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KNGDES001

Patient choice in HIV prevention, treatment, care and support interventions in Africa: a systematic review.

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ABSTRACT

Introduction: Africa has the highest burden of HIV globally. A growing number of evidence-based HIV intervention are being scaled up to eliminate HIV transmission and minimise morbidity and mortality. We reviewed the published HIV literature to describe interventions in which patients are given a choice in their HIV care, and examine the impact of patient choice on reported health outcomes among studies including a non-choice comparison group.

Methods: We searched PubMed and reference lists, from 1 January 2010 to 8 December 2023. Included studies were HIV related interventions where patients were making a choice in some aspect of their care and carried out in Africa. The choice components and related results were described, and grouped by HIV continuum focus area. Measures of association were summarised for studies reporting comparison of health outcomes between choice and non-choice groups.

Results: Eleven out of 593 studies were included. Six focused on HIV prevention, four on HIV treatment and one on HIV care and support. Five studies described choices offered in routine care; six were research interventions. Choices provided included product choice, location of services, duration of dispensing and choice treatment support. Limited details were provided on the implementation of the choice intervention in most studies. In two prevention studies comparing a choice and non-choice group, pre-exposure prophylaxis coverage was significantly higher in the choice arm compared to the control. In one HIV treatment study, there was no difference in viral suppression but retention in care was significantly higher in the choice arm compared to the non-choice arm.

Conclusions: This review shows that patient choice is being offered in HIV preventative and treatment services and is allowing people to select what they need when needed. More research is required to understand how patient choice can be sustainably implemented in HIV services in high-burden and low-resource settings.

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PART B: PROTOCOL

STUDY SYNOPSIS

Background and rationale: This study is being done as part of a Master in Public Health degree, majoring in Epidemiology and Biostatistics. HIV is a major public health burden in Africa, mostly in the sub-Saharan region. There is no cure but there are multiple evidence-based prevention, treatment, care and support measures which help prevent HIV and help people living with HIV (PLHIV) lead a normal fulfilling life. With multiple potential interventions and models of care available, there is interest in including patient choice in HIV services. Patient choice has been incorporated into HIV prevention measures mostly, and we need to see how it has been used throughout the cascade. This review aims to explore how patient choice is included in HIV interventions in Africa, and whether providing patients with a choice improves HIV prevention, treatment, care and support outcomes.

Patient choice has been used for many years in public health interventions such as family planning but there has been an increase in offering patients choices within HIV prevention, treatment, care and support interventions. HIV is a chronic disease which poses a burden to PLHIV in all their spheres of life: economically, socially, physically and mentally. There are lots of gaps which exist in providing HIV prevention, treatment, care and support interventions. This study seeks to find out how the use of patient choices can close those gaps. Patient choice within health services is relatively common in high resource settings and providing choice may improve patient engagement in their health care. However, while patients can theoretically make choices for their care along the HIV cascade, practical interventions in high burden and low resource settings are often based on guidelines and algorithms that limit patient choice.

Aim and Objectives: This study will synthesise the available published literature to describe how and in what settings patient choice has been included in HIV interventions in Africa, and whether including choice is associated with improved outcomes.

The objectives of this review are: 1) to describe studies in which the patient is making a choice in an HIV prevention, treatment, care or support intervention, 2) to compare and contrast the HIV interventions in which patients are making a choice by HIV continuum focus area, and 3) among the subset of studies that include a non-choice comparison group, to describe the associations between patient choice and reported health outcomes.

Methods: Electronic searches will be done in PubMed using search terms including terms related to: HIV, patient choice or preference or options or alternatives, treatment or prevention or

support, primary health care and Africa. Inclusion criteria will be all studies in English published from 1 January 2010 to 8 December 2023 that include adults, are conducted in Africa and in which patients are making a choice of services within an HIV prevention, treatment, care or support intervention. Studies presenting hypothetical choices (stated choice and discrete choice experiments) and review articles will be excluded.

This systematic review will follow the PRISMA guidelines (Page et al., 2021). Two independent authors (TP & DK) will screen titles and abstracts using uniform methods to select eligible studies for full text reviews and extraction. Disagreement regarding inclusion of studies will be resolved by a third reviewer (PM). The PRISMA flow chart will be used to show included and excluded studies and reasons for exclusion of a study will be documented.

A standardised data extraction form will be used, two independent authors will extract the data from studies and disagreements between the authors will be resolved by the third reviewer. A narrative synthesis of studies meeting the inclusion criteria will be conducted. To address objective 1) we will describe all included studies in a table and synthesise the relevant aspects of the included papers. To address objective 2) we will group the included papers by focus point on the continuum of HIV prevention. treatment, care and support. We will draw out any similarities and differences in how choice is offered and what choices were offered in these groups. To address objective 3) we will look at any included papers that compared outcomes between people assigned to a specific intervention and people who were offered a choice within an intervention. We will describe any reported outcomes (the specified outcome, measure of effect and confidence interval) in the studies comparing choice to no choice. We anticipate a large amount of heterogeneity and that a meta-analysis will not be possible.

An exemption for ethical clearance is requested as this study includes no human subject data. Only publicly available published literature will be included in this study.

Patient-centred interventions are going to be critical to close the remaining HIV gaps and patient choice is one aspect of this. This review study will provide valuable insight into how choice has already been included in published studies, the evidence on the association between choice and health outcomes, and areas for consideration in future research.

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INTRODUCTION

Background to the review

HIV continues to be a global burden with nearly 40 million people living with HIV and more than 1.3 million HIV incident cases in 2022 globally (UNAIDS, 2023). The African continent carries most of this burden (more than 60%) with the greater part being in its Sub-Saharan Africa (SSA) region (UNAIDS, 2023; World Health Organisation, 2023). Globally, more than 600,000 people died in 2022 from HIV-related illnesses (UNAIDS, 2023). The HIV/AIDS pandemic has been affecting most African countries in several ways such as politically, economically and socially. Effective interventions are therefore needed to cater for the devastating effects of the disease (Boutayeb, 2009).

To reduce the morbidity and mortality burden the global focus is targeted on preventing and treating HIV. Many evidence-based ways to prevent the spread of HIV exist, such as knowing your status through HIV voluntary counselling and testing (VCT) & over-the-counter and self-administered home HIV testing, using barrier methods such as condoms, antiviral gels, pre-exposure prophylaxis (PrEP)/post-exposure prophylaxis (PEP) for high risk/key populations, HIV education in schools and the community, text message (SMS) health advice, and referral services (Shaver et al., 2017). There is currently no cure for HIV, but antiretroviral (ARV) drugs can however be used effectively to suppress the virus and prevent transmission. People living with HIV (PLHIV) who are on effective antiretroviral therapy (ART) and have a fully suppressed viral load have a zero risk of transmitting the virus to their sexual partners (Haider et al., 2021). This is treatment as prevention in HIV control. As a result, PLHIV can enjoy healthy, long and productive lives (World Health Organization, 2021). As with HIV prevention, there are many possible evidence-based models of care to deliver HIV treatment and interventions to support engagement in care. More available options, patients should be able to select from these “toolboxes” of evidence-based interventions. Alternative service delivery approaches, or differentiated service delivery (DSD) models are being rolled out nationally in many countries. These include facility-based individual models, out-of-facilty-based individual models, client-led groups and healthcare worker-led groups (Long et al., 2020). These evidence-based interventions for treatment “differ from conventional HIV care in the location and frequency of interactions

with the healthcare system, cadre of provider involved, and/or types of services provided" (Duncombe et al., 2015).

In 2015, the WHO recommended differentiated models of care (DMOCs) or DSD models, emphasising that the continuum of HIV care needed to be strengthened in order to improve all aspects of services in high burden countries such as those in sub-Saharan Africa including service quality, access, efficiency, cost, adherence and retention, as well as clinical outcomes (World Health Organization (WHO/OMS), 2016). Historically these models have been aimed at clinically stable, adult patients and established facilities have continued to provide clinical care to other populations (Huber et al., 2021). In more recent years there has been an emphasis on broadening the population reach of DMOCs with a focus on patient-centred care. Grimsrud et al wrote "If the client is at the centre, then the client's voice must be central to the design of differentiated care. When assessing which model(s) to choose, it is fundamental to speak with the clients or recipients of care" (Grimsrud et al., 2017).

To some extent the battle to end HIV/AIDS is being prolonged by the fact that patient participation is limited in both the prevention and treatment programmes of HIV as care is largely decided by the country's national guidelines. Patients also carry the notion that the physician knows best what is in their interest. This results in health care workers making choices for patients about their treatment options in most situations (paternalistic model) (Faller, 2003). Health care workers may not think that patients are able to make their own choices about their own health and health care, or to exercise control over decisions about their health and that of their communities (Barrett et al., 2016; World Health Organization (WHO/OMS), 2016). However, incorporating choices and shared-decision making into routine care, along with addressing specific misconceptions, myths and fears with better information can help patients make the best personal choices (Hubacher et al., 2013).

