so many different issues with patients, that they just sat on things and would not necessarily – like one lady thought she had blood cancer and she’d just been – had a really bad consultation. She just needed to be kept under review and Dr [name] phoned the... London clinic and taped it all for her and explained it but for like four months she thought she was dying, she hadn’t told her daughter, and just honestly, I called it wobbly Wednesday for a few months ‘cos every week I had a patient that – one day I had patient that had a breakdown, curled up in a ball”.

Interview 37

7.3.16 Ageing

When staff were asked what they believe were the main concerns for older PLWH, many stated comorbidities, financial situations, the death of those around them leading to loneliness, menopause, anxiety, and dying. Moreover, one staff member reported an incident of an older individual being diagnosed with HIV late and dying within three years showcasing the importance of early diagnosis in the ageing population. Staff reported the oldest person living with HIV who is registered to the clinic being 90 years old and quite isolated, lonely, and frail; One of the nurses conducts home visits to keep an eye on this individual.

“People with younger HIV dementia, usually late diagnosis, usually significantly life shortening life course, so this person died within three years of their diagnosis, they didn’t make it till they were sixty”.

Interview 31

Many of the staff stated that fifty is quite young and some reported that they do not think that older PLWH worry about getting older and just want to be alive. It was reported that after 40 years old, PLWH attending these clinics have annual assessments for their bone density, lipid profiles and HbA1c, an indicator for diabetes.

Care home

As PLWH are getting older, there may be a need for them to go into care homes in the future. Staff recounted past challenges in placing some older PLWH into care homes, citing difficulties to find a home that would admit them. It was reported that nursing home managers decide which residents are accepted into their home. Staff suggested that further training is required amongst care workers to dispel stigma surrounding HIV and increase the intake of older PLWH into care homes. They also stated that they hoped that as PLWH get older, the prejudice against HIV would get better in care homes. One staff member reported that they haven’t seen a wave of PLWH going into care homes yet and that older PLWH have been trying to keep their independence. It was reported that they expect to see more older PLWH requiring nursing or residential care in the next five to ten years.

“I think nursing home and care home support, so when eventually some of our patients will need, and some have already need to go into a care home, we have had challenges where we’ve not been able to get them placed because sometimes, they just don’t want somebody with HIV. So, we need to do or there needs to be some education to care home workers and also managers that if you’ve got a patient that is in your care home that is HIV positive and is on treatment, actually, they’re at a lessor risk – there’s no risk to anybody there, and it’s better that you know their HIV status than not. You know, there’s bound to be people residing in care homes with dementia that might be HIV-related dementia that nobody has ever tested for. So that has been a challenge for us where we’ve had, you know – a discharge has been delayed for those patients because they haven’t been able to access a care home. It’s terrible”.

Interview 27

“We’ve had a couple of patients who’ve had to go into residential or nursing care, who were... probably mid-fifties, getting those people into nursing care is always with a lot of prejudice. Unfairly so, I think people were worried about, you know, I’ve got someone, an HIV positive resident, what does that mean to my other residents? Absolutely nothing because they’re undetectable, that U=U message hadn’t quite got out and it means everything. It can change their – you know, if they require toileting management, you can change them, you are at no risk if they accidentally wee on you. Trying to reassure them of things like that and it was very, very hard”.

Interview 31

7.4 Discussion

The observations and practices reported by staff shed light on crucial aspects of healthcare provisions for older PLWH.

Comorbidities

With the notable rise in conditions, such as hypertension, heart disease, and diabetes, among this demographic, staff highlighted the challenge of polypharmacy and managing multiple comorbidities, a concern frequently noted in literature. (258,282) Staff have reported concerns of some older PLWH neglecting to seek medical attention from their GPs despite elevated blood pressure levels and increased risks of heart attacks.

To address the multifaceted healthcare needs of older PLWH, staff reported utilising assessments for identification of comorbidities, including using the FRAX tool and evaluating mental health. (281) However, the logistical constraints of conducting assessments within the time limit of appointments posed a significant challenge for staff. Moreover, they found a delicate balance was needed between thorough assessment and overwhelming patients.

Additionally, staff have observed the specific challenges faced by older female PLWH, particularly concerning menopause-related symptoms and screening for breast cancer and cervical abnormalities. Particularly as staff report that menopause has often been mistaken for consequences of living with HIV or taking ARVs by GPs and older female PLWH themselves. This has also been previously noted in literature. (283-284) Cultural preferences, such as use of herbal medications over hormone replacement therapy have added complexity to care for some individuals. The importance of routine inquiries about menstrual history and menopausal symptoms is evident, as overlooking these aspects of care can lead to delayed diagnosis and management of symptoms. Enhanced awareness and education initiatives around menopause and living with HIV targeting both healthcare providers and older PLWH are deemed necessary.

Furthermore, it is evident that some older PLWH may not prioritise the management of their comorbidities to the same extent as their HIV, despite the potentially severe consequences for their health. Educating older PLWH about the importance of managing their comorbidities and providing support on how to do this is important. This includes aiding with lifestyle changes such as smoking cessation, exercising, and joining support groups.

Adherence

Staff recommendations for maintaining adherence encompass a range of strategies, from Dosette boxes and reminder alarms to incorporating medication intake into daily routines, along with support from family and friends. However, challenges in providing free adherence aids from within clinics have been observed, with discontinued free supplies from drug companies. Although, it was noted that some PLWH may be averse to taking products or information with HIV or ARVs outside the clinic due to accidental HIV disclosure.

Discrepancies between self-reported adherence and viral load levels among some older PLWH was reported, possibly due to forgetfulness or non-adherence due to side effects. Moreover, non-adherence during time away

from home or holidays poses challenges for older PLWH, with one individual reportedly going extended periods without ARVs. Clinic staff employ various methods to monitor adherence, including tracking medication stock levels kept by PLWH and investigating discrepancies to identify potential non-adherence or other causes. Additionally, staff recognised the difficulty of maintaining daily medication regimens for some older PLWH, particularly when they feel healthy, as it serves as a reminder of their diagnosis. They also noted instances of survivor's guilt, fatigue from prolonged medication use, and the incorporation of ARVs into daily routines in long-term HIV survivors.

It was reported that religious beliefs can have an impact on adherence behaviours, for instance, one religious person living with HIV reportedly went on and off treatment to test if their prayers to be cured had been answered. Moreover, other factors for non-adherence included concerns of toxicity and side effects. Staff stated that they typically inform PLWH about potential side effects that they may encounter, noting that the anticipation of experiencing these side effects could be overwhelming for individuals who have been recently diagnosed.

Despite high adherence to ARVs, it was reported that some older PLWH were reluctant to engage with medications for comorbidities, which has also been noted in literature. (115,120) This again highlights the differing views older PLWH hold regarding the importance of their comorbidities compared to HIV. Reiterating the need for increased education around the importance of managing comorbidities among older PLWH.

Treatment burden

Staff highlighted the varying frequency of appointments for older PLWH, including appointments with the consultant or for a blood test. While stable individuals typically attend every six to twelve months, others require more frequent visits. Acknowledging the complexities of managing comorbidities, staff sympathised with older PLWH tasked with having to track multiple conditions, treatments, and appointments. Staff utilised blood results from those conducted in GP practices, when possible, to minimise the number of blood tests taken from older PLWH.

In response to the diverse needs of older PLWH, the clinics offered flexibility with appointments including virtual or in-person appointments. Virtual appointments proved particularly valuable for older PLWH who were blind or had impaired mobility. Additionally, older PLWH were able to communicate with clinic staff via multiple avenues, including texts, calls, and emails. To safeguard privacy, appointment reminders were sent via text message without disclosing sensitive information regarding the individual's HIV serostatus.

The provision of medication delivery services offers convenience and privacy, allowing older PLWH to choose their preferred delivery address or collection point, whether that be at home, work, at the clinic or a community pharmacy. Medications are discreetly packaged, although, staff reported that there could be possibilities of pharmacy staff opening the packages leading to accidental disclosure. Despite rare issues with delivery companies, most older PLWH experienced smooth medication delivery, with only a minority encountering difficulties according to staff.

It is important for healthcare professionals to consider older PLWH's treatment burden, and studies have shown the usefulness of symptom screening in identifying and evaluating treatment burden in populations diagnosed with long-term conditions, including HIV. (285-287) Treatment burden can lead to non-adherence to care, viral resistance, and increased mortality. (286)

Medicine burden

It was reported that older PLWH who use Dosette boxes, receive one with their ARVs and another with their medicines prescribed by their GP. Having two separate Dosette boxes doubles the task of taking medications out of each for older PLWH and this may add to their medicine burden. Individuals who rely on Dosette boxes include those with visual impairments, mobility limitations or cognitive challenges.

Despite the challenges associated with medication management, the majority of older PLWH are stable on their ARVs. However, there is growing interest among this demographic for injectable ARVs as an alternative treatment option. However, according to staff, there is a lack of awareness among older PLWH about the requirements involved, such as the need for frequent lengthy clinic visits for injections. (288)

Changes to the supply of ARVs can induce anxiety among older PLWH, showcasing their relationship with their HIV medications. It was reported that some older PLWH prefer to have a longer supply of ARVs as a safety net to ensure they do not run out or to mitigate any disruptions in their supply. Additionally, a staff member shared a case involving an older male living with HIV who mistakenly took two tablets instead of one for two weeks. This occurred because the pharmacy dispensed two bottles that appeared different but contained the same drug. The individual, accustomed to a specific bottle, assumed he needed to take one tablet from each bottle, resulting in adverse effects and prompting him to contact the HIV clinic for assistance. This showcases the importance of pharmacy involvement with older PLWH's care, with the need to explain any medication supply differences.

The complexities of polypharmacy and medication management can exacerbate the medicine burden experienced by older PLWH, particularly if navigating the side effects from both ARVs and medications for their comorbidities. (267)

Polypharmacy

As PLWH age, an increase in comorbidities and subsequently a higher prevalence of polypharmacy is noted by staff, as noted in previous chapters and literature. (266) This accumulation of medications poses challenges, particularly when prescriptions are managed separately by both the HIV clinic and GP practices. As highlighted within this study, there may be instances where the GP is unaware of the individual's HIV serostatus and use of ARVs or the HIV clinic may not have a comprehensive list of all the medications the individual is using. This fragmentation in medication management and access can affect the ability of healthcare providers to prevent drug-drug interactions, duplications of medications and provide medicine-related support. (289) This underscores the need for improved communication and collaboration between healthcare providers involved in the care of older PLWH.

Adverse drug reactions

Staff shed light on the complexities that older PLWH face regarding adverse drug reactions. It was stated that older PLWH may inadvertently disregard symptoms, attributing them to the ageing process or overlooking the possibility of improvement compared to their current state. This suggests a potential gap in recognising and communicating side effects with healthcare providers, whether due to a lack of awareness or an acceptance of certain symptoms as normal due to ageing or HIV. Furthermore, the fear of altering a stable treatment regimen, especially when viral load and CD4 counts are satisfactory, may deter older PLWH from exploring alternative ARVs. Staff noted situations where medications prescribed by GPs interacted with ARVs, leading to undesirable ADRs. Common observations included older PLWH experiencing nausea and fatigue when transitioning to a different ARV, symptoms that typically resolved after a few weeks.

Medicine reviews

Staff reported the need to rationalise older PLWH's prescribed medications, advocating for the discontinuation of unnecessary drugs while stressing the need for primary care support for those prescribed by them. The need to view older PLWH's treatment holistically was emphasised by staff as well as the importance of managing the long-term effects of ARVs, such as their impact on bone density, renal and cardiovascular risks. Staff also proposed simplifying ARV treatment regimens for older PLWH as they age, but stated this may be more possible in larger settings, such as teaching hospitals, with clinics involving multiple departments in managing comorbidities. Studies have shown the effectiveness of two-drug regimens in stable PLWH, limiting the number of drugs these individuals are exposed to. (270)

The pharmacy team's role in conducting medicine reviews for older PLWH upon hospital discharge was highlighted in staff interviews. They utilised clinic records, the National Care Records Service (previously the Summary Care Record), and various other resources, Liverpool HIV Drug Interaction checker, Stockley's Interactions, British HIV Association guidelines, and NAM aidsmap, to ensure medication safety and efficacy. However, it was stated that challenges arise when the national care records are incomplete or outdated, highlighting the importance of improved communication between older PLWH, GP practices, and the HIV clinic staff. Staff suggested the implementation of a pro-forma with prompting questions to facilitate medicine optimisation interventions. The pharmacy team reported commonly receiving inquiries on the use of herbal medicines, drug-drug interactions, and travel health.

An essential aspect emphasised by staff is the importance of older PLWH's involvement in treatment decisions, considering their needs and lifestyle. The patient-centred approach extends to prescribing ARVs tailored to individual circumstances, such as accommodating work schedules or dietary requirements. Desired outcomes of medicine optimisation interventions included enhancing safety, satisfaction, and adherence. Moreover, improving patient understanding of prescribed medications, including adherence and side effects, is key as it was reported that some older PLWH were given medications without the explanation of what it is, how it works and how to take it. However, barriers to implementing medicine optimisation interventions included time constraints, staff shortages, and resource limitations. Moreover, it was reported that these barriers were also the reason for the difficulties in conducting medicine reviews for older PLWH in care homes. Staff reported that clinic appointments were already short for time and were concerned at how medicine optimisation interventions

could be implemented into this. It was suggested that a solution to this issue could be more dedicated time for older PLWH with the HIV specialist pharmacy team within the clinic. Similarly, it was reported that staff struggled to conduct medicine reviews for older PLWH in care homes due to staff shortages and a lack of resources. Staff stated there was a lack of specific medicine optimisation interventions being conducted for older PLWH.

It was reported that medicine reviews occurred either as a better medication was found for those individuals or because they came to the clinic with concerns. One notable trend observed by staff was the increase in medicine reviews prompted by the rising prescriptions of DOACs, as they may interact with certain ARVs. Moreover, Tenofovir disoproxil fumarate was commonly changed to Tenofovir alafenamide in older PLWH due to declining renal function. These changes aimed to minimise interactions between medications and ensure the safety and efficacy of ARVs in older PLWH.

The pharmacy team reported plans to implement specific medicine optimisation interventions for older PLWH had to be halted until further notice due to staff shortages. During the limited time it was active, staff noted that older PLWH raised concerns about medications prescribed by their GPs, such as difficulties obtaining repeat prescriptions and medications not being available on the same date, causing frustration. To address these challenges, staff proposed establishing a pharmacy presence at each clinic site once a month to focus on medicine optimisation interventions for older PLWH.

NHS England switches

Changes to ARV medication were reported within clinics due to the NHS England medicine switches (as described in chapter six). This entailed transitioning from a single tablet to multiple tablets for some, a shift that posed challenges for older PLWH by increasing their overall tablet burden. To monitor the transition's impact, the pharmacy team conducted follow-up calls two weeks post-switch, emphasising the importance of adherence and addressing any potential side effects.

According to staff, a primary challenge associated with the NHS England switches in older PLWH stemmed from their longstanding use of their current ARV regimens. Many individuals harboured apprehensions rooted in their familiarity and confidence in their existing treatment's efficacy. They feared that the proposed switch might not deliver comparable results or could introduce unwanted side effects. Notably, a couple, both living with HIV, staunchly refused to participate in the medication switches, prompting staff to respect their autonomy and allow them time to reconsider their decision, with plans to revisit the matter during subsequent appointments. Contrary to this, some staff members reported not encountering individuals who refused the medication switches thus far. Nevertheless, they remained conscious of the potential challenges that certain individuals might face when confronted with the necessity of switching medications. This highlights the need for a nuanced approach to address individual concerns and ensure successful transitions in ARV regimens to ensure optimal adherence.

Social support

Staff highlighted that some older PLWH experience significant loneliness and difficulties reaching out to others due to their HIV serostatus. Several staff members recognised the vital role of social and medicine-related

support in promoting adherence. Staff also stated the positive impact of the social support group organised locally. However, despite the evident need for social support, reluctance persists among some older PLWH to engage with support groups due to fears of potential sharing of their serostatus without their consent or encountering acquaintances who may be unaware of their diagnosis. Staff described the existence of a list of vulnerable individuals who, despite requiring support, refrain from participating in any support groups. To address this, staff initiated periodic phone check-ins and casual conversations with these individuals, aiming to cultivate a sense of connection and support. Amid the COVID-19 pandemic, staff intensified their efforts, conducting weekly phone calls to those experiencing heightened loneliness and mental health challenges, with observations indicating positive responses from older PLWH to these outreach efforts. Increased social support has been shown to increase adherence, and to counteract social isolation and stigma experiences. (110,117,155)

Stigma

Staff recounted numerous instances of witnessing or hearing accounts of stigma directed towards PLWH. This stigma has been reported to come from the public and also from healthcare professionals, which has also been commonly noted in literature. (131,168) It was reported that some older PLWH who are healthcare professionals themselves, conceal their serostatus from colleagues out of fear of stigmatisation.

Staff stated that some older PLWH who have not shared their serostatus with others have difficulties with their medication, with some individuals being hesitant to take medication openly or resorting to decanting their ARVs into nondescript containers to conceal packaging. Additionally, it was reported that certain older PLWH refrain from carrying their ARVs when travelling, driven by the fear of others discovering them.

Furthermore, staff stated that some older PLWH opt to use pseudonyms when attending the HIV clinic, a practice that poses challenges in accessing their GP records and may potentially complicate medical care, particularly in hospital settings where NHS numbers are tied to real names. This underscores the profound impact of stigma on older PLWH, leading to strategies aimed at concealing their HIV status and navigating healthcare systems anonymously. Such behaviours not only highlight the pervasive nature of stigma but also the significant barriers it erects in accessing and receiving comprehensive medical care for older PLWH.

Clinic services

Staff emphasised the importance of ensuring PLWH can contact the HIV clinic staff easily and promptly. It was reported that older PLWH regularly contact the specialist nurses and the pharmacy team with any questions or concerns they have. To address the challenge of extended wait times due to appointments being fully booked months in advance, staff initiated a monthly urgent clinic for PLWH requiring more urgent attention.

Budget constraints have led to the discontinuation of specialist care managers, leaving a gap in support services for PLWH, particularly regarding housing, benefits, and employment queries. This funding limitation, attributed to fixed contracts with local councils, hampers the flexibility needed to accommodate the increasing demand for care services amidst rising numbers of PLWH and evolving care needs, especially among older

individuals. Furthermore, insufficient funding posed challenges in delivering support services for older PLWH. The absence of a dedicated social care team further exacerbates challenges in providing holistic support, particularly in addressing mental health needs among older PLWH. Staff expressed a desire to replicate the service model implemented in Brighton, although they acknowledged the disparity in population size and funding allocation between Brighton and their own setting.

To enhance care for the ageing HIV population, staff proposed periodic joint clinics involving geriatricians and cardiologists, to improve care coordination, and address age-related health concerns more effectively. Additionally, staff highlighted the utility of seeking advice from virtual clinics, such as those offered by Chelsea and Westminster Hospital, particularly for complex cases involving resistance or drug-related issues.

Staff described challenges with the electronic health record system used within clinics, cited for its time-consuming nature and occasional unreliability, prompting calls for a more robust and user-friendly system to streamline care delivery.

In response to improving care for older PLWH, staff advocated for regular multidisciplinary meetings involving HIV consultants, the pharmacy team, nurses, and GPs to facilitate closer monitoring, reduce polypharmacy, and mitigate drug interactions. Drawing inspiration from successful models observed in cities with larger HIV services, such as Brighton, where such meetings are reportedly beneficial, staff expressed a commitment to providing personalised care, contrasting with perceptions of impersonal care experienced by some PLWH transferring from larger healthcare systems. The presence of a responsive pharmacy team within clinics was lauded as instrumental in addressing queries promptly, underscoring the collaborative efforts to support the diverse and evolving needs of older PLWH attending the clinics.

Clinic settings

The organisation of sexual health and HIV clinic appointments varied across different clinics, with some allocating separate days for each type of appointment, while others shared the same space for both. Amid the COVID-19 pandemic, procedural changes were implemented in certain clinics, where PLWH arrived at their appointment time and rang a bell to gain entry, with a staff member letting them in. This contrasts with the pre-pandemic practice of PLWH walking in and waiting in the waiting room before their appointments. These adjustments reflect the evolving dynamics of clinic operations in response to public health considerations, highlighting the ability of healthcare facilities to ensure the safety and wellbeing of patients amidst challenging circumstances.

Provider relationships

Staff interviews emphasised the importance of the relationship between healthcare providers and older PLWH in shaping their care experiences and treatment outcomes. A shift in the dynamics over the past few years was noted, with a growing number of PLWH attending the clinic, leading to a negative change in familiarity between staff and patients. Additionally, they highlighted that while many long-term attendees frequently approached the pharmacy team with queries, there's a need to raise awareness among newer attendees about the availability and role of the specialist pharmacist team.

According to staff, most older PLWH have shared their HIV serostatus with their GP. However, some individuals have chosen not to share this information, posing challenges in managing their comorbidities. Convincing these individuals to seek GP assistance for conditions such as high cholesterol was challenging for staff, particularly as they were not be able to directly communicate with the GP. Studies have shown that encouragement from HIV clinics to register and share their serostatus with GPs has been effective. (226) Individuals with uncertain immigration status are not registered to a GP, complicating access to comprehensive care. It was reported that over time, older PLWH would prefer direct communication between the HIV clinic and their GP, rather than engaging in back-and-forth exchanges between the two.

One recurring challenge highlighted by staff is when older PLWH are prescribed a medication with an interaction that their GP may not be aware of. Moreover, despite efforts to communicate relevant information through clinic letters, staff reported to receive minimal information back from GPs and other healthcare professionals. However, this did not stop staff from maintaining open lines of communication and offering the opportunity for reciprocal contact.

Staff speculated about the future possibility of transferring stable older PLWH's care to GP practices, questioning the longevity of specialist HIV services given effective treatment outcomes rendering HIV less of a concern than other comorbidities. Some older PLWH expressed a desire for integrated HIV care and GP services. This sentiment reflects a preference for a cohesive approach to healthcare delivery, where all aspects of their medical care are consolidated into a single, coordinated system. However, studies have shown that some PLWH are reluctant for this change to occur. (226)

The COVID-19 Pandemic

Staff highlighted various challenges faced by older PLWH during and following the COVID-19 pandemic, including increased loneliness, mental health issues, and logistical difficulties in accessing medication and healthcare appointments, which is also evident in literature. (279) These issues may have been the cause of the higher viral loads observed by staff during lockdown periods. Moreover, travel restrictions prompted new transfers to the clinics, as individuals were unable to access services in their usual locations.

Anxiety regarding contracting COVID-19 among older PLWH was prevalent according to staff. It was reported that most individuals within the service had not contracted or did not have a severe case of the virus at the time of interviews. However, studies have shown that PLWH with comorbidities are at a higher risk of worsened outcomes from COVID-19. (290) The pandemic brought about both negative and positive impacts to service delivery according to staff: reduced face-to-face contact was noted as a downside, although virtual appointments offered increased flexibility for stable individuals as a positive. The pandemic also led to a decrease in blood tests for stable older PLWH, with some transitioning to annual blood tests. Staff speculated if the pandemic may have contributed to lower HIV diagnosis rates due to reduced testing accessibility.

It was reported that the absence of clinic visits during lockdowns was felt keenly by older PLWH, who considered the clinic a crucial part of their routine and expressed concern for the wellbeing of staff, reflecting a familial bond between staff and patients. Comparisons were drawn between the early days of HIV emergence and the onset of the COVID-19 pandemic, highlighting shared experiences of uncertainty and fear. Upon

resumption of in-person appointments, staff noted signs of domestic violence and alcoholism, indicating the significance of maintaining in-person appointments to identify concerns that cannot be seen virtually. Additionally, staff outlined the challenges experienced by some older PLWH when clinic services were disrupted, noting that individuals did not seek assistance with their concerns, leading to these issues only surfacing months later when they were back at the clinic.

Ageing

Staff interviews revealed a spectrum of concerns among older PLWH, including comorbidities, finances, loneliness due to loss of peers, anxiety, and mortality. Moreover, menopause emerged as a particular concern for older women living with HIV as mentioned earlier within this chapter's discussion under comorbidities, highlighting the additional age-related health issues faced by these individuals. Furthermore, staff recounted a poignant incident where a late HIV diagnosis resulted in the individual's death within three years, underscoring the critical importance of early detection in the ageing population. Studies have shown that late diagnosis of HIV significantly increases the risk of mortality. (291) Staff reported conducting home visits to monitor a 90-year-old person living with HIV registered at the clinic, experiencing isolation, loneliness, and frailty. This showcases the extent of the relationship between older PLWH and staff, with them taking the extra steps to ensure the safety and wellbeing of PLWH.

Several staff members expressed the view that 50-years-old is relatively young, and some suggested that older PLWH may not be concerned about ageing but simply desire to remain alive. Routine health assessments, encompassing bone density, lipid profiles, and HbA1c monitoring for diabetes, for individuals over 40 years old attending the clinics were reported, highlighting proactive measures to address age-related health issues by the clinic.

Care home

The growing population of ageing PLWH prompts considerations about their potential future needs for care home placements. Staff shared historical challenges in securing care home admissions for older PLWH, citing instances where finding a facility willing to admit them posed significant difficulties. Decisions regarding resident admissions are typically left to nursing home managers, and clinic staff advocated for increased training among care workers to combat HIV-related stigma and foster greater acceptance of older PLWH within care home settings. They expressed optimism that as PLWH age, societal attitudes toward HIV would evolve positively, leading to improved reception and support within care home environments. While acknowledging a current trend of older PLWH prioritising independence over care home placements, staff anticipate a future rise in demand for nursing or residential care among this demographic. This projection underscores the importance of proactive measures to enhance care home readiness and address the unique needs of ageing PLWH in the years to come. There is currently limited data regarding the long-term care preferences, requirements and options for older PLWH, therefore further research is required. (292)

Strengths and limitations

This chapter included semi-structured interviews with staff members working at a HIV clinic. This study has notable strengths and limitations.

A significant strength of the research in this chapter is its focus on a under-researched area, offering valuable insights into the perspectives of clinic staff regarding the medicine optimisation needs and care for older PLWH. Utilising semi-structured interviews both in-person and virtually, provided more flexibility for staff and enabled the collection of detailed data. This approach was especially beneficial as it offered a safer option if participants wanted post-COVID-19.

However, the study also had limitations that need to be considered. The use of both in-person and virtual interviews may have introduced variability in the data due to the differences in non-verbal communication and rapport-building. Additionally, as interview data was exploring the perspectives of healthcare professionals, this can be affected by personal views and opinions, creating bias in answers. Moreover, the researcher's professional background as a pharmacist, may have led to social desirability bias in the responses of participants. It should also be noted that staff were based at different sites across the South-East of England or travelling between sites, this may mean that experiences and perspectives vary as each clinic site has differing numbers of staff and resources present. Finally, as this study was conducted at one NHS Trust, the results may not accurately represent the broader population of HIV clinic staff or the experiences of older PLWH in different contexts.

7.5 Chapter Summary

Staff provided insights regarding the healthcare challenges faced by older PLWH, showcasing the complexity of managing multiple comorbidities. Staff highlighted the rise in conditions, such as hypertension, cardiovascular diseases, and diabetes among older PLWH, noting the challenge of polypharmacy. The logistical constraints of thorough assessments for comorbidities during limited appointment times were described. Older PLWH may not be prioritising managing their comorbidities as much as their HIV, which could have severe health consequences. Moreover, older female PLWH faced specific challenges related to menopause, often mistaking menopause symptoms for HIV or ARV side effects. It was emphasised that routine inquiries about menstrual history and menopausal symptoms are crucial to prevent delayed diagnosis and to help manage symptoms.

Managing multiple medications, including separate Dosset boxes for ARVs and other medications, increase the medicine burden for older PLWH. Staff highlighted the complexities of ADRs, noting that older PLWH dismiss symptoms and attribute them to ageing or HIV. Fear of changing a stable regimen stops older PLWH from exploring alternatives. Pharmacy involvement was regarded as crucial in addressing medication-related issues and ensuring patient safety. Understanding factors contributing to treatment and medicine burden was deemed essential, as it can lead to non-adherence, and viral resistance, and increased mortality. Communication challenges between HIV clinics and GPs complicate polypharmacy and medication management, highlighting the need for better collaboration.

Effectively addressing the healthcare challenges faced by older PLWH requires a multifaceted approach. This approach should involve several interconnected strategies, such as educating healthcare providers about the unique needs of this population, implementing proactive screening protocols to detect and manage comorbidities early, and providing support services that address both medical and psychosocial aspects of care. Importantly, HIV clinic staff emphasised the current one-sided nature of communication with other healthcare professionals, particularly with primary care, where they frequently send correspondences but rarely receive a response. To enhance the care of PLWH as they age, it is crucial to improve this communication.

CHAPTER EIGHT

Discussion

8.1 Summary of key findings

Since the mid-1990s, the care for individuals living with HIV has been transformed by effective treatments, resulting in life expectancies comparable to the general population. A sense of hope and the possibility of survival due to advances in ARVs gradually shifted the perception of HIV from a death sentence to a manageable condition. Changing the belief that survival was not only possible but even likely. Consequently, the need for palliative and terminal care diminished, rendering some well-established services from the early years of the epidemic as increasingly redundant in subsequent years. (260) To meet the UNAIDS target of ending AIDS by 2030, viral suppression in diagnosed individuals is crucial to preventing further transmission (undetectable=untransmittable). (294) However, this requires high adherence rates, which is further complicated as PLWH are living longer and are at risk of experiencing increased comorbidities, polypharmacy, toxicities, drug resistance, drug-drug interactions, and other difficulties. Therefore, it is crucial to study the effects of living with HIV within the context of ageing and to consider the future care needs of these individuals. Additionally, the UNAIDS 2025 targets aim for less than 10% of people with HIV to experience stigma. HIV-associated stigma continues to significantly impact the experiences of PLWH and hinders their access to testing and healthcare.

The exploration of medicine-related burden and medicine optimisation experiences among the ageing HIV population, as presented in this thesis, highlights significant gaps in understanding and addressing the complex needs of older PLWH. The findings presented in chapters 4 through 7 converge on several critical themes: the interplay of ageing and HIV, the challenges of comorbidities and polypharmacy, and the impact of stigma and social support. These interconnected themes collectively underscore the necessity for a more nuanced, holistic approach to the care of older PLWH.

An in-depth systematic review (chapter 2) at the start of the enquiry defined the priority issues and concerns in the ageing HIV population as comorbidities, HRQOL, polypharmacy, drug interactions, adverse drug reactions, adherence, medicine burden, treatment burden, stigma, social support, and patient-healthcare provider relationships. Nine intervention studies were identified out of the 79 appraised, with the majority of the studies being conducted in the USA. The studies reviewed indicated that as PLWH grow older, they experience an increase in both the number of comorbidities and the prevalence of polypharmacy. It was also shown that this population holds uncertainty about the physical, psychological, and social impacts of ageing with HIV. Studies highlighted mental health conditions as a concern among older PLWH, including depression and anxiety. (109,169) Moreover, frailty is a significant concern with clinical care and health outcomes in this population. (182) Medicine reviews were shown to reduce polypharmacy, pill burden, PDDIs, improve health outcomes and simplify ART. (107) If left unaddressed, these factors can contribute to medicine-related burden. The usefulness of tools such as the Beers and STOPP criteria were evident in several studies. (59,100,115,126,149) Combined with the demands of attending clinic appointments, making lifestyle changes, undergoing laboratory tests, and engaging in self-monitoring, this can further intensify treatment burden. Additionally, stigma, which remains a prevalent issue among older PLWH, can pose significant barriers to accessing care and support. Older PLWH highlighted the need for enhanced support services addressing mental health, stigma, and social

isolation. (106,111) The interventions identified in the nine studies focused on adherence, medicine reviews, and self-management strategies, with several being technology based. Key concerns specific to older PLWH identified in the systematic review were underrepresented, emphasising the need for further research to develop tailored interventions for this population to enhance health outcomes. The absence of medicine optimisation interventions specifically tailored for older PLWH underscores the need for further research to address key issues impacting this group. Through a combination of quantitative and qualitative approaches, chapters 4 to 7 sought to explore and uncover the unique needs and preferences of this population in relation to their medications and overall care.

Chapter 4 explored medicine-related burden, stigma and sharing of serostatus among younger and older PLWH, using the LMQ-3 and SSCI-8. The study revealed that while overall medicine-related burden was low across both age groups, a minority experienced high burden, underscoring the importance of targeted interventions. This perhaps could be explained by participants reporting feeling “lucky effective treatment for HIV exists” and thus were happy to take the “life saving medication”. Free-text quotes provided a deeper insight into how PLWH perceive their medications. For instance, it was indicated that some PLWH may feel unable to voice concerns about their medication experiences, believing they have no option but to adhere to their treatment. This aligns with existing literature highlighting the perception of medicines as essential for maintaining health. (220) Furthermore, the study found a correlation between higher medicine-related burden scores and increased levels of stigma experienced among both age groups. It was found that older PLWH were more likely to share their serostatus with healthcare professionals, whereas younger PLWH preferred sharing with close friends. This finding shows how different age groups navigate their HIV status within social and healthcare contexts.

Chapter 5 then explored the medicine-related and other social support needs of PLWH. A high medicine-related burden among PLWH was found, particularly among those using fewer medicines, suggesting that even minimal treatment regimens can pose significant challenges for these individuals. This study also discussed the impact of COVID-19 on the ageing population, noting increased loneliness and difficulties accessing medicine-related support. The pandemic may have contributed to the differences in medicine-related burden reported between chapters 4 and 5 due to several factors. The disruptions caused by the pandemic, such as limited access to healthcare services, difficulties in attending medical appointments, and interruptions in medication supply chains, could have increased the challenges associated with managing treatment regimens. Social isolation and reduced access to community or peer support during lockdowns may have exacerbated the emotional and logistical difficulties of adhering to treatment. Additionally, chapter 5 highlighted the barriers and underutilisation of using primary care providers by older PLWH, particularly GPs and community pharmacists, due to issues such as stigma, lack of training, and negative past experiences. This chapter suggested that optimising the use of social support groups could enhance health outcomes in PLWH.

Chapter 6 delved deeper into the lived experiences of older PLWH, offering a qualitative perspective on their interactions with healthcare systems and their coping mechanisms. The significance of comorbidities was emphasised, which overshadowed HIV in the daily lives of older PLWH, raising concerns about the adequacy of current healthcare approaches in addressing these issues. While older PLWH generally adhered to ARV regimens, there was a noted gap in the perceived importance of non-ARV medications. This was also

emphasised in the studies reviewed in chapter 2, indicating that some individuals prioritise medications according to their beliefs and perceived importance. (116,121) The distinction between long-term survivors and those diagnosed later in life is particularly noteworthy, as it highlights the different adaptive strategies and challenges faced by these groups. Literature has shown the resilience and coping methods adopted by PLWH, however, there is a scarcity of research on this population of long-term survivors. (295-297) As PLWH age, the potential transition to care homes becomes an important consideration. However, older PLWH expressed concerns about disclosing their HIV serostatus in such environments. Many reported hearing distressing accounts of homophobia and mistreatment by care home staff due to their HIV diagnosis, further amplifying their apprehensions. This chapter reinforces the complexity of ageing with HIV and the need for tailored care strategies that address the physical, emotional, and social aspects of living with HIV.

Finally, chapter 7 brings in the perspectives of healthcare professionals, shedding light on the challenges of managing older PLWH's care, particularly in the context of polypharmacy and comorbidities. This chapter highlights the logistical constraints faced by HIV healthcare providers, such as limited appointment times and communication barriers between HIV clinics and primary care. The specific challenges faced by older female PLWH, including the misattribution of menopause symptoms to HIV or ARV side effects, underscore the need for gender-sensitive approaches in HIV care. The emphasis on the role of pharmacists in managing medication-related issues and the need for improved communication between healthcare providers aligns with the broader theme of integrated, patient-centred care. The chapter concludes with a call for a multifaceted approach to care, one that includes educating healthcare providers, implementing proactive screening protocols, and enhancing communication between different levels of care to better support the ageing HIV population.

8.2 Strengths and limitations

This thesis makes several important contributions to the understanding of the experiences and care needs of older PLWH. A key strength is the comprehensive mixed-methods approach employed, combining qualitative and quantitative data. This provides a robust foundation for understanding the multifaceted challenges faced by older PLWH, including medicine-related burden, stigma, and the role of social support. The inclusion of both PLWH and healthcare professional perspectives enhances the depth of analysis, offering a balanced view of the issues at hand.

However, this study had several limitations specific to each study, which have been discussed in respective chapters of this thesis. Additionally, while the study successfully identified critical themes, further research is needed to develop and test specific interventions to address the identified challenges.

8.3 Implications for research and contribution to knowledge

This thesis contributes to the understanding of the complex interplay between ageing and HIV. The lack of tailored interventions for older PLWH points to the need for more nuanced approaches to address their unique healthcare needs. These findings expand the knowledge base, particularly in relation to the interconnected roles of stigma, social support, and mental health in shaping the experiences of older PLWH.

The research highlights critical inefficiencies in the current HIV care system, particularly with the communication barriers between HIV clinics and primary care providers. Additionally, the study's exploration

of the unique challenges faced by older female PLWH, including the misattribution of menopause symptoms to HIV or its treatment, contributes to the call for gender-sensitive approaches in HIV care. Finally, the insights into the experiences of long terms survivors compared to those diagnosed later in life provide a foundation for further research into HIV survivorship.

8.4 Implications for practice and policy

The persistent challenges associated with comorbidities, polypharmacy, and stigma among older PLWH highlight the urgent need for integrated healthcare models. Policymakers should prioritise systems that facilitate seamless communication and collaboration between HIV clinics and primary care providers to address the multifaceted needs of this population.

Encouraging the role of pharmacists in managing medicine-related issues in PLWH is another critical area for policy intervention, given their ease of access and pivotal role in addressing polypharmacy and drug interactions. Pharmacists are uniquely positioned to lead annual medication reviews for older PLWH, particularly given the complex nature of their treatment regimens. Evidence from the ‘Care Homes Use of Medicines Study’ underscores the clinical value of pharmacist-led reviews, demonstrating their ability to identify a wide range of medication-related issues, including ADRs, inappropriate polypharmacy, and DDIs. (295) Pharmacists were shown to play a pivotal role in optimising therapy through dose adjustments, deprescribing, and ensuring treatment plans were appropriate. Utilising the clinical expertise of pharmacists embedded within general practice offers a scalable and sustainable solution. Their integrative role within multidisciplinary teams further strengthens care coordination and continuity, which are key to managing the complex, long-term healthcare needs of older PLWH.