Purpose and justification of this review

The population that requires chronic disease care is on the rise in Africa as a result of expanding lifelong HIV treatment coverage, rising life expectancies, and a rapid increase of non-communicable diseases (NCDs) (Bosire et al., 2021). This means that these health care users will

need ongoing attendance at appointments, adherence to tests and medications for prevention and treatment, healthy living and active self-management thereby putting pressure on the healthcare system (Bosire et al., 2021). This active self-management in HIV care involves action-oriented health-related behaviours and patients having active involvement in the treatment plan themselves (self-care, self-monitoring, symptom management and maintaining emotional health) (Keene et al., 2022).

As a result, healthcare systems are increasingly adopting integrated and patient-centred practices that aim to deliver quality care and value for money, while acknowledging the role that patients play in chronic care (Bosire et al., 2021). For example, in high income settings with increasing burden of chronic diseases (diabetes, hypertension, mental health illnesses), existing systems of healthcare are still greatly focused on hospital-based management of individual clinical episodes whereas in the low-or-medium income countries (LMICs) there is a well-established growth of vertical donor-funded disease-specific programmes (Global Fund HIV, TB and Malaria Control Programme). These disease-specific programmes have disturbed horizontal, or comprehensive care which promotes more inclusive ways of managing health problems by injecting funds to strengthen the existing health services permanently (Mounier-Jack, Mayhew & Mays, 2017). This integrated care is even made more difficult to implement as the health systems in LMICS also face many competing priorities that stretch the limited available resources (Keene et al., 2022).

As the number of available evidence-based interventions increase, incorporating patient choice into public health interventions could help to make these HIV interventions more successful and effective. An example from the TB literature in the TB preventive therapy randomised controlled study in Uganda, found that patients who were empowered to make informed decisions about how they take tuberculosis (TB) preventive therapy, choosing between either by directly observed therapy (DOT) or self-administered therapy (SAT), improved treatment completion rates (Lim et al., 2021). Compared to patients randomised to the DOT arm, participants randomised to the choice scenario expressed higher confidence and greater intention to complete 3HP (isoniazide and rifapentine) due to the benefit of taking the tablets at home (Lim et al., 2021).

It has been suggested that an understanding of patient experiences and developing patient-centred approaches to HIV care will be necessary to close the gaps in engagement in HIV care (Duncombe et al., 2015). Choice has been increasingly recognized as important to HIV services but evidence on the feasibility and impact of offering choice in HIV interventions has not been synthesised. Therefore, this systematic review will seek to describe how choice is offered in HIV interventions in the published literature, and help to elucidate the relationship between the use of patient choice and HIV prevention and treatment outcomes. Importantly, this study will enhance our understanding of how patient choice has been incorporated into HIV prevention, treatment, care and support interventions in Africa, and the available evidence on whether incorporating choice could help to close the remaining gaps in the fight against HIV. Findings will be able to inform the development of strategies for using patient choice in HIV and other public health interventions in Africa.

Systematic reviews are considered the pillar of evidence-based healthcare as they provide more reliable and meaningful findings from which conclusions can be drawn and decisions made by the end users. This is done by synthesising the findings from various studies through the use of rigorous, explicit and systematic methods (Munn et al., 2018).

Research question for the proposed review

How is patient choice included in HIV prevention, treatment, care and support interventions in Africa, and can the inclusion of patient choice improve intervention outcomes?

LITERATURE REVIEW

Burden of HIV in Africa and where we are now in epidemic control.

The sub-Saharan Africa has the largest burden of HIV worldwide (UNAIDS, 2023). According to the WHO 2021 Global Report, it was estimated that more than two-thirds of PLHIV globally were from SSA (World Health Organisation, 2023). Countries such as Eswatini, Lesotho, and South Africa were found to have a high prevalence of HIV due to factors such as stigma, poverty, inadequate medical care, lack of prevention and education (UNAIDS, 2023). In contrast, Zimbabwe has reduced its HIV prevalence rates by more than half, from 25 per cent of

the population in 2002 to around 11.58 per cent in 2021 (UNICEF, 2023) through focused HIV prevention interventions, making it one of the five countries in Africa to reach the 95-95-95 targets by 2022 (UNAIDS, 2023).

WHO, Global Fund and UNAIDS "95-95-95" targets need 95% of all PLHIV should have a diagnosis by 2025, 95% of whom should be on lifesaving antiretroviral therapy (ART) and 95% of whom to have sustained virologic suppression (UNAIDS & JUNP, 2023). These new targets were released in December 2020 to reduce the burden of HIV to a low level by 2030 once these targets are reached by 2025. Africa as a continent is doing quite well relative to other contexts, however gaps still remain. Currently, 90% of PLHIV in the WHO African Region have been diagnosed with HIV; 82% of PLHIV are on ART and 76% have sustained virologic suppression (World Health Organisation, 2023).

HIV Prevention Cascade

The HIV prevention cascade helps to find out the barriers and gaps to fight HIV, and to develop ways to increase the impact of focused of HIV prevention interventions (Pickles et al., 2023). The framework (Figure 1) shows the gaps in the cascade across motivation, access, and effective use, and some of the reasons for these gaps. The reasons shown above are not a complete list and, "although some of these reasons are likely to be widely applicable, they may differ in relative importance between settings, populations, and prevention methods. The reasons provide links to interventions and platforms for interventions to improve motivation, access, and effective use in the priority population." (Schaefer et al., 2019)

HIV prevention cascades enhance the ability of managers to monitor and evaluate their projects and to compare effectiveness of the programme across different sites. Prevention programmes use a few distinct prevention methods (e.g. communication for behavioural change, pre-exposure prophylaxis (PrEP) and condoms) for specific populations (UNAIDS, 2021). However, these prevention methods are used in combination (e.g. condom use and PrEP among (MSM) men who have sex with men) in practice (UNAIDS, 2021).

Figure 1: *A generic and unifying HIV prevention cascade framework.*

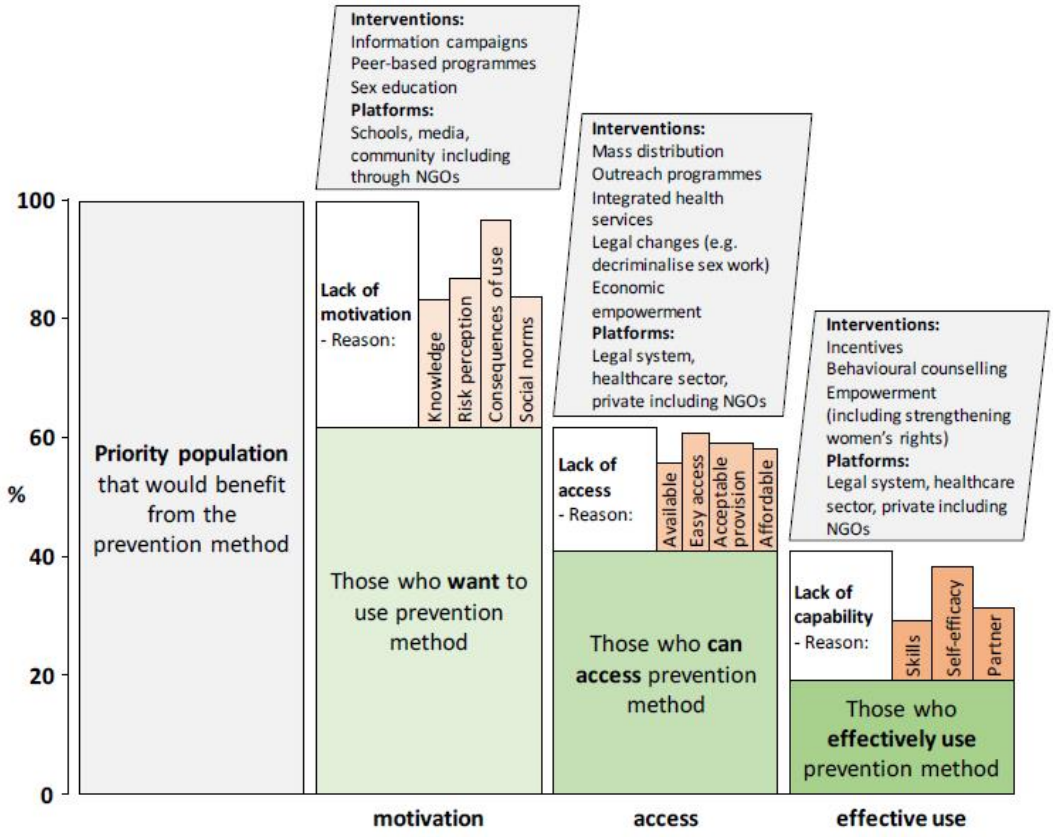

Figure taken from (Schaefer et al., 2019)

HIV care continuum

The HIV care continuum (Figure 2) is an internationally-recognized framework that models the dynamic stages of HIV care. The cascade consists of five main steps which include "diagnosis, linkage to care (LTC), retention in care (RiC), adherence to antiretroviral therapy (ART), and viral suppression" (Kay, Batey & Mugavero, 2016). HIV treatment cascade is usually drawn in a linear, unidirectional scheme, people living with HIV can initiate and default treatment several occasions during their lives, creating a "side door" into the continuum through which they can be re-initiated on ART (Hallett & Eaton, 2013; Ehrenkranz et al., 2021).

The first stage is entry into the HIV treatment cascade, beginning with diagnosis which involves testing for HIV. This can be done at a facility or home using HIV self-test kits. It can be client initiated or provider initiated thus there is an element of choice demonstrated at this stage (Ehrenkranz et al., 2021).

Figure 2: *HIV care continuum*

Figure taken from HIV.gov (https://www.hiv.gov/federal-response/policies-issues/hiv-aids-care-continuum)

The second stage, LTC, is being connected to services and access to care after the diagnosis is made, whether this is initiation of treatment or a visit to a facility for baseline assessments (Kay, Batey & Mugavero, 2016). In this stage, newly diagnosed patients are usually offered counselling and support from family, health care workers or relatives before they are initiated on ART (UNAIDS, 2016). However, some clients might access other forms of care like herbs and symptomatic treatment even though antiretroviral therapy is standard (Peltzer et al., 2008). Stage 3 is initiation of ART, which refers to the person being started on antiretrovial drugs. The 2021 WHO HIV guidelines strongly recommend that the viral load be reviewed by 6 months after initiating ART (Ehrenkranz et al., 2021; World Health Organization, 2021).

HIV retention in care (RiC) is also represented by the PEPFAR indicator (TX_CURR) which is the number of PLHIV currently receiving ART at the end of the reporting period. The number excludes clients who have defaulted treatment within 28 days of their last missed ARV pick-up from health facilities (USAID, 2020). PLHIV may be inaccurately designated as "out of care" due to undocumented life events such as death, mobility or emigration, incarceration and or changes in their health provider (Kay, Batey & Mugavero, 2016).

The last step in the continuum is HIV viral suppression as a result of taking ART (Kay, Batey & Mugavero, 2016). The WHO considers PLHIV with an HIV viral load less than 1000 copies per

millilitre (c/mL) measured within the past year, as being virally suppressed and viral load less than 50 c/mL means HIV is undetectable (World Health Organization, 2021). There is strong evidence that once the virus is undetectable it is also not transmissible. Although adherence is not explicit in the cascade, viral load suppression is directly linked to medication adherence. Since there are no standard objective measures in routine care for confirming that patients consistently stayed on ART medication, health providers must use proxy measures such as patient self-report or treatment dispensing as a measurement of ART adherence (Kay, Batey & Mugavero, 2016).

HIV care and support

Care and support "refers to key non-antiretroviral therapy clinical services, prevention and treatment of HIV-related infections, and non-clinical services that in combination with antiretroviral therapy contribute towards the reduction of rates of ill health and HIV-related deaths among, and increase the well-being of, people living with HIV" (UNAIDS, 2016). Care and support help PLHIV to be started on ART soon after diagnosis, to adhere to ARVs resulting in sustained viral suppression, to prevent opportunistic infections as well as HIV infection to others (UNAIDS, 2016).

Table 1: *HIV care and support services*

Care and support services[1]

Universal	• Linkage to care for immediate initiation of antiretroviral therapy for people newly diagnosed with HIV, with clinical and laboratory monitoring, including viral load monitoring • Tuberculosis screening • Cotrimoxazole prophylaxis • Optimization of retention in care and adherence to antiretroviral therapy
Contextual	• Clinical care • Physical care • Social support • Pain and symptom management and end-of-life care • Mental health and substance (including alcohol) abuse services • Nutrition assessment, counselling and support • Legal support

[1] Services are not listed in any particular order.

Figure taken from (UNAIDS, 2016)

In conclusion, care and support (Table 1) is a comprehensive set of services, such as "basic nursing and end-of-life care, access to social grants, psychosocial and mental health support, livelihood-strengthening activities and food security" (UNAIDS, 2016). All those services are vital to the lives of people living with HIV and social supporting people at home (UNAIDS, 2016).

HIV prevention, treatment, care and support strategies.

Since there is no cure for HIV, ART is our primary intervention in reducing the morbidity and mortality from HIV together with multiple preventive interventions. There is a large and growing evidence-based toolbox of prevention strategies for HIV including: HIV testing services (HTS), sexually transmitted infection (STI) prevention and management, voluntary medical male circumcision (VMMC), use of male and female condoms, pre-exposure prophylaxis (PrEP), post exposure prophylaxis (PEP), treatment as prevention HIV in sero-discordant couples (TasP) (Ward et al., 2019; Ministry of Health and Child Care, 2022). Even with all these prevention strategies, Africa as a continent is struggling to close the gaps in the epidemic control of HIV (World Health Organisation, 2023). The reasons for the high level of HIV spread in Africa especially in the sub-Saharan region include poverty, cultural issues, inadequate medical care, social inequality, migratory labour practices, taboo & stigma, sexual behavior, prostitution, sexual violence against women and lack of prevention and education even to be included in prevention, treatment, care and support of PLHIV (Sovran, 2013). Men are lagging behind women as well in the HIV epidemic control (UNAIDS, 2023; World Health Organisation, 2023).

The World Health Organization recommended the 'Universal Test and Treat' (UTT) strategy – starting all patients diagnosed with HIV on ART without taking into account their clinical stage and CD4+ count (Nicol et al., 2023). This means that once diagnosed with HIV the patient is linked to care which is an important step to viral suppression (Owusu, Adu-Gyamfi & Ahmed, 2019). Delaying linkage to care, for PLHIV, allows the disease to progress further resulting in increased HIV related mobility and mortality (Ankomah et al., 2016). Comprehensive HIV care, such as same day ART, point of care CD4+ testing and assisted partner services, in urban settings of SSA region was associated with improved linkage to care (Owusu, Adu-Gyamfi &

Ahmed, 2019). Patients are offered choice by health workers to access these services at a health facility or in the community.

Since geographical areas with HIV incidence also have prevalence of NCDs (cardiovascular disease, diabetes and cancer), food insecurity and the effects of endemic infections (diarrhoea, malaria and tuberculosis), many of the contextual care and support services are required in different situations as well as in different categories of people living with HIV (UNAIDS, 2016) (Table 2).

Table 2: *Key care and support packages across categories of PLHIV*

Key care and support packages across categories of people living with HIV

Treatment initiation	Treatment continuation
Early	**Stable**
Clinical priorities • Sexually transmitted infection screening and treatment, access to family planning and sexual and reproductive health services • Screening and management of mental health disorders • Screening and management of noncommunicable diseases • Tuberculosis (TB) screening/cotrimoxazole prophylaxis/intermittent preventive therapy (IPT) **Operational priorities** • Retention services • Adherence support	**Clinical priorities** • Sexually transmitted infection screening and treatment, family planning and access to reproductive health services • Immunization • Nutrition support • TB screening/cotrimoxazole prophylaxis/IPT **Operational priorities** • Retention services • Viral load monitoring • Adherence support • Frequency of visits • Frequency of dispensing antiretroviral therapy
Delayed	**Treatment failure**
Clinical priorities • Treatment education • Antiretroviral therapy initiation • Opportunistic infection screening, diagnosis and management (cryptococcal infections, cytomegalovirus) • TB screening, diagnosis and treatment/cotrimoxazole prophylaxis/IPT **Operational priorities** • Referral network	**Clinical priorities** • Opportunistic infection screening and management (cryptococcal infections, cytomegalovirus) • Screening and management of mental health disorders • TB screening, diagnosis and treatment/cotrimoxazole prophylaxis/IPT **Operational priorities** • Retention programmes • Viral load monitoring • Adherence support • Frequency of visits • Frequency of dispensing antiretroviral therapy

Source: Adapted from: Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: recommendation for a public health approach, second edition. Geneva: World Health Organization; 2016.

Figure taken from (UNAIDS, 2016)

Patient centred care and shared decision making in public health services

The incorporation of patient choice and presenting clients with healthcare options is different in different settings. Choice and share-decision making is quite common in high income settings or private health care institutions where service users are able to research and read about their

conditions and providers support patients to make informed decisions (Thomson & Dixon, 2006). There may also feasibly be more alternatives available to patients in higher socio-economic settings. For example, allowing patients with psychosis in Norway to choose between pharmacological and non-pharmacological treatment, within existing mental health care, was found to improve relationship between therapist and patients as well as increase motivation in their personal recovery processes (Oedegaard et al., 2020). In high income settings, it was noted that contraceptive users were offered many options of contraceptive methods by health workers from which they chose according to their efficiency, user friendliness, and side effect profile (Yeh et al., 2022).

However, in public health care in resource-constrained contexts or places where there is a very high burden of HIV, prevention and treatment interventions and models of HIV care are very much driven by global and national guidelines and algorithms. Patient choice is a routine part of some public health interventions such as family planning (Kim, Kols & Mucheke, 1998), and increasingly in HIV prevention services (Sewell et al., 2021), but plays less of a role in HIV services (Belay et al., 2021). One study (Lim et al., 2021) in the context of TB preventive therapy in a high burden setting in Uganda, found that considering patient preferences promoted completion of therapy.