Moreover, it is essential that policymakers adopt a person-centred approach when making decisions. Despite longstanding evidence highlighting the harms associated with polypharmacy, older PLWH have, as discussed in chapter 6, been required to increase their tablet burden due to the NHS England-led medication switches. This illustrates a disconnect between policy decisions and individual patient needs.

The thesis underscored the ongoing impact of stigma on healthcare access and treatment among older PLWH. This necessitates the development and implementation of stigma-reduction programmes targeting both healthcare providers, PLWH and the general public. Additionally, the findings emphasise the need for accessible mental health services and peer support initiatives, which are inconsistently available. A policy focus on nationwide standardisation of these services would improve equity in care provision. Lastly, targeted training for healthcare providers, including GPs, HIV specialists, and pharmacists, is essential to equip them with the skills to address the complex needs of older PLWH, including issues related to ageing and gender-sensitive care.

8.5 Recommendations for future research

Future research should prioritise the development of tailored interventions to address the unique needs of older PLWH. Specifically, studies should focus on interventions targeting medicine optimisation, stigma reduction,

mental health, and loneliness. Additionally, research should examine the distinct experiences of older female PLWH to inform the design of gender-sensitive approaches to care.

As PLWH age, it becomes increasingly important to plan for their future care, ensuring that their unique needs are met in a comprehensive and compassionate manner. This includes understanding the challenges they may face in transitioning to care homes, an area that had been underexplored in HIV research. Care homes often cater to a general ageing population, but the specific medical, psychological and social needs of older PLWH, such as managing complex medication regimens, addressing stigma, and providing appropriate social support, require tailored approaches. Research into HIV care within these settings is crucial to identify potential barriers, such as staff training gaps, fear of discrimination, and insufficient policies to protect residents with HIV. Proactive research and preparation can help create a care system that not only supports ageing PLWH but also promotes dignity and equity as they navigate this stage of life.

Comparative studies investigating the experiences of long-term survivors and those diagnosed in later life are warranted to understand their respective challenges. This research could inform personalised care approaches that draw on the resilience and adaptive methods observed in long-term survivors.

The long-term impact of the COVID-19 pandemic on the ageing HIV population also requires further investigation. Studies should examine how disruptions in healthcare access, increased isolation, and other pandemic-related factors have shaped the experiences and outcomes of older PLWH.

Given the well documented disparities in HIV prevalence, access to care, and health outcomes across different ethnic groups, future research should aim to include a more diverse participant pool to ensure a more comprehensive understanding of the varied lived experiences of PLWH. To enhance participant recruitment, particularly amongst those who may have had negative healthcare experiences or be disengaged from care, a more targeted approach could be employed. One potential strategy would be to assess the frequency of healthcare visits over a specified period and prioritise outreach to individuals with the fewest interactions. This would help ensure that the study captures a broader spectrum of experiences. Finally, Given the predominance of studies conducted in the USA, future research should aim to capture the experiences of older PLWH in diverse sociocultural and healthcare settings to ensure generalisability and applicability of findings across different contexts.

8.6 Conclusion

By delving into the experiences and perspectives of both staff and older PLWH with respect to medicines, this thesis aimed to elucidate key considerations for optimising care delivery and enhancing the overall wellbeing of older PLWH. The findings from chapters 4 through 7 collectively highlight the multifaceted challenges faced by this population. The availability of HIV peer support, psychosocial, and mental health services varies nationwide and is implemented through differing models. The importance of peer support has been noted throughout this thesis, with the potential to enhance wellbeing and support continued engagement with HIV care. A key theme across the chapters is the importance of personalised care strategies that consider the unique experiences and needs of older PLWH in managing their medicines. Insights from long-term survivors could

provide valuable strategies to support all individuals living with HIV, particularly younger and newly diagnosed individuals who have yet to develop the experience of managing HIV, comorbidities and medicines.

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APPENDICES

Appendix 1. Systematic review supplementary information.

a) Preliminary full text age screening form.

Full text reviewed?	Age over 50? How many?	Age under 50? How many?	Comparison between older vs younger?	Reasons for rejection?	Notes
Y	Y/31	Y/48	N	No age comparison/tool examining	

b) Population Intervention Comparison Outcome (PICO)

Participants/population	<p>Inclusion criteria:</p> <ul style="list-style-type: none"> • Studies reporting issues and concerns of older PLWH (age 50 years or older) about their medicines. • Studies discussing any aspect of medicine optimisation (e.g. medicine burden, adherence, drug-related problems, medicine reviews, prescribing or deprescribing, medication reconciliation in older HIV-positive adults. • Studies reporting medicine-related interventions for HIV-positive older adults. • Studies published in English. <p>Exclusion criteria:</p> <ul style="list-style-type: none"> • Studies including children, adolescents, and younger adults (under the age of 50) • Studies of HIV-negative adults • Studies that do not discuss any aspect of medicines optimisation
Interventions/exposures	We are interested in studies relating to any aspect of medicines optimisation, medication reviews, medication reconciliation, deprescribing, or strategies being undertaken to support the older HIV-positive patient population with safe and effective use of ART and/or non-HIV medicines.
Comparators/control	Not applicable.
Context	Studies involving older people (those aged 50 years or greater) living with HIV, who are currently taking antiretroviral medications and/or non-HIV medicines, reporting older people's issues/concerns and targeted interventions in any setting (e.g. HIV clinics, hospitals, GP surgeries, community pharmacies, or in the community).
Outcomes	<ul style="list-style-type: none"> • Medicine-related problems, e.g. polypharmacy, drug-drug interactions, adverse drug reactions, drug-related hospitalization and other medicine safety issues • Medicine information needs • Deprescribing outcomes • Medication adherence and impact on clinical outcomes (e.g. viral load) • Prescription appropriateness • Medicine burden and quality of life • Psychosocial concerns • Social support needs <p>Additional outcome(s)</p> <ul style="list-style-type: none"> • Mental health and general wellbeing • Patient satisfaction • Shared decision-making

c) Search strategy.

Search Strategy used for MEDLINE, Abstracts in Social Gerontology, Academic Search Complete, CINAHL, DARE and OpenGrey:

- Ageing OR aging OR age* OR old OR older OR old* OR elderly OR geriatric OR adult* OR 50 years OR 50 years or older OR over 50 years old OR patient OR consumer OR senior OR retiree
- HIV OR HIV-1 OR "human immunodeficiency virus" OR AIDS OR "acquired immunodeficiency syndrome" OR ARV OR ART OR HAART OR "anti-retroviral" OR "antiretroviral" OR antiretroviral therapy OR anti-retroviral therapy OR HIV adj2 positive OR people living with HIV OR PLWH OR person adj3 HIV OR viral load OR CD4 OR undetectable
- Concern* OR understand* OR knowledge OR needs OR priorit* OR belief OR stress OR issues OR problem* OR outcomes OR burden OR medic* burden OR drug burden OR treatment burden OR medic* complexity OR regime* complexity OR medication regimen complexity OR polypharmacy OR drug-drug interactions OR adverse drug reactions OR drug related hospitalisations OR medicine safety issues OR medicine information needs OR prescriptions appropriateness OR quality of life OR patient satisfaction OR patient preference OR preference OR perception OR expectation OR attitude OR view OR experience OR shared decision making OR clinical outcome* OR ((issues OR concerns OR problems) AND psychosocial) OR social support needs OR mental health OR wellbeing OR stigma OR discrimina* OR retire* OR pension OR cost OR insur* OR insurance
- Drug therapy OR medication* OR medicine* OR agent OR product OR drug* OR therapy OR treatment OR pharmacotherapy OR nonprescription OR non-prescription OR prescription OR prescription* adj2 drug* OR medication error* OR inappropriate prescribing OR potentially inappropriate prescribing OR problematic prescribing OR suboptimal prescribing OR deprescrib* OR stop OR reduc* OR cessation OR dos* reduc* OR STOPP OR BEERS OR over the counter OR otc OR compliance OR non-compliance OR adher* OR non-adher* OR medication adherence OR "quality of life" OR "HRQL" OR life adj3 quality OR health adj3 quality adj3 life OR decision making OR pharmaceutical care OR treatment OR therapy OR decision support techniques OR decision support system OR decision* OR choice* OR support* OR behavior OR behaviour OR aid* OR drug therapy problem OR information OR communication OR advice OR counsel* OR social adj3 support OR social adj3 needs OR medicines optimisation OR medicines optimization OR optimise OR optimize OR optimization OR optimisation OR optim* OR medicine* management OR medication* management OR medication* therapy management OR drug* therapy management OR drug* management OR medication* review OR medicine* review OR MTM OR medicine adj3 review OR ((psychosocial OR behavioural OR pharmaceutical OR digital OR medicine-related) AND intervention*) OR intervention* OR review OR treatment adj3 (compliance OR adherence) OR psychology* OR emotional
- Pharmacists OR pharmacist* OR pharmacy OR pharmacies OR pharmacist* intervention OR pharmacist-led OR chemist OR druggist OR pharmac* technician OR doctor OR nurse OR health worker OR health adj3 professional OR social worker OR healthcare provider OR health provider OR consultant OR specialist OR nutritionist OR psychologist OR psychiatrist OR health personnel OR primary care OR secondary care OR tertiary care OR community OR carer* OR care worker

Search strategy used for The Cochrane Central Register of Controlled Trials (CENTRAL):

- Drug therapy OR medication* OR medicine* OR agent OR product OR drug* OR therapy OR treatment OR pharmacotherapy OR nonprescription OR non-prescription OR prescription OR medication error* OR inappropriate prescribing OR potentially inappropriate prescribing OR problematic prescribing OR suboptimal prescribing OR deprescrib* OR stop OR reduc* OR cessation OR dos* reduc* OR over the counter OR otc OR compliance OR non-compliance OR adher* OR non-adher* OR medication adherence OR "quality of life" OR "HRQL" OR life adj3 quality OR decision making OR pharmaceutical care OR treatment OR therapy OR decision support techniques OR decision support system OR decision* OR choice* OR support* OR behavior OR behaviour OR aid* OR drug therapy problem OR information OR communication OR advice OR counsel* OR social adj3 support OR social adj3 needs OR medicines optimisation OR medicines optimization OR optimise OR optimize OR optimization OR optimisation OR optim* OR medicine* management OR medication* management OR medication* therapy management OR drug* therapy management OR drug* management OR medication* review OR medicine* review OR MTM OR intervention* OR review OR psychology* OR emotional

Part 1: Abstract screening form.

Abstract screening form

Abstract screening for Medicines optimisation needs and interventions for older people living with HIV/AIDS - protocol for a systematic review

* Required

Reviewer's name: *

Choose ▼

Author's name: *

Your answer

Publication Year: *

Choose ▼

Does this study report issues or concerns of older PLWH (age 50 years or older) about their medicines? *

- ☐ Yes
- ☐ No
- ☐ Maybe

Does this study discuss any aspect of medicine optimisation? (e.g. medicine burden, adherence, drug-related problems, medicine reviews, prescribing or deprescribing, medication reconciliation in older HIV-positive adults) *

- ☐ Yes
- ☐ No
- ☐ Maybe

Is the study outcome relevant to the review? *

- ☐ Yes
- ☐ No
- ☐ Maybe

Based on your reflection, should this study be included in the analysis? *

- ☐ Yes
- ☐ No
- ☐ Maybe

If No, What is your reason for excluding this study?

Your answer

Submit

Full article screening

Full article screening for Medicines optimisation needs and interventions for older people living with HIV/AIDS - protocol for a systematic review

*** Required**

Reviewer's name: *

Choose ▾

Author's name: *

Your answer

Publication Year: *

Choose ▾

Is this study Quantitative or Qualitative? *

☐ Quantitative

☐ Qualitative

☐ Other: _____

Does this study report issues or concerns of older PLWH (age 50 years or older) about their medicines? *

☐ Yes

☐ No

☐ Maybe

Does this study discuss any aspect of medicine optimisation? (e.g. medicine burden, adherence, drug-related problems, medicine reviews, prescribing or deprescribing, medication reconciliation in older HIV-positive adults) *

☐ Yes

☐ No

☐ Maybe

Does this study report medicine-related interventions for HIV-positive adults? *

☐ Yes

☐ No

☐ Maybe

Does this study report any non-medicine-related interventions for HIV-positive adults? (e.g. psychosocial, behavioural, digital interventions) *

☐ Yes

☐ No

☐ Maybe

Have these interventions been used in older adults? (age 50 years or over) *

☐ Yes

☐ No

☐ Maybe

Is the study outcome relevant to the review? *

☐ Yes

☐ No

☐ Maybe

Based on your reflection, should this study be included in the analysis? *

☐ Yes

☐ No

☐ Maybe

If No, What is your reason for excluding this study?

Your answer

Submit

d) Part 1: Data extraction table.

Title	Author(s)	Year published	Study design	Study population/setting	Country	Methods – data collection	Intervention	Outcomes	How were the outcomes measured? What tools were used?	Key findings	Limitations	Qualitative, Quantitative, Mixed methods?
Health-related quality of life and its predictors among adults living with HIV/AIDS and receiving antiretroviral therapy in Pakistan.	Ali Ahmed, et al.	2021	Cross-sectional descriptive study	602 PLWH/32.9% >50 years old/Hospital	Pakistan	Participants were given a validated generic HRQOL questionnaire	-	Participants adherent to ARV had good HRQOL, although they also had significantly higher depression.	EuroQol quality of life scale EQ-5D-3L and Visual Analogue Scale	59.5% (n=358/602) participants did not report any impairment in self-care. 63.1% (n=380/602) of participants were extremely depressed/anxious. Overall, the mean EQ-5D utility and Visual Analogue Scale scores were 0.388 (SD=0.41) and 66.20 (SD=17.22), respectively. Multiple regression analysis has shown that age over 50, the female gender, primary or secondary education, less than a year since HIV diagnosis, having a detectable viral load, and a longer time to ART were all factors significantly associated with HRQOL.	The results cannot be generalised to non-adherent PLWH as participants who failed to show up regularly according to their dispensing records were excluded from the study. Moreover, the cross-sectional study design does not allow for causality analysis and there is a possibility of social desirability bias as participants are likely to underreport socially undesirable behaviours.	Quantitative

e) Part 2: Thematic synthesis categories.

Polypharmacy	Stigma	QOL/HR-QOL	ADR (Adverse drug reactions)	Medicine burden	Treatment burden	Medicine reviews	Adherence	Comorbidities
		Asymptomatic HIV participants reported significantly higher mean EQ-5D scores (0.58 ± 0.37) than symptomatic HIV participants (0.26 ± 0.34) and AIDS converted participants (-0.38 ± 0.22). Asymptomatic participants also had the highest VAS mean scores (74.75 ± 15.27) compared to those who were symptomatic HIV (59.15 ± 15.02) and AIDS-converted (45.10 ± 5.12). Factors such as gender, younger age, employment, higher CD4 counts, being undetectable, and being asymptomatic were significantly associated with higher HRQOL. Older age and lower education levels were predictors of poor HRQOL.						Over 63% of participants reported having severe anxiety or depression.

Appendix 2. Systematic review: characteristics of included studies.

First author, year (country)	Participant characteristics and study setting	Methods	Intervention reported or tools used for medicine optimisation	Key findings	Limitations
Ali Ahmed et al, 2021 (Pakistan) [65]	<ul style="list-style-type: none"> n=602 32.9%>50 years Hospital 	Participants were given a validated generic HRQOL questionnaire.	EuroQol quality of life scale EQ-5D-3L and Visual Analogue Scale	59.5% of participants reported no impairment in self-care, however, 63.1% were extremely anxious/depressed. Overall, the mean EQ-5D utility and Visual Analogue Scale scores were 0.388 (SD=0.41) and 66.20 (SD=17.22), respectively. Multiple regression analysis has shown that age over 50, the female gender, primary or secondary education, less than a year since HIV diagnosis, having a detectable viral load, and a longer time to ART were all factors significantly associated with HRQOL.	The results cannot be generalised to non-adherent PLWH as participants who failed to show up regularly according to their dispensing records were excluded from the study. Moreover, the cross-sectional study design does not allow for causality analysis and there is a possibility of social desirability bias as participants are likely to underreport socially undesirable behaviours.
Ana Ventuneac et al, 2020 (USA) [53]	<ul style="list-style-type: none"> n=406 M=50.7 Community 	Intervention study: This study consisted of a single-arm prospective study design with assessments at baseline and 6-months.	Rango (mobile health application)	Missing at least one dose of ART in the three days prior and being virally suppressed at baseline was reported in 18% and nearly 82% of participants, respectively. 95% of participants returned for a follow-up visit, with 59% (38/65) of those who were unsuppressed at baseline achieving viral suppression. 5% of participants who had viral suppression at baseline reported an increase in viral load at 6 months, in spite of having ART non-adherence risk.	The findings are limited by the short study duration and a lack of useability data. Usage changes were not analysed over the 6 months.
Annie L. Nguyen et al, 2018 (USA) [62]	<ul style="list-style-type: none"> n=176 M=58.7 years (SD=5.4) Community 	Data pertaining to HIV-positive participants was obtained from the 2012 baseline cohort from the Research Core of the Rush Centre of Excellence on Disparities in HIV and Aging.	The CESD-10, the 30-item MMSE, the 5-item De Jong-Gierveld Loneliness Scale, and the Everyday Discrimination Scale.	Participants with good/excellent health showed greater purpose in life, fewer depressive symptoms, more education, and less loneliness than those with poor fair health. Less depressive symptoms, disabilities, adverse life events, and loneliness were associated with higher healthy days index scores. Health related quality of life was linked to disabilities, smoking status, depression, race/ethnicity, and purpose in life.	The cross-sectional study design does not allow for causality interpretations, and self-reported data may include response bias. The participants in this study had good virologic control and thus generalisability to those with less virological control may be reduced.