There is a rise in the belief that patient choice should be part of the selection of prevention and treatment interventions in public health care (McKay et al., 2015). Faller described the deliberative model in which "both physician and patient engage in an open discussion about the values the patient could and should pursue. The physician is allowed to present his own preferences, and conflicting values are discussed explicitly" (Faller, 2003). Thus, patient empowerment is promoted and there is shared decision making since information is shared and interactive discussion is being carried out (Krist et al., 2017).

One study in Germany, (Faller, 2003) about strengthening patient participation in care showed that involving patients in care gives them some control over their personal health, they will be more satisfied with treatments, and more like to adhere to treatments leading to better outcomes. The concepts of patient-centred care, shared decision-making and patient choice are directly

interconnected and cannot be looked at independently from one another (Irvine et al., 2021). And, patient choice, through being offered options, is the cornerstone of patient-centred care. Also, without being given choices, patients cannot share a role in making decisions involving their care (Irvine et al., 2021).

Critics of shared decision-making argue that most clients reject to take part in decisions and that telling them what could go wrong in their medical care can be dangerous since they will end up refusing the treatment (Barrett et al., 2016). Moreover, it may not be possible to give them all the details of the risks and benefits of all treatment options and that when you involve patients too much in decision making, they end up asking for some expensive and unnecessary investigations and tests putting a strain on health care resources (Coulter, 1997). Studies which concentrated on shared decision making between patients and health care providers noted several barriers in the process such as time constraints, patients' beliefs and institutional inflexibility (Barrett et al., 2016; Waddell et al., 2021). However, providing choice in treatment options could therefore improve clinical outcomes and increase intrinsic motivation of patients to commit to and persevere with treatments (McKay et al., 2015).

Rationale for the proposed review

As a result of the gaps, I have mentioned above, this review will help us understand the use of patient choice in HIV prevention and treatment interventions. Through synthesising the available literature, we will enhance our understanding of how choice is being incorporated and what the evidence is for the association between having an element of choice and improved HIV prevention and treatment outcomes. The results will allow potentially effective interventions for improving management and self-management to be designed and later systematically evaluated in more in-depth studies. As more and more evidence-based strategies and models of care for HIV prevention, treatment, care and support are being discovered and introduced in public health, understanding how to incorporate patient choice into routine services will be crucial. This allows services to be more person-centred thus increasing adherence, reducing HIV-related morbidity and mortality since people will be choosing what they are comfortable with. Moreover, incorporating patient choice into routine services will increase healthcare coverage as more people become active patients.

The ultimate goal is not only about giving patients choices to various HIV interventions, but for patients to be fully included as partners in their HIV care and for patients and providers to be willing and able to collaborate to achieve optimal health outcomes. Bosire et al defined a concept called patient activation saying "This requires patients to acquire adequate knowledge, motivation, skills, and confidence to participate in their own care and manage their conditions" (Bosire et al., 2021). Patients who were more active in managing their health conditions made less use of health services compared with their less active counterparts (Bu & Fancourt, 2021). Therefore, better health management and health behaviours may help to reduce pressure on the health providers and increase their motivation to empower more PLHIV through health coaching, peer support and self-management education (Jonk et al., 2015).

REVIEW AIM

The overarching aim of this systematic review is to describe the use of patient choice in HIV prevention, treatment, care & support interventions published from Africa and evaluate whether the inclusion of choice is associated with improved health outcomes.

REVIEW OBJECTIVES

1. To describe studies in which the patient is making a choice in an HIV prevention, treatment, care or support intervention
2. To compare and contrast the HIV interventions in which patients are making a choice by HIV continuum focus area.
3. Among the studies that include a non-choice comparison group, to examine the impact of patient choice on reported health outcomes.

METHODOLOGY

Search methods for identification of studies

Detailed searches will be done on published studies in English language only. The electronic database (MEDLINE/PubMed) will be systematically searched using a comprehensive search strategy as well as MeSH, keywords and free text terms used to identify studies published from 1

January 2010 to 8 December 2023. Over the past decade there has been a rapid development and improvement in HIV treatment and prevention interventions with more opportunities to provide choice. Also, as scale up of differentiated models of care - so more options available in HIV and possibly PrEP, hence the focus on this period for review. A standardised template will be used to extract data and compare study characteristics and findings (Appendix 1).

Search strategy

The search strategy was developed in consultation with research librarians at the University of Cape Town included Medical Subject Headings (MeSH terms) and keywords related to the two main search concepts: patient choice and HIV interventions. Commonly used terms included in the search as subject headings and keywords (Table 3)

Table 3. *Search strategy*

Keywords	**Search terms**	**MeSH terms**
Patient choice	patient choice OR patient preference OR patient options OR patient alternative OR self selected	Patient preference
HIV	HIV OR human immunodeficiency virus OR human immuno-deficiency virus OR human immunedeficiency virus OR human immune-deficiency virus	HIV
Therapy	therapy OR therapies OR treatment OR interventions	Therapy
Public health	public health OR primary health OR community health	Public health Primary health care
Africa	Africa OR African OR Algeria OR Angola OR Benin OR Botswana OR "Burkina Faso" OR Burundi OR "Cabo Verde" OR Cameroon OR Cameroun OR "Canary Islands" OR "Cape Verde" OR "Central African Republic" OR Chad OR Comoros OR Congo OR "Cote d'Ivoire" OR "Democratic Republic of Congo" OR Djibouti OR Egypt OR Eritrea OR eSwatini OR Ethiopia OR Gabon OR Gambia OR Ghana OR Guinea OR	Africa

	Guinea- Bissau OR "Ivory Coast" OR Jamahiriya OR Kenya OR Lesotho OR Liberia OR Libya OR Madagascar OR Malawi OR Mali OR Mauritania OR Mauritius OR Mayotte OR Morocco OR Mozambique OR Namibia OR Niger OR Nigeria OR Principe OR Reunion OR Rwanda OR "Saint Helena" OR "Sao Tome" OR Senegal OR Seychelles OR "Sierra Leone" OR Somalia OR "St Helena" OR Sudan OR Swaziland OR Tanzania OR Togo OR Tunisia OR Uganda OR "Western Sahara" OR Zaire OR Zambia OR Zimbabwe)	
Date	From January 2010 to 8 December 2023	
Restriction	NOT discrete choice experiment	

Inclusion and exclusion criteria for this review

Published studies that met the following criteria will be included: (i) HIV prevention interventions among people at risk for HIV, and HIV treatment, or care and support interventions for people living with HIV; (ii) studies in which the patient is making a choice between options in the intervention; (iii) observational studies such as case control studies, cross sectional studies, population-based studies and experimental studies such as randomised controlled trials; (iv) interventions for people aged 15 and older (v) studies conducted in Africa; (vi) studies published in English. Studies conducted outside Africa, studies in which only stated or hypothetical choices were described, and papers written in languages other than English will be excluded. Articles published from 1 January 2010 to 8 December 2023 will be included.

Data collection

Selection of studies

Two independent authors (TP & DK) will screen titles and abstracts using the inclusion criteria above. Eligible studies will be selected and full text reviews done on them. Disagreement regarding inclusion of studies will be resolved by a third reviewer (PM). The Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) flow chart (Page et al., 2021) will

be used to show included and excluded studies and reasons for exclusion of a study will be documented. A table of studies that met the inclusion criteria will be included in the final review.

Data extraction and management

A standardised data extraction form will be developed by the student (DK) and reviewed by the supervisors (TP & PM) (Appendix 1). Two independent authors (DK & TP) will extract the data from studies using the final standardised data extraction form and disagreements between reviewers will be resolved by the third reviewer (PM). The data extraction form will first be piloted on five random studies in the inclusion list. For each study the following will be noted: author, year, setting, sample characteristics, study design, sample size, HIV continuum focus area (HIV prevention, treatment, care and support), description of the interventions/strategies including choice, choices offered and choice uptake, presence and description of a non-choice comparison including outcomes where applicable, study limitations, choice-related lesson learned.

Data analysis and synthesis

We will conduct a narrative synthesis of studies papers the inclusion criteria (Conserve et al., 2017). Narrative synthesis is used when statistical meta-analysis is not feasible due to considerable methodological diversity between papers identified. The process of data analysis and synthesis allows us to describe, analyse and draw conclusions on the research evidence found and to assess the association between patient choice and health outcomes in various HIV treatment, prevention, care and support interventions. A narrative synthesis approach will allow the researcher to synthesise and interpret evidence from multiple sources. This approach also allows the facilitation and incorporation of diverse forms of evidence into the systematic review.

To address objective 1 we will describe all included studies in a table and synthesise the relevant aspects of the included papers. To address objective 2 we will group the included papers by focus point on the continuum of HIV prevention. treatment, care and support. We will draw out any similarities and differences in how choice is offered and what choices were offered in these groups. To address objective 3 we will look at any included papers that compared outcomes between people assigned to a specific intervention and people who were offered a choice within

an intervention. We will describe any reported outcomes (the specified outcome, measure of effect and confidence interval) in the studies comparing choice to no choice. We anticipate a large amount of heterogeneity and that a meta-analysis will not be possible.