Anthony DeFulio et al, 2021 (USA) [99]	<ul style="list-style-type: none"> • n=50 • M=52.4 years (SD=10.7) • Community 	<u>Intervention study:</u> Medication Event Monitoring System (MEMS) cap were given to participants attached to their primary ART medication bottle to measure adherence. Participants were placed into either the intervention or control group. Participants were given smart phones that had the intervention app and had to submit videos of medication consumption. At the beginning and every month after surveys were given to participants.	Medication Event Monitoring System (MEMS) cap and smartphone-based intervention app ("SteadyRX").	Participants in the intervention group submitted 75% of required videos, of which 81% met validity criteria, thus indicating a high usability level. Over the study duration the percentage of adherent participants decreased in the control group (p=0.031). The control group self-reported an average adherence of 91.10% adherence and 94.34% was reported by the intervention group, but this was not a significant difference.	A limitation of this study is the small sample size and single site recruitment, reducing generalisability of the findings. Another study limitation could be the lack of requiring a detectable viral load. Finally, the biometric data collecting procedure was flawed, creating another study limitation.
B Lopez-Centeno et al, 2020 (Madrid) [20]	<ul style="list-style-type: none"> • n=1292 • Mdn=69 years (67-73) • Community and Hospital pharmacies 	Dispensation registries of community and hospital pharmacies from the Madrid Regional Health Service was analysed between January to June 2017. The Beers criteria was used to identify potentially inappropriate medications among older PLWH.	The 2019 American Geriatrics Society Beers criteria.	Polypharmacy was observed in 65.9% of older PLWH. Cardiovascular (69.7%), gastrointestinal and metabolism (68.2%), and nervous system (61.0%) drugs were among the most prescribed co-medications among participants. At least one potentially inappropriate medication was identified in 37.3% (482) participants. 667 potentially inappropriate medications were identified in 482 participants, 60.8% (293) involved benzodiazepines, and 27.2% (131) involved nonsteroidal anti-inflammatory drugs.	One limitation to the study is that over-the-counter medicines were not included, this may have led to an underestimation of potentially inappropriate medications. Moreover, the study is limited by a lack of information on participants comorbidities, medical managements, such as potential dosage adjustments, and the absence of information on the clinical outcomes of patients with potentially inappropriate medications.
Bernadette Jakeman et al, 2021 (Switzerland) [74]	<ul style="list-style-type: none"> • n=1019 • Mdn=70 years • Nationwide 	Prescriptions of eligible participants from the Swiss HIV Cohort Study (SHCS) were reviewed to assess anticholinergic (ACH) medication.		An average of 5 (± 3.6) non-HIV drugs were taken by participants. 20% of participants were on one ACH medication, reporting average ACH scores of 1.7 (± 1.3). Self-reported neurocognitive impairment was	A limitation to this study includes that adherence to ACH medications were not assessed so it cannot be determined if participants were taking their prescribed medications. Dose or duration of ACH medication and history of CNS infection

				associated with depression and being on one ACH medication.	was not evaluated, which all impacts neurocognitive impairment. Self-reported depression rating scales were not available; thus, the diagnosis of depression may have been missed in some of the cohort.
Brian fischetti et al, 2022 (USA) [51]	<ul style="list-style-type: none"> • n=1144 • Mdn=52 years • Community 	Data was collected retrospectively via medical chart reviews.		Most participants (48%) had one or two comorbidities, with two participants having 5 comorbidities. 80% of participants had an undetectable viral load. Higher viral suppression was seen in participants with more comorbidities ($p=0.009$). It was reported that participants with psychiatric disorders had the lowest viral suppression compared to other comorbidities.	Generalisability of the study findings is reduced due to recruitment being from a single site. The number of medications taken per disease and data on disease control was not taken.
Bryan Hartzler et al, 2019 (USA) [60]	<ul style="list-style-type: none"> • n=44 • M=52.3 years • Hospital and Community 	Data was collected through focus groups and a survey for demographic information.		The study found an emerging theme across staff focus groups of wanting therapy to be patient centred, adaptable, and mission-congruent. Patients reported desiring therapy to have patient autonomy in illness management and fairness among service users. Staff perceived higher compatibility for motivation interviewing than cognitive behavioural therapy or contingency management, this was similar among patients albeit a less robust or reliable pattern.	A limitation of the study includes potential bias in participant responses within the focus groups due to social desirability. The generalisability of the study findings are reduced due to the small sample size.

Charles Furlotte et al, 2017 (Canada) [93]	<ul style="list-style-type: none"> • n=11 • Age: 52-67 years • Community 	Semi-structured interviews, a checklist of health and social services, and a demographic questionnaire were used to collect data.		Three main themes emerged from the interviews: uncertainty, stigma, and resilience. Uncertainty impacting on mental health was reported due to unexpected survival, medical uncertainty, and perception of one's symptoms. Stigma experiences were caused by discrimination in health care interactions, being stigmatised due to physical appearance, anticipated stigma, misinformation, and compounded stigma. Individual approaches to resilience helped participants cope with these experiences, examples include decreasing the space that HIV consumes in their life, making lifestyle changes around the condition, and using social supports.	Limitations to the study include that recruitment was of participants attending their local clinic service and the results cannot be generalised to those not attending care services. Full mental health histories were not taken; thus, it is not possible to determine whether participants had mental health concerns before or after their HIV diagnosis.
Christine J Lee, 2019 (USA) [82]	<ul style="list-style-type: none"> • n=97 • M≥50 years for all groups • Community 	Self-report measures were used to collect data on demographics, ART medication information and medication adherence. Pharmacy and medical records were also used for data collection.		Medication adherence, both self-reported and pharmacy-based, or executive functioning was not significantly associated with cigarette smoking. Poor self-reported medication adherence was associated with symptoms of clinical and subclinical levels of anxiety and depression.	Generalisability of the study findings are reduced due to recruitment being from a single site. Overall status of health was not measured, which may have impacted the findings. Some participants found the self-reported adherence questionnaire to be difficult to understand, this may have affected the findings, also pharmacy-based adherence data was based on pharmacy refill data, which may not always mean participants are taking the medications they collect.
Christine Jacomet et al, 2020 (France) [59]	<ul style="list-style-type: none"> • n=1137 • M=50.2 years • Hospital and community 	Data was collected through surveys.		The presence of comorbidities were reported in 64.2% of participants and 90% had a undetectable viral load. 58% of participants knew of the medication file, however, only 40% of pharmacists reported to offering it systematically. 32% of participants would like to use the medication file programme, particularly those with shorter ARV duration, a less often undetectable viral load and those who experience anxiety more often.	Generalisability of the study results are reduced due to the sample population being predominantly male.

Chunyuan Zheng et al, 2022 (China) [61]	<ul style="list-style-type: none"> • n=185 • M=58 years (SD=7.5) • Hospital and community 	Data was collected using questionnaires.	The Chinese version of the Living with Medicines Questionnaire version 3 (LMQ-3) and the Centre for Adherence Support Evaluation (CASE) Adherence Index.	Polypharmacy was reported in 40% of participants. A higher level of medicine-related burden was reported in females, who took more drugs and had a lower monthly income. ART adherence was negatively associated with medicine-related burden (p=0.001).	Limitations include that data was collected via self-report and was not verified using medical records, prevalence of PDDI in this study may have been underestimated as the Liverpool interaction database does not include information on traditional Chinese medicines or herbal drugs, and as recruitment occurred only at two sites in the Hunan province, findings may not be generalisable elsewhere.
Constance R Uphold et al, 2004 (USA) [46]	<ul style="list-style-type: none"> • n=19 (≥50 years) and n=18 (<40 years) • Older group: M=58 years (SD=7) • Hospital 	Data was collected using electronic medical records.		Adverse side effects from highly active antiretroviral therapy (HAART) was uncommon in the two age groups, with only 4 participants stopping HAART due to adverse effects. Viral load improved significantly for both groups on HAART (p=0,0001).	Generalisability of the study results are reduced due to the sample population being predominantly male.
D. Keith McInnes et al, 2013 (USA) [81]	<ul style="list-style-type: none"> • n=1871 • 36%=45-54 years, 43%=55-64 years and 11.7%≥65 years • Community clinics 	Data collected via the Veterans Aging Cohort Study was used to investigate an association between patient electronic personal health record use and ARV adherence. Pharmacy-refill data was used to assess adherence.	Personal health record: My HealtheVet.	The study found that younger participants (under 45 years) were less adherent than older participants (over 55 years). Participants ≥65 years old were less likely to use the personal health record than those <45 years old. Personal health record use was linked to better adherence.	The cross-sectional study design limits the ability to establish a causal relationship between personal health records and adherence. Moreover, there may be unmeasured confounding factors. Pharmacy refill data may overestimate adherence as patients may be collecting their medications without administering them.
Dana Rosenfeld et al, 2020 (UK) [41]	<ul style="list-style-type: none"> • n=100 • Mdn=56 years (50-87) • Hospital and community 	Focus groups, life-history interviews, and surveys were used to collect data.		Distinguishing support from HIV-negative (Goffman's 'the wise') people and support based on experiences of PLWH themselves (Goffman's 'the wise'), participants viewed the former as requiring supplementation by the later. Experientially based support varied across groups.	A limitation to this study is that focus groups may have led to social desirability bias or moderator bias.

Donald Gardenier et al, 2010 (USA) [80]	<ul style="list-style-type: none"> • n=56 • M=50.5 years (SD=8.5) <p>Community (AIDS day health care program)</p>	Information was extracted from medical records then reviewed and corrected by participants. Participants also completed the Social Provision Scale and the AIDS Clinical Trial Group adherence follow-up instrument.	Social Provision Scale (SPS) and the AIDS Clinical Trial Group (ACTG) adherence follow-up instrument.	There was a statistical significance between adherence and social support ($p=0.02$). Out of the 51 participants who were prescribed ART, 28 (55%) were adherent. There was a statistically significant difference between CD4 T-cell counts between the adherent and non-adherent group, with the latter being lower ($p=0.004$).	The study is limited due to the sample size, recruitment not being randomised, and the participants being recruited at two New York city locations from the AIDS Day Health programme.
Edna N Bosire, 2021 (South Africa) [57]	<ul style="list-style-type: none"> • n=15 • 40-70 years • Hospital and community 	Data was collected using an ethnographic approach and through 90-minute interviews.		Participants access to care to manage their comorbidities were impeded by fragmentation of care, having multiple clinic appointments, conflicting information, and poor patient-provider communication.	The small sample size and single site for recruitment reduces the generalisability of the study findings. Language barriers and the use of an interpreter may have changed the meaning of statements reported by participants.
Emma L Frazier et al, 2018 (USA) [79]	<ul style="list-style-type: none"> • n=3672 over 50 years old • Hospital and community 	Matched interview and medical record abstraction data from a surveillance system, the Medical Monitoring Project (MMP), was analysed.		Women living with HIV over 50 years old were more likely to be prescribed antiretroviral therapy, be virally suppressed, be dose adherent, and are less likely to have received sexually transmitted infection prevention information from a healthcare provider, have condomless sex with a negative or unknown partner and report depression compared to women under 50 years old.	The limitations to this study are that generalisability of findings are reduced due data being collected from HIV positive women who are in care and not those who are not receiving medical care and the cross-sectional study design does not allow for causality analysis of findings.
Enid Schatz et al, 2021(South Africa) [48]	<ul style="list-style-type: none"> • n=23 • Age ≥ 50 years • Community 	In-depth semi-structured interviews.		Perceived shame of sexuality and disrespect by clinical staff, disclosing serostatus to others, affording transport to clinics and comorbidities were key age-related barriers to ART access. Age-related facilitators were financial and moral support from families and access to social grants.	Limitations to this study include the small sample size and recruitment of participants who were already tested and linked to care, reducing the generalisability of the findings. Moreover, there may be other barriers or difficulties relating to not testing, late testing, and failing to attend care services that the study was unlikely to identify due to the sample population.

Enid Schatz et al, 2022 (South Africa) [84]	<ul style="list-style-type: none"> • n=161, PLWH>40 years • Community 	Focus group discussions.		Participants reported fewer negative consequences of disclosure in 2018 compared to 2013. Participants reported positive outcomes such as building trust, and greater support with adherence and medication collection.	A limitation of the study is that participants in the 2013 focus group were different to those in 2018, which may have influenced the findings.
Enrique Contreras-Macias et al, 2020 (Spain) [73]	<ul style="list-style-type: none"> • n=19 • M=69.4 years • Outpatient 	Data was obtained from medical records, the electronic prescription programme, and the outpatient dispensing programme.	Medication Regimen Complexity Index (MRCI), The European AIDS Clinical Society (EACS) guideline of “Selected Top 10 Drug Classes To Avoid (Top-10-A) in elderly PLWHIV”, and the STOPP-Beers criteria.	Polypharmacy was reported in 84.2% (16) of participants and a Top-10-A potentially inappropriate prescription was evident in 47.4% (9) of participants. The most prevalent group of prescribed drugs were benzodiazepines, reported in 30% (6) of participants. 57.9% of participants were complex patients with a MRCI index above 11.25. A higher sum of STOPP-Beers criteria was identified in older patients. Analysis using the t-student test showed a statistically significant relationship between MRCI score and the sum of the STOPP-Beers criteria with increasing age ($p<0.05$).	The generalisability of the study findings is reduced by the single-centre study design and small sample size. Moreover, the STOPP-Beers criteria were validated to non-HIV patients 65 years or older.
Enrique Contreras-Macias et al, 2021 (Spain) [70]	<ul style="list-style-type: none"> • n=428 • M=50 years (SD=10.9) • Outpatient 	Data was collected using the Capacity-Motivation-Opportunity pharmaceutical care model at routine follow-up appointments.	Medication Regimen Complexity Index (MRCI) and the EQ-5D-5L questionnaire.	Polypharmacy was identified in 25.9% (111) of participants, with 5.4% (23) being on 11 or more medications. A negative correlation between ED-5D and MRCI scores was identified ($p=0.0002$). The relationship between comorbidity and quality of life was statistically significant in the thyroid-mechanic ($p=0.002$) and geriatric-depressive ($p=0.003$) patterns.	Although the study had a large sample size, the generalisability of the findings are limited due to the study being based at a single urban safety net hospital. Moreover, participants included in the study were those engaged in the care and cannot be generalised to patients who fail to attend care.

Esther A.N. Engelhard et al, 2018 (Netherlands) [26]	<ul style="list-style-type: none"> • n= 331 (HIV positive) • M=51 years (SD=11.2) • Outpatient 	HRQOL was measured using a survey in a nationwide sample of PLWH. Data from studies in diabetes and rheumatoid arthritis were added.	Medical Outcomes Study Short Form 36-item Health Survey.	The HIV sample had the lowest mental health score, with the odds of poor mental HRQOL being higher in HIV patients than other groups. The chances of poor physical HRQOL were similar in both the HIV and diabetes groups, but lower in the rheumatoid arthritis group. Poor physical HRQOL among PLWH was linked to a history of AIDS, longer time on combination ART and severe comorbidity. Being of Sub-Saharan African descent and having CD4+ counts of less than 350 was linked to poor mental HRQOL.	A limitation of this study is that comparing HRQOL between different datasets may lead to findings resulting from other unmeasured factors and not the diversity of the diseases. Socioeconomic status, substance use, and sexual orientation were potential confounders that the study was unable to adjust for, due to inconsistent recording across data sets. Other limitations include that disease severity was not corrected for and participant samples of the other diseases were not a national cross-section of the patient populations.
Ethan Moitra et al, 2011 (USA) [87]	<ul style="list-style-type: none"> • n=16 • M=52.5 years (SD=5) • Community clinic 	Intervention study: 3-5 weekly 60-minute acceptance-based behaviour sessions were conducted in groups of 3-5 participants. Discussions included overall acceptance-based principles, with each session being a stand-alone intervention.	Acceptance-based behaviour therapy.	37.5% (6) participants found the groups to be very helpful and another 37.5% (6) found them to be moderately helpful, whilst 25% (4) found them minimally helpful. The study reported that qualitative observations suggested that the acceptance-based intervention strategies were well suited in the target population. A significant point made in every session was that avoiding the realities of living with HIV can lead to worsened health.	The small sample size reduces the generalisability of the study. Group formats for each session may have impeded recruitment or undermined treatment acceptability for potential participants.
Fayssal M. Farahat et al, 2020 (Saudi Arabia) [47]	<ul style="list-style-type: none"> • n=13 • M=50.1 years • Hospital 	Data was collected retrospectively via medical chart reviews		Out of 130 participants that were included, 48.5% had one or more comorbidities. Diabetes (15.4%), dyslipidaemia (10.8%), hypertension (10.8%) and lymphoma (10.0%) being the most common comorbidities. An increase in comorbidities was seen with an increase in age, with 40.7% of participants aged 60 years or older having three or more comorbidities. Logistic regression analysis showed that only patients aged 50 years and older were more likely to have at least one comorbidity.	The generalisability of the study is limited by the small sample size. Also, the cross-sectional study design does not allow for causality analysis. Moreover, the study did not look at adherence and medical records were reviewed over an 18-year period, but several ART medication doses and durations were missing.

G Guaraldi et al, 2017 (Italy) [28]	<ul style="list-style-type: none"> n=482 M=53.9 years (SD=6.9) Multidisciplinary clinic 	Patients were evaluated using two frailty tools as part of routine protocol.	The Frailty Index and frailty phenotype.	The frailty phenotype categories were: 51.9% pre-frail, 3.1% frail, and 45% robust. The mean Frailty Index score was 0.28 ± 0.1 . Falls and disability were linked to the Frailty Index but not the frailty phenotype.	Due to the cross-sectional study design, the Frailty Index could not be assessed over time for the prediction of adverse outcomes. The lack of a HIV-negative control group and more objective tools to assess disability are further limitations.
Gareth Owen et al, 2012 (UK) [71]	<ul style="list-style-type: none"> n=10 Mdn=57 (52-78) years Hospital and community 	A biographical narrative approach was used to collect data.		Findings showed that some participants were positive about ageing regarding it as progressing towards valued life goals, whereas others were more conflicted with future prospects. The individual's biographic relationship with the HIV epidemic history rather than their age influenced the differences in views of the future. Participants who were involved with HIV for longer were more likely to have interrupted careers due to illness, depend on state benefits, and have damaged social networks.	The study findings were limited by the small sample size and recruitment location.
Heather A Leake Date et al, 2022 (UK) [102]	<ul style="list-style-type: none"> n=164 Age: MOR: Mdn=59.5 (SD=50-78) years; Standard care: Mdn=60 (SD=50-82) years Hospital 	Intervention study: Participants were randomized to either receive standard care or a Medicines Management Optimisation Review (MOR).	Medicines Management Optimisation Review toolkit, the University of Liverpool and Toronto General Hospital HIV drug interaction references, EuroQol five-dimension five-level (EQ-5D-5L) questionnaire and visual analogue scale (EQ-VAS).	Seventy participants were in the intervention group and ninety-four in the standard care group. Significantly more medicine-related problems were identified in the intervention group at baseline ($p=0.001$) and 6 months ($p=0.001$). There was a significant reduction in new medicine-related problems at 6 months in the intervention group compared to baseline ($p=0.001$), with 44% being resolved at baseline and 51% at 6 months. There were no changes in HRQOL identified between groups or after the intervention. Participants and healthcare professionals found the MOR highly acceptable.	The limitations to this study include the sample size, MORs required extra attendance to the clinic which may have precluded some participants, and as this was a feasibility study, it was not powered to measure the effectiveness of the intervention.
Hwayoung Cho et al, 2018 (USA) [101]	<ul style="list-style-type: none"> n=36 Control group: M=52 years (SD=6.6) 	Intervention study: Follow-up focus groups lasting 60-90 minutes were conducted using semi-structured discussion guides to allow	mVIP (a web-app).	Focus groups revealed the five following themes related to predisposing factors: ease of using the app, being user-friendly, self-efficacy for management of symptoms, design preference of illustrated strategies with	The generalisability of the findings may be limited due to the small sample size and the study sample being predominantly female. The app was only in English, therefore PLWH who are

	<ul style="list-style-type: none"> Intervention group: M=51 years (SD=13) Community 	participants to discuss their experiences and any issues with using the mVIP app, after the clinical trial had ended.		videos, and user-control. The four themes identified relating to enabling factors included: information requirements of symptom management, tracking symptoms, fit in lifestyle/living/schedule conditions, and more languages. The five themes reported relating to reinforcing factors included: communication with healthcare providers, information visualisation for each user, social networking, improvement in quality of life, and individual-tailored information quality.	primary-Spanish speakers (an underserved population in the US) were not included in the study.
Ian R. McNicholl et al, 2017 (USA) [38]	<ul style="list-style-type: none"> n=248 M=57.8 years (SD=5.1) Community 	Intervention study: Electronic medical records were used for medication reconciliations conducted by pharmacists.	Pharmacist medication reconciliation, Beers and STOPP criteria, Patient Health Questionnaire-9, the Montreal Cognitive Assessment, and the Veterans Ageing Cohort Study (VACS) Index.	Hypertension (56%), depression (52%), COPD/asthma (48%), dyslipidaemia (39%), coronary artery disease (27%), and diabetes (22%) were the most common comorbidities found. 35% of participants were taking 16 or more medications and 16% were taking more than 20. Beers and STOPP criteria were present in 156 and 134 participants, respectively. 25 contraindicated drug interactions were identified in 20 participants. A mean of 2.2 medications were stopped after medication reconciliation.	A limitation to this study is that only a subsample of the clinic's population was included due to limited resources. Underestimations of the pharmacist's role in correcting potentially inappropriate prescribing may have occurred as only medications that can be corrected without collaboration and conducted during the clinic visit were measured. Interventions undertaken after the clinic visit was not included.
J Carlo Hojilla et al, 2021 (USA) [96]	<ul style="list-style-type: none"> n=584 M=50.5 years Hospital 	Secondary analysis of data collected from a RCT of behavioural interventions for reducing unhealthy alcohol use in PLWH.	Berger HIV stigma scale, the 12-item short form survey (SF-12).	African American participants reported higher personalised stigma scores and disclosure concerns compared to Caucasians. Both Hispanic/Latinx and African American participants were more likely to report having concerns around public attitudes towards PLWH than Caucasians. Women were more likely to have increased negative self-image scores than men.	Sample size limited the studies ability to evaluate correlates of HIV stigma within sex and race/ethnicity subgroups. The generalisability of the results are reduced as participants are an insured cohort with well managed HIV.

J McAllister et al, 2013 (Australia) [88]	<ul style="list-style-type: none"> • n=335 • M=52 years • Hospital 	Data was collected via anonymous surveys.		<p>19.6% (65) of participants reported meeting pharmacy dispensing costs as difficult or very difficult, 14.6% (49) stated that due to pharmacy dispensing costs they have delayed purchasing medications, and 9% (30) reported stopping medication due to pharmacy costs. Amongst the 19.6% of participants finding difficulty meeting pharmacy costs, 29.2% (19) had stopped medication compared to 4.1% (11) of the remaining 270 patients ($p<0.0001$). 5.7% (19) patients found travel to the clinic difficult or very difficult. Difficulty meeting pharmacy and clinic travel costs were independently associated with treatment cessation and interruption. 4.9% of patients reported being asked if they were having difficulty with payments for medication.</p>	The study findings are limited due to a single-site recruitment, participants being mostly male, and the lack of viral load data meaning that clinical significance of patient responses could not be determined.
Jack E Heron et al, 2019 (Australia) [31]	<ul style="list-style-type: none"> • n= 2,406 (HIV-positive) and n= 648,205 (HIV-negative) • Age: 45-64 years=58.9%; 65-74 years= 10.3%; over 75 years=2.3% • Community 	Data was collected directly from MedicineInsight - a national primary care data programme.		<p>HIV-positive males were less socioeconomically at a disadvantage than HIV-negative males. The HIV-positive males in this cohort were at an increased risk of cancer, chronic kidney disease, anxiety, depression, and osteoporosis. Younger PLWH are at risk of premature onset of osteoporosis, cancer, and cardiovascular disease. A high prevalence of depression and anxiety was reported among HIV-positive males.</p>	A limitation to this study includes the potential of duplicated patient records on MedicineInsight as it is not linked across practices, thus if a patient were to visit more than one practice it would be entered as separate records.
Jacqueline M. McMillan et al, 2019 (Canada) [67]	<ul style="list-style-type: none"> • n=716 • Age range=50-92 years and M=59.2 (SD=6.5) • Outpatient clinic 	Health data routinely collected at the Southern Alberta Clinic that included laboratory, self-reported and clinician-reported results.	The 29-item Frailty Index developed for Southern Alberta Clinic.	<p>The mean Frailty Index, 0.303 (± 0.128), did not differ between genders. It was not linked to current CD4 counts or nadirs. Frailty Index increased with age, ART duration, and duration since HIV diagnosis. Higher Frailty Indexes was seen in those who died compared to the survivors.</p>	The cross-sectional design of the study limits the ability to draw conclusions of causality and directionality of the associations found. Another limitation is that the data used was collected for purposes other than calculating frailty, raising questions about accuracy and comprehensiveness.

Jepchirchir Kiplagat et al, 2019 (Kenya) [34]	<ul style="list-style-type: none"> • n=57 • Age: 50-59 years=33.3%; 60-69 years=49.2%; 70-79=17.5% • Hospital and community 	In-depth interviews and four focus groups were used to collect data.		Participants reported that comorbidities and visiting multiple healthcare providers to manage their HIV as factors that impact their adherence to medication and clinic attendance. Other challenges included poor quality of facilities and patient-provider communications. Matched gender and older age for healthcare providers were reported as preferential by participants.	The generalisability of the results are reduced as patients that had been lost to follow up or disengaged from care were not included, also participants included had been in care for at least a year, thus their views and experiences may have improved within that time.
Jochen Drewes et al, 2021 (Germany) [50]	<ul style="list-style-type: none"> • n=897 • M=57 years (SD=6.7) • Community 	Data was collected using a self-administered questionnaire.	An Adapted version of the negative self-image subscale of the HIV Stigma Scale, the Silver Lining Questionnaire (SLQ), the OSLO 3 Social Support Scale (OSSS-3), and the UCLA Loneliness Scale.	18% (165) of participants reported having one or more falls in the 12 months prior to the study. A higher risk of falling was significantly associated with a lower economic status, living alone and being single. Having one or more comorbidity increased the risk of falls by 2.5 times. Diseases of the central nervous system, heart disease, rheumatism, osteoporosis, and chronic pain were strongly associated with fall risk. In addition, internalised and experienced HIV stigma, social support, and loneliness were significantly related to a fall risk.	The cross-sectional study design does not allow for causality analysis. The self-administered questionnaires may have led to bias on recall and social desirability. The study was not able to fulfil a probability sample of people ageing with HIV in Germany, thus reducing the generalisability of the results. Moreover, several potential risk factors for falls were not included in the analysis of this study, for example, specific medication, problems with balance or gait, or mobility.
Jose M Vinuesa-Hernando et al, 2021 (Spain) [49]	<ul style="list-style-type: none"> • n=30 • Mdn=71 • Hospital 	Observational study using data from patient hospital medical records.	The Medication Regimen Complexity Index (MRCI), the Simplified Medication Adherence Questionnaire (SMAQ), the Screening Tool of Older People's Prescriptions (STOPP) and List of Evidence-based depreScribing for CHRONic patients	The most common comorbidities were dyslipidaemia (70%), hypertension (66.7%), diabetes (43.4%), mental health disorders (26.7%). 30% of participants were taking 10 or more medications and 70% were taking more than five. 66.7% of participants were adherent to their medications. The MRCI score of concomitant medications was higher than the score of ART at 18.3 points and 5.1 points, respectively. Potentially inappropriate prescribing was present in 70% of participants according to the STOPP or LESS-CHRON	Limitations to this study include the use of dispensing records as some information may be missing and the reliability of the information depends on the inputting physician. Furthermore, the small sample size limits the generalisability of the data.

			(LESS-CHRON) criteria.	criteria. Polypharmacy was significantly associated with meeting deprescribing criteria (p=0.008).	
Julia Rozanova et al, 2020 (Ukraine) [98]	<ul style="list-style-type: none"> • n=123 • Age=55-81 years • Community 	Data was collected via telephone surveys.		Older PLWH with substance misuse disorders maintained their HIV and substance use disorder therapies over the COVID-19 lockdown, however, social support was highlighted to be critical to avoid treatment interruptions.	A limitation to this study is that telephone surveys may have led to social desirability bias in participant answers.
Koharu L Chayama et al, 2021 (Canada) [55]	<ul style="list-style-type: none"> • n=42 • Age=50+ years • Community 	Semi-structured in-depth interviews were used to collect data.		Participants viewed comorbidities as more urgent and prioritised them over HIV. Access to care for comorbidities were hindered by stigma and discrimination. Participants reported difficulty concurrently managing their comorbidities and HIV due to poorly managed comorbidities. Concerns and frustrations were stated regarding the potential impact of ART on the development of comorbidities. Treatment approaches that integrated services aided engagement with care.	The study was only conducted with English speaking participants, thus the opinions and experiences of marginalised individuals such as immigrants and refugees were not collected.
Krista J. Siefried et al, 2017 (Australia) [85]	<ul style="list-style-type: none"> • n=522 • M=50.8 years (SD=12.3) • Hospital and community clinics 	A study-provided laptop was used by participants to complete a 204-item questionnaire.	University of Liverpool HIV drug interaction database, and the Charlson comorbidity Index.	77 (14.8%) of participants reported being linked to one or more HIV community organisations or peer support groups. The median duration on ART was 11 years. 78 (14.9%) of participants missed an average of one or more ART medications per month in the 3 previous months.	The self-reported nature of the questionnaire for adherence may overestimate true adherence levels. Due to recruitment strategies, there is a risk of selection bias. The study findings are less generalisable to patients without subsidised healthcare, community supports, those with virological failure, females, and heterosexual males.

Krista J. Siefried et al, 2018 (Australia) [44]	<ul style="list-style-type: none"> • n=522 • M=50.8 years (SD=12.3) • Hospital and community clinics 	Participants were given a 204-item questionnaire on dedicated laptops.	204-question questionnaire incorporating other existing or pre-validated instruments.	<p>292 (55.9%) participants reported having comorbidities. 392 (75.1%) participants took at least one concomitant drug. The daily pill burden for concomitant drugs was 6 and the ART daily pill burden was 1.2.</p> <p>Cardiovascular, antidepressants, over the counter, endocrine agents and anti-effectives were the most common classes of concomitant medication. 122 (23.4%) participants were taking at least 5 concomitant medications. The concomitant medication taken in 17 participants were contraindicated with their ART. Overall, 730 ART-concomitant combinations were identified as being a potential drug-drug interaction. 178 participants reported adverse drug reactions.</p>	A majority of the participants were male and in a country with subsidised healthcare systems, thus reducing generalisability to females and those in countries without subsidisation. The cross-sectional study design does not allow for causality analysis. The study did not collect data on concomitant medication dosage, therefore it cannot report whether dose adjustments would mitigate potential drug-drug interactions.
Laura M Bogart et al, 2021 (USA) [95]	<ul style="list-style-type: none"> • n=76 • Mdn=52.9 (SD=12.9) • Community 	<u>Intervention study:</u> Individually randomised group-treatment trial using cognitive behavioural therapy. Participants were clustered into groups. Semi-structured interviews were conducted post intervention.	Medication Event Monitoring System (MEMS) bottle cap.	The intervention group showed improved adherence compared to the control group (electronically monitored: p=0.06; Self-reported: p=0.02). There was significantly lower medical mistrust amongst the intervention group compared to the control group (p=0.02).	Generalisability of the study findings are reduced due to convenience sampling at one community site and the small sample size.
Lesley M. Harris et al, 2020 (USA) [64]	<ul style="list-style-type: none"> • n=35 • M=58.3 years (SD=5.4) • Community and hospital 	Data was collected through surveys, interviews, and focus groups.	The Berger HIV Stigma Scale, Perceived Stress Scale, Engagement with Health Care Providers Scale, and the Composite of Engagement in HIV care.	54.3% of participants were reported to be moderately engaged in care. The overall stigma in participants were high and participants were reported to be moderately stressed. There was a significant correlation between engagement in care and the stigma subscales, including negative self-image stigma (p=0.03). Perceived stress was also associated with overall stigma, disclosure stigma, personalised stigma, negative self-image stigma, and public attitudes stigma. Race was highlighted as an additional cause of stigmatisation among African Americans.	Limitations include data collected from surveys being self-reported, and items related to engagement in care were not based on reviews of medical charts. Self-reports may have led to bias on recall and social desirability. The small sample size limits generalisability.

Limin Mao et al, 2018 (Australia) [37]	<ul style="list-style-type: none"> • n=98 • Mdn=51.5 years (26-65) • Community 	Intervention study: A 6-week randomised SMS reminder intervention for ART adherence was conducted, followed by a mixed-method evaluation consisting of one-to-one interviews and a self-completed online survey.	SMS reminders to mobile phones.	The most common reasons for previous ART interruption were experiencing side effects and attending to other life priorities. There were no statistically significant differences between the intervention and control arms at the end of the SMS campaign. A common suggestion for improvement of the intervention was that it should be tailored to each individual's needs and synchronised with their dosing regimens. The SMS campaign had several positive responses, describing impacts beyond ART adherence.	The small sample size may reduce generalisability of the findings and limits the ability to find differences between the experiment groups. The cross-sectional mixed methods evaluation does not allow causal conclusions to be drawn. Moreover, evaluation consisted of self-reported data.
Lorena Jiménez-Guerrero et al, 2018 (Spain) [77]	<ul style="list-style-type: none"> • n=242 • Mdn=57.5 years (54-62) • Hospital 	Data from electronic clinical records were used with a computer system (Diraya) to identify home treatment and an application for outpatient dispensing (Farmatools). Interactions were identified using four independent prescribers, product specification and an online database (www.drugs.com).	www.drugs.com	61% (148) of participants were receiving concomitant treatment and 243 potential interactions were detected among 110 participants. 46 of the interactions were considered severe, whilst 197 were moderate. 76% (35) of the severe interactions were associated with boosted protease inhibitors. Statins and inhaled corticosteroids caused most severe interactions.	The retrospective nature of the study could be a limitation, however, being merely descriptive, it may be considered irrelevant. Another limitation could be that over the counter and herbal medicines were not included.
Lucia Knight et al, 2018 (South Africa) [35]	<ul style="list-style-type: none"> • n=23 • PLWH\geq50 years • Community 	In-depth semi-structured interviews.		Participants received care for both HIV and other conditions provided by different healthcare professionals and at different health facilities. Older PLWH and non-communicable diseases experience several physical and structural barriers to accessing care. These difficulties can worsen health outcomes.	A limitation to this study is that recruitment was conducted via referrals from the HIV service, thus this may have led to participants with more or less barriers being missed.

M. O Halloran et al, 2019 (UK/Ireland) [14]	<ul style="list-style-type: none"> • n=698 PLWH\geq50 years and 374 PLWH\leq50 years • 304 HIV-negative participants\geq50 years old • Hospital 	Potential drug-drug interactions were analysed using two interaction checking tools. The Pharmacokinetic and Clinical Observations in People Over 50 (POPPY) study is a prospective, observational, multicentre study that collected data over a three-year period from 2013-2016.	The Lexicomp database and the Liverpool drug interaction database (www.hiv-druginteractions.org).	Polypharmacy was prevalent in 65.8%, 48.1% and 13.2% in older PLWH, younger PLWH and the HIV-negative group, respectively. This reduced to 29.8% of the older group and 14.2% of the younger group when ARVs were excluded. 36.1% of older PLWH, 20.3% of younger PLWH and 16.4% of the HIV-negative group had a prevalence of ≥ 1 PDDI involving non-ARV medications. The prevalence of ≥ 1 PDDI between ARV and non-ARV medication was 57.3% in older PLWH and 32.4% in younger PLWH.	One limitation of this study was a lack of data on dosing information of most medications, leading to some interactions being overestimated. Another limitation is that the medication lists were self-reported by participants, which may have been underreported. Lexicomp is a sensitive interaction checker and some of the interactions flagged may not be clinically relevant in daily practice.
Malcolm John et al, 2016 (USA) [32]	<ul style="list-style-type: none"> • n=359 • Mdn=57 years (50-80) • Hospital 	The following four domains were evaluated using a questionnaire: social support, physical health and function, mental health, and behavioural and general health.	The Lubben Social Network Scale-6, the Social Provisions Scale, the UCLA 8-item Loneliness Scale, the Patient Health Questionnaire-9), the Generalised Anxiety Disorder-7, the Breslau 7-item PTSD screen, and the Montreal Cognitive Assessment.	Participants experienced the burden of ageing related conditions over the domains evaluated. Nearly 60% reported mild symptoms of loneliness, 50% showed low social support, 41% had a fall in the last year and 34% met the criteria for possible mild cognitive impairment. Participants 60 years old or over had higher frequencies of balance issues compared to the group aged 50-59 years old. Fewer participants reported "very good" or "excellent" HRQOL in the 50-59 years old age group compared to the older group.	The cross-sectional study design meant that changes were not measured over time. The findings may not be generalisable as the participants were largely male and from one city. Patients in long-term care facilities were not included. Most of the participants were diagnosed over 10 years prior, thus results may not be generalisable to newly diagnosed older PLWH.

Mary L Townsend et al, 2007 (USA) [63]	<ul style="list-style-type: none"> • n=58 • M=51.5 years (SD= 8.8) • Hospital 	Data was collected using electronic medical records.		Findings showed a non-significant correlation between viral loads and 6 month pharmacy medication refill-based adherence ($r=0.1$). Adherence rates lower or equal to 70% led to CD4+ levels progressively declining. AIDS-related events incidence or past ARV experience did not significant affect the distribution of participant CD4+ levels or adherence.	Limitations to this study include that pharmacy refill data was used to measure adherence as patients may have collected their medications but not taken them, the small sample size, and short study duration.
ME Levy et al, 2017 (USA) [36]	<ul style="list-style-type: none"> • n=7018 • Mdn=50 years (39-57) • Hospital and community 	Electronic medical records were used for data collection.		Half of the participants reported having hypertension, 48% had dyslipidaemia, and 35% had obesity. A higher prevalence of comorbidities was seen in older PLWH ($p<0.001$). Hypertension was reported more in black patients, diabetes and obesity were reported more in female and black patients, and dyslipidaemia was reported more in male and white patients (all $p<0.001$). Metabolic comorbidities were associated with controlled immunovirological factors, longer time since HIV diagnosis, and a greater duration of ART.	Limitations to this study include the cross-sectional study design does not allow for temporality or causality analysis, electronic medical records may have missing information, thus this may affect the results. Information on ARV adherence was not collected.
Mercedes Gimeno-Gracia et al, 2014 (Spain) [76]	<ul style="list-style-type: none"> • n=130 • M=56.7 years (SD=6.2) • Hospital 	Data was collected from out-patient pharmacy records at a University Hospital in Spain.		At the end of the study, 90% of participants had an undetectable viral load and 58% had a CD4 count over 500 cells/mm ³ . Treatment that was based on protease inhibitors were used by 51.5% of older patients and 54.4% of the younger patients, whilst nonnucleoside reverse transcriptase inhibitors were used by 43.8% and 39.8%, respectively. The older group used treatments with abacavir more frequently ($p=0.054$) and with tenofovir less frequently (0.105) compared to the younger group.	Due to the retrospective nature of this study, some data was incomplete. Also, the varying number of years since diagnosis among patients could have influenced their degree of adherence, the ART received, etc.