Assessment of risk of bias in included studies

A formal risk of bias assessment will be completed only for studies that report on comparison between choice and no-choice with a health outcome using the Downs and Black checklist (Downs & Black, 1998). For other studies, any missing information around the choice offered will be described to provide a sense of quality and clarity of the description.

Measure of intervention effect

Measure of intervention effect will be available only for the subset that includes effect size for choice versus a non-choice comparison, objective 3. The methodological quality of the studies with comparison was assessed using the Downs and Black checklist (Downs & Black, 1998).

Assessment of heterogeneity

We expect that the included studies will be very heterogeneous and that a meta-analysis will not be appropriate. This will therefore be a narrative synthesis.

Dealing with missing data

Missing data will be described and at this point we do not plan to contact corresponding authors of included studies for additional data. However, this may be reconsidered following completion of the extraction.

ETHICAL CONSIDERATIONS

The systematic review will use published data publicly available and there are no human subjects involved. We request a waiver of human research ethics review.

Risk and benefits

This is a desktop study. It is a low-risk study as no human subjects are involved. It will promote their welfare and support the moral rules that defend and protect the right of the recipients of

care. No harm to individuals will be done since this research is focusing on the power of clients to make rational decisions and moral choices in HIV interventions. Distributive justice of health-care resources should also be considered when patients are making choices in these public health interventions. Moreover, the potential benefits are significant as the systematic review will provide knowledge on how patient choice is incorporated in HIV prevention, treatment, care and support interventions.

TIMELINE

The review protocol development: July to October 2023

Data searches and extraction: November and December 2023

Writing up: December 2023 and January 2024

Submission: February 2024

FUNDING

No funding is required for this study.

DISSEMINATION

The results of this work will be submitted for fulfilment of the MPH mini-dissertation and manuscript will be submitted to a peer reviewed journal. Results will also be shared with relevant stakeholders including reported back to the IAS global differentiated service delivery consortium.

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APPENDICES

Appendix 1. *Data extraction table*

Study number	
Author, year	
Title	
Location	
Urban/rural	
Study period	
Study Design	
Sample size	
Study population	
HIV continuum focus area (prevention, treatment, care & support)	

Description of the intervention including choice	
Choices offered	
Description of how the choice was offered (context, by who, when)	
Uptake of the choices offered (% choosing each option)	
Any results pertaining to changes in choice uptake over time	
Choice-related lessons	
Study limitations	
Non-choice comparison presented? (Y/N) *if Y complete these questions and risk of bias assessment	
Describe the non-choice comparison group	
Reported associations between choice and the reported outcomes	

PART C: MANUSCRIPT

Patient choice in HIV prevention, treatment, care and support interventions in Africa: a systematic review.

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Keywords: Patient choice; public health; interventions; HIV/AIDS; Africa

Word count

Abstract: 302

Main text: 3856

The review meets the requirements set out in the Instructions for Authors for the Tropical Medicine & International Health – A European Journal (TMIH). The contributions of the co-authors have been noted in the acknowledgments section of this dissertation.

ABSTRACT

Introduction: Africa has the highest burden of HIV globally. A growing number of evidence-based HIV intervention are being scaled up to eliminate HIV transmission and minimise morbidity and mortality. We reviewed the published HIV literature to describe interventions in which patients are given a choice in their HIV care, and examine the impact of patient choice on reported health outcomes among studies including a non-choice comparison group.

Methods: We searched PubMed and reference lists, from 1 January 2010 to 8 December 2023. Included studies were HIV related interventions where patients were making a choice in some aspect of their care and carried out in Africa. The choice components and related results were described, and grouped by HIV continuum focus area. Measures of association were summarised for studies reporting comparison of health outcomes between choice and non-choice groups.

Results: Eleven out of 593 studies were included. Six focused on HIV prevention, four on HIV treatment and one on HIV care and support. Five studies described choices offered in routine care; six were research interventions. Choices provided included product choice, location of services, duration of dispensing and choice treatment support. Limited details were provided on the implementation of the choice intervention in most studies. In two prevention studies comparing a choice and non-choice group, pre-exposure prophylaxis coverage was significantly higher in the choice arm compared to the control. In one HIV treatment study, there was no difference in viral suppression but retention in care was significantly higher in the choice arm compared to the non-choice arm.

Conclusions: This review shows that patient choice is being offered in HIV preventative and treatment services and is allowing people to select what they need when needed. More research is required to understand how patient choice can be sustainably implemented in HIV services in high-burden and low-resource settings.

INTRODUCTION

HIV continues to be a huge burden globally, with more than 35 million people living with the disease worldwide (UNAIDS, 2023). Africa carries the greater part (60%) of that burden, mostly in the sub-Saharan region (UNAIDS, 2023). The incidence of HIV has been going down over the years as a result of scientific progress with newer antiretroviral drugs and increasing access, more funding and resources to fight HIV, and political commitment of governments (Slutkin et al., 2006). However, the prevalence of HIV/AIDS is still high estimated at approximately 65.6% in Africa (World Health Organisation, 2023) and measures need to be taken to further reduce HIV-related morbidity and mortality. Since there is no cure available and also millions are living with HIV, epidemiological concepts of elimination and eradication are not readily applicable to HIV. The Joint United Nations Programme on HIV/AIDS (UNAIDS) has established the 95-95-95 targets, which aim for 95% of PLHIV are diagnosed HIV, 95% of them to be on antiretroviral therapy (ART), and 95% of those on ART to be virally suppressed (UNAIDS & JUNP, 2023). As a result, HIV prevention, treatment, care and support interventions are needed to help achieve these goals.

There is a large and growing evidence-based toolbox of prevention, treatment, care and support strategies. These include differentiated service delivery models, integrated care models, numerous prevention strategies (such as HIV testing services (HTS), sexually transmitted infection (STI) prevention and management , treatment as prevention (TasP) in sero-discordant couples, voluntary medical male circumcision (VMMC), pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (Ministry of Health and Child Care, 2022) and adherence support interventions (such as individual/client counselling, using treatment support groups and family-centered services) (Okonji et al., 2020). However, Africa as a continent is struggling to close the gaps in the epidemic control of HIV (UNAIDS, 2023).

Alongside the growth of evidence-based interventions, there has a been a focus on people-centred care. In 2016 the World Health Organization (WHO) implemented integrated, people-centred health services to correct fragmented health systems in many countries offering poor

quality services and responding slowly to client needs (World Health Organization (WHO/OMS), 2016). The framework highlights that integrated people-centred care systems can provide meaningful comprehensive health care to all people, as well as improved access to care, and clinical outcomes (Schwarz et al., 2022). Patient empowerment was also associated with patient-centred care systems (World Health Organization (WHO/OMS), 2016). One element of people-centred health services is shared decision making and the provision of choice.

PLHIV have historically had no choice in treatment modality or delivery. There may only be one option for care available and when there are options, there is an assumption that patients are not empowered to make their own choices about their own health and health care, or exercise control over decisions about their health and that of their communities (World Health Organization (WHO/OMS), 2016). As a result, health care workers make choices for patients about their treatment options in many situations (Faller, 2003). However, patient choice and shared decision making between health care workers and patients may have a lot of benefits including better adherence to treatment, higher satisfaction with health care services, increased treatment completion rates and improved health outcomes (Lindhiem et al., 2014). Moreover, including patient choice in public health interventions may empower patients as they will be having an active role in treatment decisions (Chewning et al., 2012; Bravo et al., 2015). In most HIV intervention research studies patients are allocated to specific intervention options and no choice is given to the patients, however there is a growing interest in incorporating patient choice in HIV prevention, treatment, care and support and there is an emerging literature in this area (Camara et al., 2020). This systematic review aims to 1) describe studies in which the patient is making a choice in an HIV prevention, treatment, care or support intervention, 2) compare and contrast the HIV interventions in which patients are making a choice by HIV continuum focus area, and 3) among the studies that include a non-choice comparison group, to examine the impact of patient choice on reported health outcomes.

METHODS

This review was conducted according to the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) statement 2020 (Page et al., 2021) (Appendix A). A comprehensive search was conducted for articles in MEDLINE via PubMed published from 1 January 2010 through 8 December 2023. To identify other potentially eligible studies, we manually searched reference lists of the identified articles. The initial search was performed in December 2022 and updated in December 2023.