Mercedes Gimeno-Gracia et al, 2016 (Spain) [72]	<ul style="list-style-type: none"> • n=119 • Mdn=52 years (51-56) • Hospital 	Data was collected retrospectively to compare polypharmacy, percentage of patients that collected each therapeutic drug class, and the median duration of each drug class between older PLWH and the general population.		<p>A higher percentage of HIV-positive males had polypharmacy than males from the general population (8.9% vs 4.4%, $p=0.01$). This was also true for females from each group, with older and younger groups having 11.3% and 3.4% of polypharmacy, respectively ($p=0.002$). HIV-positive participants received more gastrointestinal drugs, analgesics, anti-infectives, central nervous system (CNS) agents, and respiratory drugs than the general population. No differences were observed between both groups for cardiovascular drugs. HIV-positive participants had a higher estimated number of treatment days than the males in the general population for CNS agents ($p=0.02$), anti-infectives ($p<0.001$) and more were receiving sulfonamides ($p<0.001$), quinolones ($p=0.009$) and macrolides ($p=.0.02$).</p>	Generalisability of the study is reduced due to single-site recruitment and only a small number of female participants being included.
Meredith Greene et al, 2014 (USA) [13]	<ul style="list-style-type: none"> • n=89 (HIV positive) • Mdn=64 years (60-82) • Community 	<p>Structured interviews were used to obtain demographic data, HIV history and comorbidity data. Medication lists were reviewed during interviews to obtain medication usage information. Participants were asked to complete a questionnaire before the interview with all their prescribed and over-the-counter medication.</p>	Lexi-Interact drug interaction software, Beers criteria 2012, and the Anticholinergic Risk Scale.	<p>Common comorbidities amongst the participants were identified as hypertension, hyperlipidaemia, and depression. An average of 13 medications (2-38) were taken by PLWH, with only an average of four being ARVs, whereas non-HIV participants took an average of six (3-10) medications. There was at least one potentially inappropriate medicine prescribed in 46 (52%) of PLWH. Ten (11%) of the HIV participants had a Category X (avoid combination) interaction and 62 (70%) had at least one Category D (consider modification), with a third of these interactions being between two non-ARV medications. Fifteen (17%) PLWH were identified as having an anticholinergic risk scale ≥ 3.</p>	The study population consisted of highly educated, Caucasian, men who have sex with men, therefore the findings may be less generalisable. The participants were also diagnosed for an average of 20 years, so the data may not be generalisable to older patients diagnosed more recently. Information about dosing was not obtained, therefore drug-drug interactions may have been overestimated, although the findings are consistent with other studies.

Meredith Greene et al, 2018 (USA) [68]	<ul style="list-style-type: none"> • n=356 • Mdn=56 years (53-62) • Hospital 	Survey data were collected at two clinics to assess participants social, physical, mental, and cognitive health.	The UCLA eight item loneliness scale, the Montreal Cognitive Assessment, the Lubben Social Network Scale, and the Patient Health Questionnaire.	Symptoms of loneliness was reported in 58% of participants, with the majority having mild loneliness. Lonely participants were more likely to have depressive symptoms, poor or fair HRQOL, have fewer physical supports, be current smokers or at-risk drinkers and/or drug users.	The study participants were predominantly male, urban, were 57% white, and had long durations since diagnosis, therefore generalisability is limited. As the study was cross-sectional, temporal relationships between loneliness and depression with HRQOL and functional impairment was not examined. The HRQOL measure used was due to ease of administration but did not have a mental health measure. Also, a measure of stigma was not included, previous research has shown links between loneliness, stigma, and depression.
Meredith L Greene et al, 2018 (USA) [27]	<ul style="list-style-type: none"> • n= 77 surveyed and n=31 focus groups • Mdn=58 years (50-77) • Hospital 	Data was collected through focus groups and a survey.		Findings highlighted the need for greater focus on the following: 1) the need for knowledge expertise in HIV and ageing, 2) a focus on determinants of health (e.g. marginal housing) and on medical conditions, 3) locating speciality services together, and 4) social isolation. These findings informed the creation and design of a multidisciplinary care model for PLWH (the Golden Compass programme).	A limitation of this study includes single-site recruitment and that generalisability of the findings is reduced as non-English speaking participants were excluded.

<p>Monica O Kuteesa et al, 2012 (Uganda) [86]</p>	<ul style="list-style-type: none"> • n=40 • Mdn=65 years (50-80) • Hospital 	<p>Individual in-depth interviews and focus groups were used to collect data. Observations of clinic interactions were also recorded.</p>		<p>Key themes that emerged from the qualitative interviews highlighting distinctive healthcare needs in older PLWH were: difficulty disclosing (8%), stigma (43%), access to care (80%), delayed diagnosis and care-seeking (55%), quality of patient-provider relationship (75%), serodiscordance (20%), adherence support (25%), continuity of care (14%), end-of-life issues (13%) and other issues (20%). Participants reported experiencing stigma due to HIV and ageism. Concerns and anxiety regarding securing future healthcare and the lack of social services was expressed by participants. Problems with transport and food compromised adherence to ART for many participants.</p>	<p>Limitations to this study affecting generalisability of the findings include recruitment from a limited geographic area and purposive sampling. Duration since diagnosis may have affected individual perspectives reducing generalisability of the findings as interviews did not indicate any participant to be newly diagnosed.</p>
<p>Morgan M Philbin et al, 2021 (USA) [92]</p>	<ul style="list-style-type: none"> • n=59 • M=51 years • Hospital and community 	<p>In-depth interviews were used to collect data.</p>		<p>Four main groups emerged from those interviewed, firstly, those with few long-acting injection related worries who received episodic injections, secondly, those who had regular injections and did not want anymore, thirdly, those with a history of injection drug use that were worried long-acting injections would trigger a reoccurrence, and lastly, those who currently inject drugs and have few worried around long-acting injections. Most participants who have a history of using injectable medication would prefer long-acting injectable ART, but participants with regular injections already and a history of injection drug use may not.</p>	<p>The generalisability of the study findings are limited as they are based on the individual women's experiences and concerns, which may not be relatable to other subpopulations.</p>

N. L. Katende-Kyenda et al, 2008 (South Africa) [75]	<ul style="list-style-type: none"> • n=8999 (HIV-positive) • 59.42%=40-60 years and 1.58%≥60 years • National medicine claims database 	Data was collected directly from Interpharm Data systems and analysed. Prescriptions were used to determine if combinations of ARVs could cause possible drug-drug interactions.	A clinical significance rating of potential drug-drug interactions as described by Tatro [Drug Interaction Facts 2005. St Louis, MO: Facts and Comparisons (2005)].	Participants received a mean of 2.36 ARVs per prescription. 960 drug-drug interactions were identified. Patients aged 40-60 years old had the highest number of ARV prescriptions and the highest number of drug-drug interactions. The most drug-drug interactions were seen between Indinavir and ritonavir, efavirenz and indinavir, efavirenz and lopinavir/ritonavir.	A limitation to the study was that demographic and clinical information was not available on the database. Moreover, dosage information was also not supplied.
Nathanial Schreiner et al, 2019 (USA) [42]	<ul style="list-style-type: none"> • n=103 • M=53.16 years (SD=7.2) • Community 	Data from a parent study examining physical activity patterns in PLWH was used for secondary analysis to evaluate treatment burden. The parent study used one-to-one interviews and entered responses directly into Research Electronic Data Capture.	The Treatment burden Questionnaire-13, the Bullen and Onyx (2007) Social Capital Measurement Tool.	Overall, a low level of treatment burden was reported among participants, however, 16% of participants reported experiencing high treatment burden. Treatment burden was significantly associated with number of chronic conditions ($p \leq 0.01$) and social capital ($p=0.03$). The most prevalent comorbidities were hypertension, asthma, arthritis, diabetes, hepatitis B/C, and hyperlipidaemia. Remembering to take medications at certain times during the day, paperwork, the limitations linked to taking medications and maintaining a prescribed exercise regimen were items causing the highest treatment burden.	Due to treatment burden not being the primary focus of the parent study, the reanalysis could not collect data on other variables of interest. The sampling technique used may have allowed for potential sampling bias, effecting the generalisability of the study findings. PLWH who are not insured or able to afford regular medical care were not represented in this study.

Nicholas V. Hastain et al, 2020 (USA) [29]	<ul style="list-style-type: none"> • n=99 • Mdn=54 years (49-61) • Community clinic 	Electronic medical records were used to evaluate ART simplification. Drug-drug interaction scores pre- and post- simplification were calculated. Concomitant medications were identified and evaluated for drug-drug interactions with pre- and post- simplification ART regimens.	A drug-drug interaction incidence and severity score was developed and validated and the University of Liverpool's HIV Drug Interaction Checker.	A median of 3 ART pills were taken a day. After simplification, the median number of ART pills taken was 2. Discontinuing protease inhibitors and nonnucleoside reverse transcriptase inhibitors occurred frequently and ART changes to integrase strand transfer inhibitor-based regimens were common. Average interaction scores reduced from 3 (1-6) to 1 (0-2) from pre- to post- simplification. The median number concomitant medication taken was 4.5.	The results may not be generalisable due to the sample size and recruitment from only one urban site. Also, not all ART simplification strategies and HIV medications could be thoroughly evaluated. As the study relied on the completeness and accuracy of electronic medical records, it is possible that over the counter, herbal and non-prescriptions items were not included. Lastly, the scoring system does not reflect the clinical significance of drug-drug interactions, for example, some interactions may need dose adjustments or close monitoring.
Pamela P. Foster et al, 2009 (USA) [94]	<ul style="list-style-type: none"> • n=24 • Age range=50-76 years (M=57) • community 	Four focus groups were conducted, and supplementary data was obtained using two stigma instruments.	The Stigma Impact of HIV scale and the Self-Perceptions of HIV Stigma Scale.	Participants reported rarely or not experiencing stigma as they had not disclosed their HIV diagnosis to others. Stigma was reported by participants on the Internalised Shame scale. Qualitative data found four themes associated with stigma: 1) disclosure; 2) stigma experiences; 3) need for HIV/AIDS education; and 4) acceptance of the disease.	Limitations to this study include that the focus group setting may have led to response-bias and participants who have been stigmatised not wanting to participate in group discussions, data on sexual orientation and mode of sexual transmission was not collected, and the time since diagnosis ranged broadly between participants, which may have affected perceptions on stigma and disclosure.

Perry N. Halkitis et al, 2014 (USA) [66]	<ul style="list-style-type: none"> • n=180 • M=55.4 years (SD=4.6) • Community 	Data was drawn from Project Gold, a study of ageing HIV-positive men who have sex with men in New York City. Self-report data was collected for sociodemographic characteristics and clinical markers.	The AIDS Clinical Trials Group (ACTG) Adherence Questionnaire, the 21-item Beck Depression Inventory-II, the HIV Stigma Scale.	109 (57.2%) participants reported at least one suboptimal adherence behaviour, with 36 (20%) missing doses in the 4 days prior to the assessment; 97 (48.3%) failing to take medication on schedule; 40 (24.1%) failing to follow instructions; and 33 (18.3%) missing doses in the weekend prior. Participants who missed a dose in the four days prior had experienced higher levels of HIV-related stigma compared to those who did not miss doses in those days. Depression and HIV-related stigma was associated with failing to take medication on schedule in the four days before ($p=0.05$ and $p=0.01$, respectively). These factors were also associated with failing to follow instructions on how to take ARVs.	Data on adherence and psychosocial factors were collected using self-reports, which could have resulted in underreporting. The cross-sectional study design limits the studies ability to find causal conclusions and evidence of a history of adherence behaviours and psychosocial behaviours.
R A Shippy et al, 2005 (USA) [43]	<ul style="list-style-type: none"> • n=160 • Age: 50-59=85%; 60+=15% • Community 	A survey was used to collect variables of interest.		The increasing group of ageing PLWH are facing isolation from informal networks due to HIV stigma and ageism. 71% of participants lived alone. Family members and partners are critical for informal support, however, only a third of participants had a partner. 86% of participants used Medicaid.	The cross-sectional study design does not allow for causality analysis among mental health indicators, social networks, and support needs of older PLWH.
R Zepf et al, 2020 (USA) [54]	<ul style="list-style-type: none"> • n=281 • M=57.9 • Hospital 	Self-reported questionnaires were used to collect data.		Symptoms of depression ($p=0.008$), stimulant use ($p<0.0001$), and PTSD ($p=0.002$) were significantly associated with reduced medication adherence. Intimate partner violence, binge drinking and past physical or sexual abuse were not significantly associated with lower medication adherence.	Due to the study cross-sectional study design, causality or determination of the sequence of events could not be determined. Self-administered questionnaire answers are subject and may have led to desirability bias in findings.
Ramon Morillo-Verdugo et al, 2019 (Spain) [39]	<ul style="list-style-type: none"> • n=223 • Mdn=53 years (52-57) • Hospital 	Data was collected from an electronic medical record. Questionnaires and hospital dispensing records were used to measure medication adherence.	The SMAQ questionnaire, the Morisky-Green questionnaire, and the Medication regimen complexity index.	The median number of concomitant medications prescribed per participant was 3 (1-5) and the median number of comorbidities was also 3 (2-4). Polypharmacy was noted in 56.1% of participants and 9.4% had higher polypharmacy. The polypharmacy was 60% cardiovascular, 27.1% was depression-	A minor limitation is that private prescription and alternative medicines were not included. Another limitation is that the Medication regimen complexity index tool used is imperfect and has trade-offs between sensitivity and

				anxiety, 7.1% was mixed and 5.8% was COPD. Participants with high pharmacotherapy complexity indices had a 50 times greater chance of polypharmacy. It was demonstrated that 11.25 was the best cut-off point to predict polypharmacy in older PLWH.	specificity. Also, some dosing options were missed, such as monthly doses.
Rebecca Schnall et al, 2018 (Australia) [100]	<ul style="list-style-type: none"> • n=80 • Control group: M=51 years (SD=9) • Intervention group: M=50 years (SD=11.7) • Community 	<u>Intervention study:</u> Symptom burden when using a mobile app with self-care strategies to manage symptoms was compared to a mobile app without the self-care strategies between 2016 and 2017. The study used mVIP, a web-app, that was created to help users self-manage their symptoms. Surveys were given weekly on the app. The study lasted 12 weeks.	mVIP (a web-app).	Participants in the intervention group had a significantly higher improvement than the control group in the following 5 symptoms: depression (p=0.001), anxiety (p=0.001), neuropathy (p=0.002), weight loss/wasting (p=0.020), and fever/chills/sweat (p=0.037). The intervention group also showed a higher improvement in adherence rates to ART medications than the control group (p=0.017). Over the 12-week trial, mVIP was linked to improved symptom burden and adherence rates in PLWH.	The study had limitations to the generalisability of study findings with a small sample size, and as participants with access to a smart-phone or tablet were required, PLWH who do not have or are unable to use this technology were marginalised.
Reyes S Gimenez et al, 2020 (Spain) [91]	<ul style="list-style-type: none"> • n=42 • Mdn=70 years • Hospital 	Observational, prospective study where data from hospital patient records were analysed using various tools.	The Medication Regimen Complexity Index (MRCI), the Simplified Medication Adherence Questionnaire (SMAQ), the Morisky-Green questionnaire (MMAS) and the Revised Patients' Attitudes Towards Deprescribing (rPATD) Questionnaire.	A majority of participants agreed with the following three statements in relation to deprescribing, firstly, 91.9% agreed to "I have a good understanding of the reasons I was prescribed each of my medicines", secondly, 89.2% reported that "Overall, I am satisfied with my current medicines" and finally, 89.2% agreed that "I like to be involved in making decisions about my medicines with my doctors."	The small sample size limits the generalisability of the data. Another limitation is the loss of information intrinsically in relation to the dichotomisation of the indices used for analysis.

Roshani Patel et al, 2016 (UK) [40]	<ul style="list-style-type: none"> • n=299 • M=58 years (SD=2) • Outpatient clinic 	Data was collected using self-reported questionnaires.		One or more comorbidities was present in 84% of participants and 61% had two or more. High cholesterol, hypertension, depression and sexual dysfunction were commonly reported. Multivariate analysis when adjusted for lifestyle factors, showed that number of years since HIV diagnosis, age, and duration of ART were significant predictors of comorbidity. Multiple comorbidities, polypharmacy and higher use of non-HIV services were reported in older PLWH.	The self-reported nature of the questionnaire may have led to recall and self-presentation bias. As data was collected at a single timepoint, it was not possible to determine the direction of associations between comorbidity and risk factors. Generalisability of findings are reduced to due single-site recruitment with a high prevalence of white men who have sex with men.
Roula Kteily-Hawa et al, 2019 (Canada) [69]	<ul style="list-style-type: none"> • n=1422 • M=55.81 years (SD=5.25) in older women group • Community 	Survey data from the Canadian HIV Women's Sexual and Reproductive Health Cohort Study was used. The questionnaire used in the study included the following nine sections: demographics and socioeconomic status, healthcare utilisation, medical and HIV disease information, stigma, and discrimination, HRQOL, and substance misuse.	The 12-item Short Form Survey (SF-12), the Medical Outcome Trust scoring method, the 10-item Resiliency Scale, the Center for Epidemiologic Studies Depression 10-item scale, and the 4-item Abbreviated Social Support Instrument.	Older participants had poorer physical HRQOL and less social support than younger participants. Mental HRQOL was similar between the groups. Better physical HRQOL was linked to resilience. Poorer physical health was linked to poorer mental HRQOL, food insecurity and depressive symptoms.	The cross-sectional study design limits the ability to determine a causal relationship between correlates and causations of HRQOL. The self-report nature of the questionnaire may have been affected by social desirability biases. Recruitment may have been biased to include women already accessing HIV care, and thus experiencing higher physical functioning and resilience, lowering generalisability of results to those not accessing care.
S Scott Sutton et al, 2016 (USA) [83]	<ul style="list-style-type: none"> • n=15602 • M=52.1 years (SD=9.5) • Hospital and community 	Data was collected from the Veterans Health Administration electronic health record system from 2006 to 2012. Data included demographic details, vital signs, mortality, administrative claims, laboratory results, and	The Charlson comorbidity index score.	A significantly lower proportion of single-tablet regimen compared to multiple-tablet regimen participants had undetectable viral loads at baseline ($p<0.001$). It was found that the single-tablet regimen participants had double the odds of being adherent, less chances of hospitalisation, and more chances of an undetectable viral load during follow up, after controlling for baseline covariates.	A limitation to the study was that pharmacy refill data was used as a measure of adherence, however, this may have overestimated adherence. The study was unable to exclude confounding factors that could have influenced the findings, as patients were not randomised to the two treatments. Despite attempting to control for some variables through

		pharmacy dispensing records.			multivariable models, residual confounding may have remained.
Samantha M McKetchnie et al, 2021 (USA) [58]	<ul style="list-style-type: none"> • n=15 • Age ≥ 50 years • Community 	Data was collected using one-on-one interviews.		The main themes highlighted from interview transcripts were firstly, the impact of chronic pain and its treatment on HIV care engagement, secondly, the impact of substance use on chronic pain, and lastly, interventions to target substance use and chronic pain. The results showcase the need for interventions addressing structural, physical, and psychological barriers to care engagement.	The small sample size limits the generalisability of the data.
T. G. Heckman et al, 2002 (USA) [78]	<ul style="list-style-type: none"> • n=83 • M=55.2 (SD=5.1) • Community clinics in two cities 	Self-administered assessment instruments were completed by participants.	The Symptom Checklist-90-Revised, the Beck Depression Inventory, the Barriers to Care Scale, the Provision of Social Relations Scale, the HIV-related Life Stressor Burden Scale, and the Limitations Related to HIV symptoms question.	4% of participants had severe depression, 21% had moderate depression, 33% had mild depression, 42% had minimal or no depression. Participants reporting more psychological symptoms had higher HIV-related life stressor burden, less social support from friends, and experienced more barriers to services due to HIV-related stigma. Elevation of symptoms characteristic of somatisation was seen in participants.	Due to recruitment being from only two sites, this may reduce the generalisability of the study findings. Also, the study used a self-selected sample. Participants were already connected to the AIDS service organisation; therefore they might already have their life-care needs met; study findings may underestimate the life chaos among participants.
Tausi Haruna et al, 2021 (Tanzania) [56]	<ul style="list-style-type: none"> • n=27 • M=54 years • Hospital 	Data was collected through in-depth semi-structured interviews.		Participants and healthcare workers held positive attitudes towards integration of services, they reported perceived benefits with this. Inconsistent and limited supplies, for example with screening equipment or medications, low awareness of non-communicable diseases among PLWH, insufficient training of healthcare workers on how to manage non-communicable diseases in PLWH, treatment costs and payment systems were factors hindering the integrations of services.	Interviews being conducted within the clinic setting that participants usually received their care may have led to socially desirable answers. Recruitment from five large clinics in Dar es Salaam may not be representative of patients from other smaller clinics.