Search methods for identification of studies

The search strategy was developed in consultation with research librarians at the University of Cape Town included Medical Subject Headings (MeSH terms) and keywords related to the two main search concepts: patient choice and HIV interventions. Commonly used terms were included in the search as subject headings and keywords (Table 1)

Table 1. *Search strategy*

Keywords	**Search terms**	**MeSH terms**
Patient choice	patient choice OR patient preference OR patient options OR patient alternative OR self selected	Patient preference
HIV	HIV OR human immunodeficiency virus OR human immuno-deficiency virus OR human immunedeficiency virus OR human immune-deficiency virus	HIV
Therapy	therapy OR therapies OR treatment OR interventions	Therapy
Public health	public health OR primary health OR community health	Public health Primary health care
Africa	Africa OR African OR Algeria OR Angola OR Benin OR Botswana OR "Burkina Faso" OR Burundi OR "Cabo Verde" OR Cameroon OR Cameroun OR "Canary Islands" OR "Cape Verde" OR "Central African Republic" OR Chad OR Comoros OR Congo OR "Cote	Africa

	d'Ivoire" OR "Democratic Republic of Congo" OR Djibouti OR Egypt OR Eritrea OR eSwatini OR Ethiopia OR Gabon OR Gambia OR Ghana OR Guinea OR Guinea- Bissau OR "Ivory Coast" OR Jamahiriya OR Kenya OR Lesotho OR Liberia OR Libya OR Madagascar OR Malawi OR Mali OR Mauritania OR Mauritius OR Mayotte OR Morocco OR Mozambique OR Namibia OR Niger OR Nigeria OR Principe OR Reunion OR Rwanda OR "Saint Helena" OR "Sao Tome" OR Senegal OR Seychelles OR "Sierra Leone" OR Somalia OR "St Helena" OR Sudan OR Swaziland OR Tanzania OR Togo OR Tunisia OR Uganda OR "Western Sahara" OR Zaire OR Zambia OR Zimbabwe)	
Date	From January 2010 to 8 December 2023	
Restriction	NOT discrete choice experiment	

Two independent reviewers (TP & DK) screened the titles and abstracts using the inclusion criteria below. Eligible studies were selected and full text reviews. In order to be included, studies had to describe patients making actual choices within HIV prevention, treatment, or care and support interventions. From the eligible studies, data were extracted from into an excel document. Reviewers (TP & DK) discussed any disagreements in the extracted data, and a third reviewer (PM) was consulted to resolve any disputes (Conserve et al., 2017). We extracted the following data: study characteristics (author, study setting/location, study design), type of HIV intervention, study limitations, lesson learned, choice demonstrated, whether or not a non-choice comparison was included and if so, comparison of any health outcomes between choice and non-choice groups. Finally, we conducted a narrative synthesis of studies meeting the inclusion criteria (Conserve et al., 2017). Risk of bias assessments was done using the Downs and Black checklist (Downs & Black, 1998) for the studies reporting comparisons of choice and non-choice groups. A meta-analysis was not done due to considerable heterogenous nature (methodological and clinical) of the studies included in the review (Conserve et al., 2017).

Inclusion and exclusion criteria

Published studies that met the following criteria were included: (i) HIV prevention interventions among people at risk for HIV, and HIV treatment, or care and support interventions for people living with HIV; (ii) studies in which the patient is making a choice between options in the intervention; (iii) observational studies such as case control studies, cross sectional studies, population-based studies and experimental studies such as randomised controlled trials; (iv) interventions for people aged 15 and older (v) studies conducted in Africa; (vi) studies published in English. Studies conducted outside Africa, studies in which only stated or hypothetical choices were described, and papers written in languages other than English were excluded. Articles published from 1 January 2010 to 8 December 2023 were included.

Data synthesis and presentation

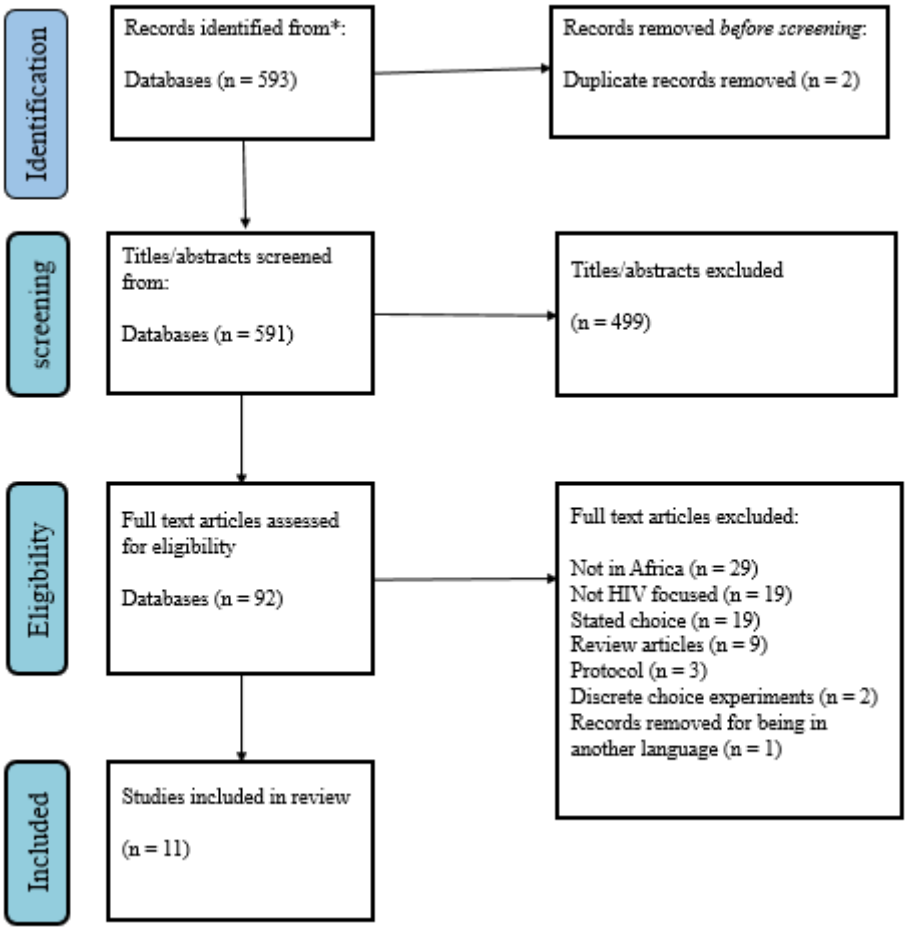
We conducted a narrative synthesis of studies meeting the inclusion criteria. The process of data analysis and synthesis allowed us to describe, analyse and draw conclusions on the available evidence describing patient choice in HIV interventions, and in a subset of studies that included a non-choice comparison group, to assess the association between patient choice and health outcomes.

RESULTS

Characteristics of included studies

The electronic database searches retrieved 593 records from PubMed. After removing 2 duplicate records, 591 records were screened (Figure 1). In total, 499 were excluded through abstract screening as they did not meet the eligibility criteria. Of 92 full text studies that were assessed for eligibility, 81 were excluded: 29 studies were not in Africa, 19 were not HIV related, 21 had stated or hypothetical choices, nine were systematic reviews, three were protocols, and one was not in English. The final sample consisted of 11 studies published between 2010 and 2023, all of which included actual patient choices in HIV prevention, treatment, care and support interventions.

Figure 1. Flow diagram of study inclusion



In the 11 included studies (Table 2), the sample size ranged from 127 participants to over 2 million participants. These articles include studies conducted in five unique countries: Eswatini (n=1), Kenya (n=6), South Africa (n=3), Uganda (n=6), and Zimbabwe (n=1). Five studies conducted a multi-site analysis. Study design types included randomised control trials, clinical crossover studies, cross sectional studies, descriptive analysis and prospective cohort studies. Four studies were conducted in urban areas only, five in rural areas only, and two were conducted in both settings. A total of six studies concentrated on HIV prevention measures. Among five studies among people living with HIV, four studies focused on HIV treatment and one study focused on care and support for people living with HIV, specifically isoniazid preventive therapy for tuberculosis.

Table 2. *Characteristics of included studies.*

Author, year	Study period	Location	Study design	Study population (sample size)	Targeted stage of HIV continuum
Adams, 2017	February 2015 to February 2016	Eswatini (rural and urban)	Prospective cohort study	People living with HIV receiving isoniazid preventive therapy (908)	HIV care and support
Ayieko, 2023	April 2021 to March 2022	Kenya and Uganda (rural)	Randomised control trial	People living with HIV (201)	HIV treatment
Foster, 2010	February 2005 to 2008 (month not mentioned)	Uganda (rural and urban)	Randomised control trial	People living with HIV (1453)	HIV treatment
Gorman, 2015	February 2002 to August 2007	Kenya (rural)	Retrospective analysis	People living with HIV (178)	HIV treatment
Kabami, 2023[1]	April 2021 to March 2022	Kenya and Uganda (rural)	Randomised control study	HIV negative participants (612)	HIV prevention
Kakande, 2023	May 2021 to July 2021	Kenya and Uganda (rural)	Cluster randomised trial	HIV negative participants (429)	HIV prevention
Koss, 2023[1]	April 2021 to July 2021	Kenya and Uganda (rural)	Randomised control trial	HIV negative participants (403)	HIV prevention
Liu, 2021	March 2016 to October 2019	South Africa (urban)	Descriptive analysis of routine program data	People living with HIV and other chronic conditions (2,069,039)	HIV treatment
Montgomery, 2019	June 2016 to June 2017	South Africa and Zimbabwe (urban)	Randomised crossover study	HIV-negative, non-pregnant, sexually active women (200)	HIV prevention
Odoyo-June, 2019	December 2017 to August 2018	Kenya (urban)	Descriptive analysis of active surveillance data	HIV negative males (3692)	HIV prevention
Radebe, 2019	October 2015 to May 2017	South Africa (peri urban)	Cross-sectional observational study	HIV negative males (127)	HIV prevention

[1]The sample in Koss et al 2023 is also included in the study population described in Kabami et al 2023

Description of choice

The choices offered in the included studies are described and presented by the targeted stage of the HIV continuum (Table 3a-c).