Teresa Fritsch, 2005 (Canada) [97]	<ul style="list-style-type: none"> • n=22 under 50 years, n=12 aged 50-65 years • Hospital and community 	Data was collected via in-depth individual interviews.		The majority of participants had positive experiences accessing medical services. PLWH over 50 years old reported being able to access the social and medical services they required to cope with HIV. Both the younger and older groups accessed a variety of medical services, although the later did slightly less. The older group utilised social and emotional supports and organisations to a similar or higher degree than the younger group.	The generalisability of the study findings are limited due to the geographic location, sample size, non-random sampling and snowballing technique used.
Theresa W Kim et al, 2017 (USA) [33]	<ul style="list-style-type: none"> • n=250 • Mdn=50 years (44-56) • Community 	Data was extracted from electronic medical records.		Sedating medication and opioids was prescribed in 80% and 50% of participants, respectively. 51% of participants exceeded risky drinking limits. Illicit opioid use and illicit opioid sedative use was reported in 23% and 9% of participants, respectively, with 37% reporting lifetime non-fatal overdose and 7% past year non-fatal overdose. Participants were taking a median of 10 (7-14) medications and a median of 2 (1-3) sedating medications. The odds of a lifetime non-fatal overdose was increased with each additional sedation medication taken and any opioid medication. The prevalence of past year non-fatal overdose was higher with each additional sedating medication (p=0.049) and non-ARV medication (p=0.048).	Limitations to this study include the absence of a validated method to assess overdose history and the examination of only non-fatal overdose.

Tinei Shamu et al, 2021 (Zimbabwe) [52]	<ul style="list-style-type: none"> • n=420 • Mdn=55 years • Outpatient clinic 	Data was collected from electronic medical records.		World Health Organisation stage 3 or 4 conditions were present in 40% of participants at baseline. 15% of participants had hypertension at baseline and a further 27% reported incident hypertension at follow-up. 61.7% of participants had one or more chronic non-communicable disease. Results from the follow-up reported the most common incident comorbidities to be hypertension, arthritis, and chronic kidney disease.	The generalisability of the results are reduced due to the nature of the study being single-sited.
Tuyen Hoang et al, 2009 (USA) [30]	<ul style="list-style-type: none"> • n=1,018 • M=50.6 (SD=9.4) • Hospital and community 	Data was obtained from electronic medical records and by interviewing the Infectious Disease clinics chiefs at the five Veterans Affairs facilities.		93% of participants had comorbidities with a mean of 3.2 comorbidities (SD=2). Viral suppression was achieved in a median of 231 days (SD=411.6) by 52% of participants. Participants attending integrated clinics offering hepatitis, psychological, psychiatric, and social services were 3.1 times more likely to achieve viral suppression compared to those visiting clinics that only offered HIV care (Hazard ratio=3.1, p<0.001).	A limitation of this study includes that findings may be affected by the unmeasured differences between participants attending different clinics and healthcare providers skills varying, rather than the comprehensiveness of the care. Also, the potency of ART or its complexity was not measured. Duration of combined ART was not measured; therefore, it is not possible to determine whether this affected viral suppression.
Veronica P. S. Njie-Carr et al, 2021 (USA) [103]	<ul style="list-style-type: none"> • n=20 completed baseline activities, n=6 completed all activities, n=7 included in focus group • Age ≥50 years • Community 	<u>Intervention study:</u> Participants were given The CARE intervention, a three-module intervention for three weeks followed by post intervention measures to test its utility.	World Health Organisation QOL BREF, Perceived Social Support Scale, Mood tracker, Geriatric Depression Scale, and HIV Self-Care for Symptom Management Survey.	Participants found the CARE intervention useful and felt empowered utilising the app. Neuropathic pain (70%), anxiety (55%), fatigue (50%), and depressive symptoms (35%) were reported to cause high-intensity distress and negative impact on life to participants. It was reported that self-regulation and self-awareness improved, and there were positive trends in outcome measures.	A small sample size limits the generalisability of the study results. Another limitation is the short intervention duration of three weeks. Also, the participants retained in the study may be healthier and more acquainted with technology.

Vhudivhusi J Singo et al, 2015 (South Africa) [45]	<ul style="list-style-type: none"> • n=12 • Age=50-83 years • Community 	Data was collected through interviews using an interview guide.		The findings showed that HIV and AIDS can have negative effects on the lives of older PLWH. Socio-economic, household, psychological and emotional health burdens are critical areas in relation to older PLWH.	The small sample size limits the generalisability of the data and the population recruited in may not be representative of other geographical areas.
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Appendix 3. Systematic review: summary of intervention studies.

First author, year (country)	N	Age of participants	Study design	Mode of delivery	Intervention/s reported	Objectives	Effectiveness of the intervention and statistical significance
Ana Ventuneac et al, 2020 (USA) [53]	406	M= 50.7	Single-arm prospective trial	<u>Mobile application</u> : Assessments at baseline and six months for pre-post within-group comparisons, and between-group comparisons with matched sample patients not enrolled in the trial	Rango (mobile health application)	Promote Care engagement and medication adherence by: <ul style="list-style-type: none"> Addressing knowledge, skills, and motivation for HIV care engagement Creating a sense of community via peer support Coordinating care and other support services Tailored medication and appointment reminders Access to integrated services within Rango for referrals to social services 	<ul style="list-style-type: none"> The majority of Rango participants were engaged in care: 95% (387/406) returned for medical follow-up appointment Significant difference in the number of unsuppressed participants (n=65) at baseline who were suppressed (n=38) at six months (p=0.006) Viral suppression among Rango participants and those receiving usual care were similar (p=0.84) and increased in both groups at six months (p<0.001)
Anthony DeFulio et al, 2021 (USA) [99]	50	M=52.4 (SD=10.7)	Randomised controlled pilot study with a two-group parallel design	<u>Mobile application</u> : Videos had to be submitted of medication consumption. Surveys were given at baseline and monthly for six months	Medication Event Monitoring System (MEMS) cap and smartphone-based intervention app ("SteadyRX")	<p>Pilot clinical trial to demonstrate feasibility and acceptability of the SteadyRX app developed to increase adherence in PLWH with a substance use disorder.</p> <p>The app consisted of:</p> <ul style="list-style-type: none"> The "PillWatch" section to record and submit selfie videos demonstrating ART adherence The "MyRewards" section to monitor monetary incentive earnings of adherence The "InTouch" section for listings and contact information 	<ul style="list-style-type: none"> At six months the intervention group using SteadyRX, had a higher adherence than the control group (p=0.037) The intervention had high acceptability and usability, with intervention participants submitting a mean of 75% of possible videos, with 81% of these meeting the validity criteria

						for community resources, adherence documents and app instructions	
Ethan Moitra et al, 2011 (USA) [87]	16	M=52.5 (SD=5)	Mixed methods	<u>Group sessions:</u> Three to five weekly 60-minute sessions. Treatment consisted of experiential group exercises, role-play, and homework	Acceptance-based behaviour therapy	<p>Core principles of sessions included:</p> <ul style="list-style-type: none"> • Developing “creative hopelessness”, highlighting issues relating to direct cognitive and emotional control strategies • Cultivating a willingness to accept HIV-related distress • Clarifying and focusing on life values <p>This study focused on:</p> <ul style="list-style-type: none"> • Feasibility and acceptability of the intervention • Changes in CD4 counts and viral loads from baseline to the end of the intervention 	<ul style="list-style-type: none"> • Six (37.5%) participants found the intervention very helpful, six (37.5%) found them moderately helpful, and four (25%) found them minimally helpful • Mean CD4 counts increased from 372.3 (SD=167.4) to 487.3 (SD=225.3) and viral loads decreased from 148.8 (SD=130.1) to 16.0 (SD=24.8) from baseline to the end of the intervention • Participants enjoyed discussing which medicines worked, which were toxic to the body, and which tasted bad • Familial and romantic relationships were discussed to be a key factor when troubleshooting life with HIV
Heather A Leake Date et al, 2022 (UK) [102]	164	MOR: Mdn=59.5 (SD=50-78) Standard care: Mdn=60 (SD=50-82)	Randomised controlled study	<u>Medicines Management Optimisation Review (MOR):</u> Participants were randomized to either receive standard care or the MOR intervention	Medicines Management Optimisation Review toolkit, the University of Liverpool and Toronto General Hospital HIV drug interaction references, EuroQol five-dimension five-level (EQ-5D-5L) questionnaire	<p>Core objective of the MOR toolkit:</p> <ul style="list-style-type: none"> • Increase patient safety by identifying and reviewing patients at high risk for polypharmacy or drug-drug interactions <p>This study focused on:</p> <ul style="list-style-type: none"> • Examining the feasibility and acceptability of the MOR intervention <p>The MOR toolkit consisted of:</p>	<ul style="list-style-type: none"> • Significantly more medicine-related problems were identified in the intervention group at baseline (p=0.001) and 6 months (p=0.001) • There was a significant reduction in new medicine-related problems at 6 months in the intervention group compared to baseline (p=0.001), with 44% being resolved at baseline and 51% at 6 months

					and visual analogue scale (EQ-VAS)	<ul style="list-style-type: none"> • A user guide • 'My Clinic Companion', a patient self-reported questionnaire of medicines and adherence • The 'MOR consultation form' to assist with and provide a record of the patient consultation 	<ul style="list-style-type: none"> • There were no changes in HRQOL identified between groups or after the intervention • Participants and healthcare professionals found the MOR highly acceptable.
Ian R. McNicholl et al, 2017 (USA) [38]	248	M=57.8 (SD=5.1)	Prospective randomised interventional trial	<u>Medicine review:</u> Pharmacists reviewed electronic drug charts	Pharmacist medication reconciliation, Beers and STOPP criteria, Patient Health Questionnaire-9, the Montreal Cognitive Assessment, and the Veterans Ageing Cohort Study (VACS) Index	This study utilised the Beers Criteria and Screening Tool of Older Persons' Potentially Inappropriate Prescriptions (STOPP) instruments to assess potentially inappropriate prescribing (PIP)	<ul style="list-style-type: none"> • Participants were prescribed a mean of 11.6 ± 5.7 non-ARV medicines. 35% were receiving 16 or more medicines • PIP was identified in 54% and 63% of participants • 25 contraindicated drug interactions were found in 20 participants • At least 69% of participants had at least one medicine stopped, with almost 10% stopping six or more after reviewed by the pharmacist • Over 40% of participants had at least one Beers or STOPP criteria that needed immediate correction
Laura M Bogart et al, 2021 (USA) [95]	76	Mdn=52.9 (SD=12.9)	Pilot randomised controlled trial	<u>Cognitive behaviour therapy:</u> Eight session group intervention. Data was collected at baseline, two-, four-, five-, and seven-months	Cognitive behaviour therapy, dialectical behaviour therapy, Medication Event Monitoring System (MEMS) bottle cap	<p>Sessions aimed to:</p> <ul style="list-style-type: none"> • Improve coping with intersectional stigma • Address medical mistrust • Improve treatment adherence <p>The intervention included psychoeducation on:</p> <ul style="list-style-type: none"> • Discrimination • HIV disparities • Treatment adherence 	<ul style="list-style-type: none"> • Primary outcome (adherence): Both electronically monitored ($p=0.06$) and self-reported ($p=0.02$) adherence increased in the intervention group compared to the control group from baseline • Secondary outcome (coping, medical mistrust, and internalised stigma): Intervention participants showed slightly lower negative religious coping ($p=0.06$) and

							significantly lower medical mistrust (p=0.02)
Limin Mao et al, 2018 (Australia) [37]	98	Mdn=51.5 years (26-65)	Randomised controlled trial and mixed-method evaluation	<u>Mobile phone reminders</u> : The project consisted of two components, the six-week campaign (intervention arm with two groups and a control arm of one group) and a mixed-methods evaluation (online survey and interviews)	SMS reminders to mobile phones	This study aimed to assess the following two topics: <ul style="list-style-type: none"> • Feasibility and acceptability of the SMS reminders for ARV adherence • The potential impact of SMS reminders on adherence and disease self-management 	<ul style="list-style-type: none"> • SMS reminders were deemed acceptable and feasible • No statistically significant differences in adherence between intervention and control • Lower perceived stigma was independently associated with better ARV adherence (p=0.026)
Rebecca Schnall et al, 2018 (Australia) [100]	80	Control group: M=51 (SD=9) Intervention group: M=50 (SD=11.7)	Randomised controlled trial	<u>Mobile application</u> : Participants were given surveys each week for 12 weeks. Both the intervention and control groups used the app, but only the intervention group received self-care strategies	mVIP (mobile health application)	The app provided 143 self-care strategies for 13 different symptoms	<ul style="list-style-type: none"> • Participants in the intervention group showed significantly higher improvement than the control group in the following symptoms: anxiety (p=0.001), depression (p=0.001), neuropathy (p=0.002), fever/sweat/chills (p=0.037), and weight loss/wasting (p=0.02) • Greater adherence to ARV were reported in the intervention group compared to the control group (p=0.017)

Veronica P. S. Njie-Carr et al, 2021 (USA) [103]	n=20 baseline activities, n=6 all activities, n=7 focus group	≥50 years	Mixed methods	<u>Mobile application:</u> Participants were given post intervention measures (Focus group and surveys) to complete after three weeks of using the app	World Health Organisation QOL BREF, Perceived Social Support Scale, Mood tracker, Geriatric Depression Scale, HIV Self-Care for Symptom Management Survey, the Treatment Management Questionnaire, the Treatment Self-regulation Questionnaire (TSRQ)	<p>The app aimed to increase the autonomous motivation and perceived competence of individuals to self-manage disease symptoms and increase engagement with others.</p> <p>The app included the following:</p> <ul style="list-style-type: none"> • two 3–5 minute videos on HIV transmission risk reduction • HIV and aging • Free text health promotion strategies • Mood tracker, reflective journal, self-efficacy measures, and links to resources for self-monitoring • Remote individual clinician and peer support 	<ul style="list-style-type: none"> • Participants found the app useful and “felt empowered” using it • Self-awareness and self-regulation improved • Increases in mean scores were reported for treatment confidence, help-seeking, and internal motivation for treatment entry and adherence
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Appendix 4. NHS Health Research Authority Hampshire B Research Ethics Committee (REC) ethics approval.



Telephone: 0207 1048 088

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

02 February 2022

Miss Priya Sarma
PhD Candidate
University of Kent
Medway School of Pharmacy, Universities of Greenwich and Kent at Medway
Anson Building, Central Avenue, Chatham Maritime, Chatham, Kent
ME4 4TB

Dear Miss Sarma

Study title: Exploring medicine optimisation needs and interventions for older people living with HIV
REC reference: 22/SC/0029
IRAS project ID: 295529

The Research Ethics Committee (REC) reviewed the above application at the meeting held on 26 January 2022. Thank you for attending to discuss the application.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Good practice principles and responsibilities

The [UK Policy Framework for Health and Social Care Research](#) sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of [research transparency](#):

1. [registering research studies](#)
2. [reporting results](#)
3. [informing participants](#)
4. [sharing study data and tissue](#)

Appendix 5. The Multidimensional Scale of Perceived Social Support (MSPSS).

Multidimensional Scale of Perceived Social Support

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the "1" if you **Very Strongly Disagree**
 Circle the "2" if you **Strongly Disagree**
 Circle the "3" if you **Mildly Disagree**
 Circle the "4" if you are **Neutral**
 Circle the "5" if you **Mildly Agree**
 Circle the "6" if you **Strongly Agree**
 Circle the "7" if you **Very Strongly Agree**

	Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree
1. There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2. There is a special person with whom I can share joys and sorrows.	1	2	3	4	5	6	7
3. My family really tries to help me.	1	2	3	4	5	6	7
4. I get the emotional help & support I need from my family.	1	2	3	4	5	6	7
5. I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6. My friends really try to help me.	1	2	3	4	5	6	7
7. I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8. I can talk about my problems with my family.	1	2	3	4	5	6	7
9. I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10. There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11. My family is willing to help me make decisions.	1	2	3	4	5	6	7
12. I can talk about my problems with my friends.	1	2	3	4	5	6	7

Scale Reference:

Zimet GD, Dahlem NW, Zimet SG, Farley GK. The Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment* 1988;52:30-41.

Scoring Information:

To calculate mean scores:

Significant Other Subscale: Sum across items 1, 2, 5, & 10, then divide by 4.

Family Subscale: Sum across items 3, 4, 8, & 11, then divide by 4.

Friends Subscale: Sum across items 6, 7, 9, & 12, then divide by 4.

Total Scale: Sum across all 12 items, then divide by 12.

More information at:

<http://qzimet.wix.com/msspss>

Other MSPSS Scoring Options:

There are no established population norms on the MSPSS. Also, norms would likely vary on the basis of culture and nationality, as well as age and gender. I have typically looked at how social support differs between groups (e.g., married compared to unmarried individuals) or is associated with other measures (e.g., depression or anxiety). With these approaches you can use the mean scale scores.

If you want to divide your respondents into groups on the basis of MSPSS scores there are at least two ways you can approach this process:

1. You can divide your respondents into 3 equal groups on the basis of their scores (trichotomize) and designate the lowest group as low perceived support, the middle group as medium support, and the high group as high support. This approach ensures that you have about the same number of respondents in each group. But, if the distribution of scores is skewed, your low support group, for example, may include respondents who report moderate or even relatively high levels of support.
2. Alternatively, you can use the scale response descriptors as a guide. In this approach any mean scale score ranging from 1 to 2.9 could be considered low support; a score of 3 to 5 could be considered moderate support; a score from 5.1 to 7 could be considered high support. This approach would seem to have more validity, but if you have very few respondents in any of the groups, it could be problematic.



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Patients needed!

- We are looking for patients receiving care in [REDACTED] and **aged 50 years old or over** to take part in our research study. We would like you to share your views and experiences of living with long-term conditions and the associated medicines.
- This will involve an interview lasting up to 60 minutes, depending on how much you wish to share. The interview will be conducted over the phone, using Microsoft Teams, or face-to-face at a mutually convenient time.
- The interview will be voice recorded with your permission, this will then be transcribed by the interviewer, and the data will be anonymised.
- It is completely up to you to decide whether to take part or not – it will not affect your care and treatment in any way.
- Please take time to read the information provided in this leaflet.