HIV Prevention studies

Among the six studies focused on HIV prevention (Table 3), two discussed choices that were being offered in routine care settings. These were choices of medical male circumcision (MMC) methods (surgical or ShangRing) and type of HIV self-screening test (using blood or oral fluid).

The male circumcision study was conducted as part of active surveillance of the roll-out of the ShangRing method in Kenya (Odoyo-June et al., 2019). The choice of method was offered at the participating health facilities where people routinely came to seek MMC and the choice was offered by health-care workers trained in both circumcision methods. The choice was offered at a single point in time. The study offering choice of HIV-self test (Radebe et al., 2019) took place in South Africa, and patients attending routine care received a choice of collecting tests at a facility or out of facility. The paper only described that the choice was given to patients and that they were provided with their choice of test type at the visit where they were enrolled, and at a 3 month follow up visit at which time they could make a different choice. No other details or results about how the choice was implemented were provided.

Four studies described choices in HIV prevention that were offered in a research context. One study (Montgomery et al., 2019) followed a randomised crossover design over four months, allowing participants to experience each of four different vaginal inserted prevention methods. In the fifth month the participants were asked to choose which product they accepted and preferred to use for the final month. Three papers described findings from two ongoing randomised studies (SEARCH; NCT04810650) in rural East Africa, offering various options to HIV negative participants in a person-centred, dynamic choice model for HIV prevention (Kabami et al., 2023; Kakande et al., 2023; Koss et al., 2023). In an individually randomized trial in three locations (outpatient department, antenatal care and community) and a cluster randomized trial, the following options were offered: choice of biomedical product (PrEP/PEP), location of services (clinic/out-of-clinic) and type of HIV testing modality (HIV rapid blood test and oral-based self-

testing). In the individual trial (results reported by (Kabami et al., 2023; Koss et al., 2023)), phone access to a clinician 24/7 was offered to clients, and choices were offered in research context by healthcare workers, clinical officers and nurses. However, in the cluster randomized trial (Kakande et al., 2023) choice was offered by community health workers supported by clinicians. These healthcare workers offered choice in community (Kabami et al., 2023; Kakande et al., 2023); outpatient department in clinical setting (same study sample reported in (Kabami et al., 2023; Koss et al., 2023)) and in the antenatal department in clinics (Kabami et al., 2023). Choice was offered at all clinical or study visit (Kabami et al., 2023; Kakande et al., 2023; Koss et al., 2023). In all studies, choice of intervention options varied over time. For example, in (Kakande et al., 2023) in the choice arm selection of PrEP rose to 48% from 40% at baseline by week 48, while selection of PEP fell to 24% from 46% at baseline. Also, clients who chose self-testing increased to 71% from 52% at baseline and those who chose to be seen at an off-site location increased to 99% from 93%.

3.2.2 HIV treatment studies

Among the four studies which focused on HIV treatment (Table 3b), two (Gorman, Martinez & Olson, 2015; Liu et al., 2021) discussed choices that were offered in routine care. The choices were options to pick up medication at various points (independent pharmacies, community-based clubs or fast lanes at health facilities) and options on location to continue care after HIV diagnosis (at the semi mobile clinics or hospital). In the South African study (Liu et al., 2021) the choice was offered by routine health-care workers at facilities that were participating in the Central Chronic Medicines Dispensing and Distribution (CCMDD). The choice of pick-up points varied over a one-year period. The proportion of active clients selecting clinic-based fast lanes decreased to 52% from 55% while the proportion choosing external pick-up points (PuPs) rose to 35% from 31% and outreach & and adherence clubs dropped to 13% from 14% over a period of 1 year. In rural Kenya (Gorman, Martinez & Olson, 2015), the choice of either continuing HIV care in the hospital or using the semi mobile clinics was given by either nurse, clinical officer or counsellor at a single point in time after HIV diagnosis. Overall, 70% chose the semi-mobile clinic. In subgroup analyses, more women than men chose to continue HIV care in hospitals and semi mobile clinics (27% versus 73%, respectively). This study did not provide details on who gave the participants the choice or how the choice was provided.

Two HIV treatment studies described choices that were offered in a research context. In a study in Kenya (Foster et al., 2010) newly diagnosed HIV patients enrolled in a trial were offered to choose a medication companion when initiating ART. The choice was given at one point in time by study clinicians either at the facility or in the participants homes. Relatives/household members (45%), biological children (33%) and spouse/partner (18%) were the most commonly selected medication companions. More women than men chose a medication companion under 21 years of age. In a study in rural Kenya and Uganda focused on supporting mobile people living with HIV (Ayieko et al., 2023), also part of the SEARCH randomised trials of dynamic choice, the study mobility coordinator at each clinic offered participants a choice of options to use during times of mobility. Choice was offered at baseline and at all routine visits. Choice of intervention options were a travel pack, out-of-clinic refills, longer ART dispensing or transfers from local clinics to out-of-community HIV clinics. Participant choices varied over time. The travel pack was the most popular intervention component followed by longer refills and out-of-clinic refills.

3.2.3. HIV care and support studies

Only one study in Eswatini (Adams et al., 2017)described a choice in an HIV care and support intervention. Choice was offered in HIV care facilities where routine out-patient HIV and TB care is provided (Table 3c). Four nurses and a trained peer educator offered people living with HIV options at each HIV care facility to have their isoniazid preventive therapy (IPT) delivered to them, either at the facility, in the community or through peer-supported delivery. Participants were given the choice to switch IPT delivery models throughout the six months IPT course. The majority of clients (87.8%) chose the facility-based model and the rest selected the community-based model at baseline. No participants selected peer delivery. Participants were free to switch between models at any time during their follow-up. Most patients (92.9%) did not change their IPT course. Of the (7.1%) who changed delivery models, (95.3%) switched to the facility-based model from the community-based. The majority (89.1%) switched models only once. Only (7.8%) switched twice and (3.1%) switched thrice.

Table 3a. *Description of choices offered to study participants – HIV prevention.*

Author, year	Choices offered	Description of how choice was offered	Implementation context	Choice uptake	Changes in choice uptake over time	Presence of non-choice comparison
Kabami, 2023[1]	1. Prevention product (PrEP or PEP) 2. Service location (clinic or out-of-clinic) 3. HIV testing modality (HIV rapid blood test or oral-based HIV self testing)	Choice was offered by clinical officers and nurses to persons at risk of HIV in antenatal clinic (ANC), outpatients department (OPD) and in the community at each clinical visit	Research	1. At baseline, 98% of ANC, 84% of OPD and 40% of community participants selected PrEP. Selection of PEP was 46% in the community 2. Overall, 35% of clients preferred off-site visits 3. 38% of participants chose oral HIV self-testing (HIVST) modality	1. At week 24, 100% of ANC, 86% of OPD and 50% of community participants selected PrEP. Selection of PEP was 23% in the community; 3% in the ANC and 11% in the OPD setting 2. Off-site visits rose to 65% 3. Interest in HIVST rose to 58% at week 24	No
Kakande, 2023	1. Prevention product (PrEP or PEP) 2. Service location (clinic or out-of-clinic) 3. HIV testing modality (HIV rapid blood test or oral-based HIV self testing)	Participants were offered choices in the community by community health workers at baseline and follow up visits	Research	1. At baseline, PrEP was selected by 40%, while PEP selection was 46% and 2. 52% chose HIV self-testing; 3. 93% of clients opted for an off-site visit rather than clinic	1. By week 48, selection of PrEP rose to 48%, while selection of PEP fell to 24%; 2. clients who chose self-testing increased to 71%, 3. participants who chose to be seen at an off-site location increased to 99%	Yes
Koss, 2023[1]	1. Prevention product (PrEP or PEP) 2. Service location (clinic or out-of-clinic)	HIV negative participants were offered choices in the OPD at each study visit (enrolment; weeks	Research	At baseline (84%) selected PrEP and (9%) selected PEP, 26% chose HIVST and 8% opted for out of facility visit	Over 48 weeks, 86% of participants ever chose PrEP and 15% ever chose PEP; the choice of HIVST rose to	Yes