**Scan the QR code to submit
your contact details and a
researcher will be in contact
soon!**



**Alternatively, you may call/text, or email the researcher
(Priya Sarma) to arrange an interview:**

Email: ps576@kent.ac.uk Mobile: [REDACTED]

Title: Exploring the medicine needs and experiences of people aged 50 years old and over living with long-term conditions in [REDACTED]

Name of researcher: Priya Sarma

Supervisors: Dr Barbra Katusiime, Dr Rebecca Cassidy, Dr Sarah Corlett

This research aims to explore the needs and concerns that people aged 50 years old and over living with long-term conditions in [REDACTED] may have regarding their medicines. A researcher at the Medway School of Pharmacy, Priya Sarma, is conducting this research as part of a PhD project.

We would like to invite you to take part in our research study that will consist of research interview. **All interview data will be anonymised.** Before you decide, it is important that you understand why the study is being done and what it involves.

Please read the following information, if there is anything that is unclear, or if you would like more information, please ask us. Take time to decide if you would like to take part or not.

What is the purpose of the study?

This study is being carried out to understand the issues and concerns you may have regarding your long-term medicines and your experience or need of any interventions to help with your medicines (for example, a medication review). The interview will allow us to understand your views in more detail.

Do I have to take part?

No. It is your choice whether you decide to take part or not. You can withdraw from the study if you no longer want to participate, without giving any reason. Withdrawal will not affect your care/medicines in any way.

Study procedures – If I do take part, what would I have to do?

You will be invited to take part in an interview, which will last up to an hour, depending on how much you would like to share. If you wish to take part in the interview at a time convenient to you, please complete the interview form below or scan the QR code to submit your details online and note down your unique code and phone number and/or email address. A researcher will use your unique code (e.g. 1234) and phone/email address to arrange your interview. **Please note that these details will be deleted within a week after your interview has taken place, and we will not send you any junk mail or pass your details to someone else.**

Alternatively, you may call, text, or email the researcher (Priya Sarma) to arrange an interview:
Email: ps576@kent.ac.uk
Mobile: [REDACTED]



Scan the QR code to submit your contact details online.

Interviews will be recorded and transcribed verbatim to support analysis of data. You will be asked for permission to audio record the discussion with the researcher. The recording will help the researcher to ensure they do not miss anything from your discussion and that they can pay full attention to what you are saying without having to take a lot of notes.

Are there any risks if I take part?

The only identifiable risk would be talking about upsetting or difficult subjects. If you change your mind and decide not to take part in the interview, you may do so at any time without giving a reason.

Are there any benefits if I take part?

The findings of this research study will provide feedback to the [REDACTED] and may be published for wider learning and improve services for people living with long-term conditions. We hope you find the interview useful in expressing your views and concerns about your long-term medicines, and how they may affect your daily life.

Will anyone know that I have taken part?

We will not tell anyone that you have taken part in the study. The data collected from the interview will be made completely anonymous.

What will happen to the results/How will your data be used?

The interviews are intended to identify issues and concerns associated with long-term medicines for older people living in [REDACTED]. All data will be anonymous and cannot be traced to any individual, and the results will enable us to identify medicine-related issues and concerns. Data will be handled by the research team only, including experienced researchers and pharmacists. A simplified, lay summary of collated findings will be available at the specialist clinic for viewing by all participants at the end of the study and on the university website.

Who is organising and funding the study?

The study is being carried out by a PhD researcher at the Medway school of pharmacy, as part of their thesis. It is being funded by Medway School of Pharmacy.

Who should I contact if I want to know more about the study?

Should you require further information about this study, please contact the lead researcher, Priya Sarma on [REDACTED] (ps576@kent.ac.uk), or a project supervisor, Dr Rebecca Cassidy on 01227827471 (R.J.Cassidy@kent.ac.uk).

Who should I contact if I have any concerns about the study or the way it has been conducted?

If you have any concerns about how this study has been conducted, please contact the Deputy Head for Medway School of Pharmacy, Dr Trudy Thomas (T.Thomas@gre.ac.uk).

Who should I contact if I have concerns about my medicine(s) or condition(s)?

if you have any questions about your medicines or conditions, please contact your doctor, pharmacist or relevant healthcare professional.

If you would like to know more about the university's guidance on the use of personal data, it can be found here: <https://research.kent.ac.uk/ris-operations/wp-content/uploads/sites/2308/2020/06/GDPR-Privacy-Notice-Research.pdf>


Thank you for taking time to consider taking part in this study.

medway school of pharmacy

PARTICIPANTS NEEDED

We are looking for participants to take part in a study **exploring the medicine needs and experiences** of people living with HIV.

Participation in this study will involve an anonymous interview lasting up to 60 minutes depending on how much you would like to share. Interviews by telephone/Microsoft Teams or face to face as you prefer.

- ✓ **ARE YOU HIV+?**
- ✓ **ARE YOU 50 YEARS OLD OR OVER?**
- ✓ **DO YOU RECEIVE HIV CARE IN THE**
 **AREA'S?**

IF YES TO ALL THREE THEN YOU ARE ELIGIBLE TO TAKE PART.

Scan the QR code to submit your contact details and a researcher will be in contact soon!



For further information contact: Priya Sarma, Medway School of Pharmacy
Email: ps576@kent.ac.uk Telephone:

medway school of pharmacy

v1.0 17.12.21

Title: Views and experiences of healthcare professionals on medicine optimisation needs of older people living with HIV in [REDACTED]

Name of researcher: Priya Sarma

Supervisors: Dr Barbra Katusiime, Dr Rebecca Cassidy, Dr Sarah Corlett

We would like to understand the views and experiences of healthcare professionals on the medicine optimisation needs of older people living with HIV in [REDACTED]. A researcher at the Medway School of Pharmacy, Priya Sarma, is conducting this research as part of a PhD project.

We would like to invite you to take part in our research study that will consist of a research interview. **All interview data will be anonymised.** Before you decide, it is important that you understand why the study is being done and what it involves.

Please read the following information, if there is anything that is unclear, or if you would like more information, please ask us. Take time to decide if you would like to take part or not.

What is the purpose of the study?

This study is being carried out to understand the issues and concerns people living with HIV may face with long-term medicines and your experience of any interventions to help this group with medicine-related problems (for example, medication reviews or support groups). The interview will allow us to understand your views and experiences in more detail.

Do I have to take part?

No. It is your choice whether you decide to take part or not. You can withdraw from the study if you no longer want to participate, without giving any reason.

Study procedures – If I do take part, what would I have to do?

You will be invited to take part in an interview, which will last 30-45 minutes. If you wish to take part in the interview at a time convenient to you, **please complete the interview form below or scan the QR code to complete the form online.** The researcher (Priya Sarma) will phone or email you to arrange your interview. Please note that these details will be deleted within a week after your interview has taken place, and we will not send you any junk mail or pass your details to someone else.

Alternatively, you may call, text, or email the researcher (Priya Sarma) to arrange an interview:

Email: ps576@kent.ac.uk

Mobile: [REDACTED]



Scan the QR code to submit your contact details online.

Interviews will be recorded and transcribed verbatim to support analysis of data. You will be asked for permission to audio record the discussion with the researcher. The recording will help the researcher to ensure they do not miss anything from your

discussion and that they can pay full attention to what you are saying without having to take a lot of notes.

Are there any risks if I take part?

The only identifiable risk would be talking about upsetting or difficult subjects. If you change your mind and decide not to take part in the interview, you may do so at any time without giving a reason.

Are there any benefits if I take part?

The findings of this research study will provide feedback to the [REDACTED] and may be published for wider learning and service improvement for older people living with HIV. We hope you find the interview useful in expressing your views and experiences regarding medicine optimisation needs of older people living with HIV.

Will anyone know that I have taken part?

We will not tell anyone that you have taken part in the study. The interview is anonymous.

What will happen to the results/How will your data be used?

The interviews are intended to identify healthcare professional's views and experiences on the issues older people living with HIV in [REDACTED] may face associated with their long-term medicines and any medicine optimisation interventions used to target these concerns. All data will be anonymous and cannot be traced to any individual, and the results will enable us to identify medicine-related concerns and interventions. Data will be handled by the research team only, including experienced researchers and pharmacists. A simplified, lay summary of collated findings will be available at the specialist clinic for viewing by all participants at the end of the study and on the university website.

Who is organising and funding the study?

The study is being carried out by a PhD researcher at the Medway school of pharmacy, as part of their thesis. It is being funded by the Medway School of Pharmacy.

Who should I contact if I want to know more about the study?

Should you require further information about this study, please contact the lead researcher, Priya Sarma on [REDACTED] (ps576@kent.ac.uk), or a project supervisor, Dr Rebecca Cassidy on 01227827471 (R.J.Cassidy@kent.ac.uk).

Who should I contact if I have any concerns about the study or the way it has been conducted?

If you have any concerns about how this study has been conducted, please contact the Deputy Head for Medway School of Pharmacy, Dr Trudy Thomas (T.Thomas@gre.ac.uk).

If you would like to know more about the university's guidance on the use of personal data, it can be found here: <https://research.kent.ac.uk/ris-operations/wp-content/uploads/sites/2308/2020/06/GDPR-Privacy-Notice-Research.pdf>

Thank you for taking time to consider taking part in this study.

Interview contact form:

Thank you for your interest in our research study.

If you work with older people living with HIV who are receiving care in [REDACTED] [REDACTED] you are eligible to take part in this study. Your contact details will be deleted once the interviews are complete and will not be given to anyone outside the research team.


Please enter your details below and a researcher will contact you soon.

Email and/or phone number:

What is your job title? (For example, pharmacist, HCA or pharmacy technician)

Please tell us when it would be best to contact you (for example, Mon-Thurs 10-1pm or Wed afternoon):

CONSENT FORM

Exploring the medicine needs and experiences of people 50 years old and over living with long-term conditions in areas of 

Name of researcher: Priya Sarma

Supervisors: Dr Barbra Katusiime, Dr Rebecca Cassidy, Dr Sarah Corlett

I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to ask questions to the research team or their representative, and I have considered information given. All questions have been answered to my satisfaction.	Initial Here:
I understand that my participation is voluntary and that I am free to withdraw at any time. I understand that I do not have to give a reason if I withdraw. I also understand that my medical care or legal rights will not be affected if I withdraw.	Initial Here:
I understand that all data collected during the study will be anonymous, stored securely, and will remain confidential as explained in the information leaflet.	Initial Here:
I consent to the storage of data for the purposes of this study. This may include paper or electronic information. I understand that any information that could identify me will be kept strictly confidential and that no personal information will be included in the study report or other publications.	Initial Here:
I understand that everything that I say during the research interview will be kept strictly confidential. I also understand that in the unlikely event that I or others are at risk of death or serious harm, my regular specialist clinic would be notified. I give permission for my specialist clinic to be informed of my participation in this study.	Initial Here:
I agree to the interview being audio recorded using a Dictaphone and transcribed verbatim by the researcher. I understand that verbatim quotes taken from my responses may be used in publications and reports, but that these will be anonymised and not traceable to me.	Initial Here:
I agree to take part in the above study.	Initial Here:

 Initials of participant

 Date

 Signature

 Name of researcher

 Date

 Signature

Appendix 10. Chapter 6 and 7 interview schedule.

Interview Schedule

Chapter 6:

Introduce self/study

- Could you list the medicines that you are currently taking?
 - ART – when was this started? Any previous ART?
 - Other prescriptions
 - OTC medicine
 - Vitamins, herbal medicines, supplements
- How do you usually get your ART?
 - Clinic/community/delivery
 - How have you found the service?
 - Have you ever run out of medicines and what did the service do in that situation?
 - How often do you collect/get your medicines?
- How do you usually get your other medicines?
 - Clinic/community/delivery
 - Are they on repeat from the GP?
 - How have you found the service?
 - Have you ever run out of medicines and what did the service do in that situation?
- How often do you take each medicine (ART and non-ART)?
 - Have you made any lifestyle changes in order to fit your medicines in?
 - Do you use any tools to remember to take your medicines?
 - Why do you think some people may struggle to take their medicines?
 - Do you take your medicines with you when you are away from home?
 - Is there anything you find challenging about taking your medicines?
- Have you ever experienced any side effects with these medicines?
 - What happened/how did you deal with it?
 - Who did you speak to?
- When you start a new medicine/vitamin where do you usually look or whom do you speak to for more information?
 - Do you check if it interacts with your ART?
- How often do you see your pharmacist regarding your ART/other medicines or for any issues/concerns you have for your general wellbeing?
 - Do you visit your local community pharmacist or hospital/clinic pharmacist?
 - When is the last time you met/spoke to/contacted your clinic/hospital pharmacist?
 - Do you use one pharmacist over the other? If so, why?
 - Why do you not visit your local pharmacist?
 - What changes would make you more likely to visit your community pharmacist?
- Have you taken part in any medicine reviews in the last 12 months?

- Was this with your doctor, nurse or pharmacy staff? Hospital or community?
- How effective were they? Do you believe it benefit you?
- Were any changes made to your medicine? If so, what were they?
- Do you know what each medicine is for?
- Do you know the importance of adhering to your medicines?
- Were any lifestyle changes suggested? If so, what were they?
- Is there anything you think could have improved or you would have liked?
- Is there anything that you would like to have discussed during the intervention? Or anything that could have been discussed further?
- How likely are you to recommend this service to someone else?
- Have you disclosed your HIV status to your GP?
 - If yes: has this been beneficial for you?
 - If no: may I ask why?
 - Would you disclose your status to other healthcare professionals (e.g. community pharmacists)?
- How often do you visit the clinic/GP?
 - How do you get there?
 - Do you have any difficulties getting there?
 - How does this affect you? (Prompt: work/social)
 - How much does the travel cost you?
 - How far do you travel?
- Have you had to make any lifestyle changes after you were diagnosed?
 - How has your life changed? (Prompt: work/social)
 - Is there anything you have been advised to do? (E.g. exercise, diet, stress management)
- Has there been any services suggested for you by the clinic, such as support groups? Or have you found and joined any support groups?
 - Do you think these are beneficial?
 - How could it be better?
 - What services would you like to see?
- Is there anything that healthcare professionals can do better to help older people living with HIV?

Chapter 7:

The following questions will be included in the interview for healthcare professionals:

Introduce self/study

- What is your job title?
 - Could you describe what a usual day looks like for you?
- Are there any specific ways in which you help older PLWH manage their medicines?
- Have you discussed changing medicines with any of your older patients in the last 12 months? how many?
 - Was this a specific medicine optimisation intervention?
 - How are patients referred to you for the intervention?

- How could the referral process be improved?
- Are there any challenges you face when conducting medicine optimisation interventions?
- Are there ways in which you think medicine optimisation processes could be improved? For example, would you prefer there is a standard template or tool to use? Why/why not?
- What tools do you use to help you conduct medicine optimisation interventions? / Are there any resources you use to help older PLWH with their medicines?
- How are decisions regarding a patient's medicines shared between the multi-disciplinary team?
- Do you think more medicine optimisation interventions would help improve health-related outcomes in older PLWH?
- Are there any challenges you have faced when implementing or conducting medicine optimisation interventions?
- In your opinion, what are the desired outcomes from medicine optimisation interventions?
- Is there anything you think can be done better to help older PLWH manage their medicines?
- What do you think are the main issues and concerns older PLWH face relating to their medicines?

Appendix 11. Participant characteristics of older PLWH included in chapter 6.

Interview number	Gender	Age	Ethnicity	Time since diagnosis (Years)
1	Male	64	White	14-15
2	Female	63	White	8
3	Female	50	Black	Not shared
4	Male	60	White	23
5	Female	52	Black	11
6	Male	68	White	20
7	Female	51	Black	10
8	Female	59	White	1
9	Male	61	White	12
10	Male	50	White	Not shared
11	Male	74	White	17-18
12	Male	75	White	11
13	Male	67	White	40
14	Male	62	White	Not shared
15	Male	50	White	13
16	Male	52	White	13
17	Male	60	White	Not shared
18	Male	52	White	11
19	Female	55	Black	14
20	Male	61	White	6
21	Male	64	White	15
22	Female	72	White	15
23	Male	53	White	Not shared
24	Male	50	White	Not shared
25	Male	51	White	11
26	Female	70	White	20

Medicine-related burden in people living with HIV

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Introduction

By 2030, nearly 75% of all people living with HIV (PLWH) are expected to be 50 years or older, with the median age increasing gradually over the years [1]. To achieve optimal treatment outcomes, high levels of adherence to antiretroviral therapy (ART) is required.

Ageing with HIV is associated with multiple comorbidities, frailty, and polypharmacy [2]. Medicine burden is associated with polypharmacy, regimen complexity, drug interactions, adverse drug reactions and nonadherence [3]. Regardless, there is limited research comparing levels of burden in younger and older populations.

Objective

To identify medicine-related issues or concerns that impact medicine burden experienced by younger (18<50) and older (≥50) PLWH.

Methodology

- Two validated outcome measures were used: the Living with Medicines Questionnaire (LMQ-3) [3] and the Stigma Scale for Chronic Illnesses 8-item version (SSCI-8).
- Questionnaires were distributed online and at HIV clinics located in Kent, UK (October 2018 to January 2020).
- Secondary analysis was conducted to compare experiences of younger (18-49) and older (≥50) PLWH with Mann-Whitney U-test and Spearman's correlation test using IBM SPSS (V. 27).

Results

- 141 participants completed the survey in full.
- Older PLWH were taking significantly more medicines ($p<0.001$), with 41.7% (25/60) taking five or more each day.
- Overall, PLWH reported low medicine burden with only 16.1% (10/62) and 20.0% (14/70) of older and younger PLWH being highly burdened, respectively.
- Fewer older PLWH thought that the side effects from their medicines were bothersome ($p<0.05$) or that their medicines interfered with their day-to-day life ($p<0.05$).
- More younger PLWH felt uncomfortable disclosing their HIV status to close friends ($p<0.05$).
- Higher medicine burden was related to higher stigma ($p<0.01$).

"I don't like the size of some of them as it makes it difficult to be discreet when taking them in public" Female, aged 56

"It's not the medicines that affect me, but the attitude of people towards me when they find out what my meds are for." Male, aged 63



"Some medicines are arguably difficult to take in front of people as this may lead to being stigmatised. Also lack of clear understanding makes it hard at times for people to accept you." Male, aged 49

Table 1: Patient demographics.

Variable	Total
Males, n(%)	98 (69.5%)
Ethnicity: White, n(%)	108 (76.6%)
Age in years*	49.0 (18-74)
n ≥ 50 years old (%)	70 (49.6%)
Total number of medicines taken*	3(1-20)
*median (range)	

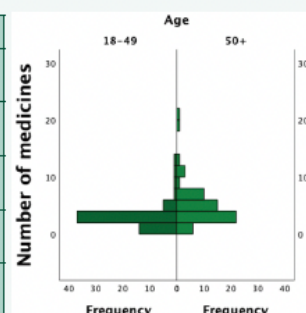


Figure 1: A graph showing the number of medicines taken in younger and older PLWH.

Conclusion

Most PLWH reported low medicine burden. Older PLWH were more accepting of the impact of taking medicines on their day-to-day lives even though they had a higher pill burden. However, a minority of PLWH across both age categories experienced high medicine burden and reported experiences of stigma. These individuals need to be identified and prioritised for medicine support.

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