	3. HIV testing modality (HIV rapid blood test or oral-based HIV self testing)	4, 12, 24, 36, 48) by clinical officers and nurses			51%, and choice of out-of-facility visits rose to 52%	
Montgomery, 2019	Choice between four vaginally delivered HIV prevention methods (Polyurethane vaginal ring, vaginal film, vaginal gel, vaginal insert)	Participants tried each of the four methods over four months (crossover design) and were offered a choice of preferred method for the fifth month. The choice was offered at the research site by health workers	Research	At month five, after trying each product, the film, ring, insert and gel were selected by 29%, 28%, 26% and 16% respectively	Nil Actual choice was only given at one time but this was different from the baseline stated preference where 29% chose the film, 28% chose the ring, 26% chose the insert, and 16% chose the gel	No
Odoyo-June, 2019	ShangRing under injectable local anaesthetic or conventional surgical circumcision	Choice was offered by voluntary medical male circumcision (VMMC) providers at the sites to clients presenting for VMMC services	Routine care	At baseline 1,079 (29.2%) chose ShangRing while 2,613 (70.8%) opted for surgical circumcision	Nil - choice offered at single time	No
Radebe, 2019	Collecting HIV Self Screening test kits at the clinic, at a pharmacy, or in community setting	HIV negative participants were given HIV self-test kits at facility or out of facility by a trained HIV test counsellor at enrolment and 3-month follow up visit	Routine care	"At baseline 49.3% preferred to collect HIVST kits at a community-based organisation (CBO) and 42.7% at a clinic, with 8% preferring a pharmacy"	Nil - change is not described in the paper	No

[1]*note the OPD sample is described in both papers while the ANC and community group are described only in Kabami et al*

Table 3b. *Description of choices offered to study participants – HIV treatment*

Author, year	Choices offered	Description of how choice was offered	Implementation context	Choice uptake	Changes in choice uptake over time	Presence of non-choice comparison
Ayieko, 2023	1. Travel pack with 14-day ART supply 2. "hotline" phone and [1]SMS contact with mobility coordinator 3. Assistance to get refills at out-of-community clinics 4. Longer ART dispensing (up to 6 months) 5. Out-of-facility refills 7. Transfers from the local clinic to out-of-community HIV clinics assistance	Choice offered by the mobility coordinator at baseline and all routine visits to support the participants engagement in HIV care if travelling	Research	At week 0: Travel pack was chosen by 91%, longer ART refills by 30%, Off-site refill 41%, Out-transfer 2%, Hotline 82%, Emergency ART 38%, Travel checklist 71% and ART packaging 42%	"The choice of intervention options varied over time, with the travel pack being the most popular intervention component, followed by longer refills and out-of-clinic ("off-site") refills" No specific data given in the paper	Yes
Foster, 2010	All patients were requested to appoint a medication companion (MC) who can be a friend or family like their spouse, children, mother, father, sister, nephew, or aunt.	Newly diagnosed PLHIV were given a choice of who to be their MC when initiating ART. The choice was offered by clinical staff as part of a trial which allocated people to either facility-based or home-based HIV care	Research	Overall, 4% of the participants chose neighbour/friend, 18% chose spouse/partner; 33% chose biological child and lastly 45% chose other relatives/household member	Nil - choice offered at single time	No
Gorman, 2015	choice of location of care (semi-	Clients who were diagnosed with HIV by either a	Routine care	Fewer men (38.9%) than women (61.1%) chose to continue	Nil - choice offered at single time	No

	mobile clinic or regional hospital)	nurse, a clinical officer, or a social worker were registered at the district hospital and were given a choice to continue care either at hospital or semi mobile clinics		care at the hospital while of those who chose to continue care at the semi-mobile units majority (73.4%) were women and 26.6% were men		
Liu, 2021	Choice to collect their medication at community-based outreach clubs or adherence clubs, external pick-up points (PuP);or fast lanes at health care facilities	PLHIV (people living with HIV) were referred to register into the program by health workers during their routine clinical visit	Routine care	In Nov 2018, 55% of active patients relied on clinic-based fast lanes, 31% were using external PuPs and 14% were using outreach and adherence clubs	Those relying on clinic-based fast lanes fell to 52% while the proportion using external PuPs rose to 35% and outreach & and adherence clubs dropped to 13% over a period of 1 year	No

[1]*SMS – Short Message Service or texting in Ayieko, 2023*

Table 3c. *Description of choices offered to study participants – HIV care and support*

Author, year	Choices offered	Description of how choice was offered	Implementation context	Choice uptake	Changes in choice uptake over time	Presence of non-choice comparison
Adams, 2017	choice of [1]IPT delivery model (facility-based, community-based or peer supported model)	Participants were given a choice by four study nurses and a trained PLHIV peer educator to select an IPT delivery model during routine clinical visit	Routine care	87.8% clients chose the facility-based model while 12.2% opted for the community-based model. However, the peer-support model was never selected.	Most patients (92.9%) did not change their IPT course. Of the (7.1%) who changed delivery models, (95.3%) switched to the facility-based model from the community-based. The majority (89.1%) switched models only once. Only (7.8%) switched twice and (3.1%) switched thrice.	No

[1]*IPT – Isoniazide Preventive Therapy*

3.3 Comparison of outcomes between choice and non-choice groups

Only three (Ayieko et al., 2023; Kakande et al., 2023; Koss et al., 2023) of the studies included in this review presented data comparing a group receiving a choice to a group who did not receive a choice (Table 4). In (Ayieko et al., 2023), comparing mobility support for people on ART in rural parts of Kenya and Uganda, it was noted that HIV viral suppression at 48 weeks was almost the same in both trial arms 85% viral in the intervention group vs. 86% in the control group, for a risk ratio (RR) of 0.99 (95% CI: 0.88 to 1.10; P = 0.595) and retention in HIV care over 48 weeks was more in the intervention group (99%) vs. (93%) in the control group participants; RR: 1.06 (1.02–1.1), P<0.001. This study also found that there were larger effect sizes among people with baseline viral non-suppression and who were very mobile. Lastly, ART possession over 48 weeks was more among the intervention participants (98%) vs in the control (91%); RR: 1.07 (95% CI: 1.03 to 1.11), P<0.001.

In (Kakande et al., 2023), who compared biomedical prevention coverage in Kenya and Uganda, it was noted that the average prevention coverage was 36.6% in the choice group vs 0.9% in the standard of care (SoC) group showing a 35.7% rise (95% CI: 27.5-43.9, p<0.001). In (Koss et al., 2023) who compared proportion of follow-up covered by biomedical products (PrEP or PEP), it was discovered that the mean follow-up time covered by biomedical products (PrEP or PEP) was higher in the choice group (47.5%) than in the control group (18.3%), a difference of 29.2% (95% CI 22.7-35.7%; p<0.001).

In a risk of bias assessment in these three studies (Supplementary Table 1), all the three studies were rated overall as having ‘good’ quality with a score between 20 and 25 out of 28 (with 28 representing best highest quality). Moreover, in the three studies adequate adjustment for confounding in the analyses was made to produce good results (Downs & Black, 1998).

Table 4. *Comparison of outcomes between choice and non-choice groups*

Author, year	**Description of the groups compared**	**Outcomes assessed**	**Reported associations between choice and the reported outcomes**
Ayieko, 2023	Clients randomised to the control group received routine care from the country Ministries of Health, which was 3 months supply of ART, adherence counselling for PLHIV with virological failure on last viral load measurement, and transfer to another clinic on patient request. Clinicians were not given any special training or instruction Choice was offered by the mobility coordinator at baseline and all routine visits to support the participants randomised to the intervention group engaging in HIV care if travelling	Viral suppression Retention in care ART possession	HIV viral suppression at 48 weeks was almost the same in both trial arms 85% viral in the intervention group vs. 86% in the control group, for a [1]RR of 0.99 (95% [2]CI: 0.88 to 1.10; P = 0.595) Retention in HIV care over 48 weeks was more in the intervention group (99%) vs. (93%) in the control group participants; RR: 1.06 (1.02–1.1), P<0.001 ART possession over 48 weeks was more among the intervention participants (98%) vs in the control (91%); RR: 1.07 (95% CI: 1.03 to 1.11), P<0.001
Kakande, 2023	Clients at risk for HIV in villages in the control group, were sent to local clinics for routine HIV prevention services such as HIV screening by a Ministry of Health (MoH) worker using standard tools, PrEP or PEP if indicated and supply of HIVST kits if requested and available [3]CHWs In villages in the intervention group, provided the ([4]DCP) model while supported by clinicians. CHWs continued doing their MoH duties in both groups	Biomedical prevention coverage	"14% of participants in the choice group were covered for 90% of follow-up while 98% of control participants had no coverage during follow-up. The intervention significantly improved prevention coverage across key subgroups" "Average prevention coverage was 36.6% among intervention participants versus 0.9% among control participants for an absolute increase of 35.7% (95% CI: 27.5–43.9, p<0.001)"
Koss, 2023	HIV negative clients in [5]SOC group were referred to standard HIV prevention services available at the health facility at the enrollment visit. These included PrEP eligibility screening based on country guidelines and a blood-based HIV test. PrEP was given as a month supply at baseline and	Proportion of follow-up covered by prevention method	Intervention effect sizes were similar among women and men (28.2% and 31% higher coverage in the choice arm, respectively). Effect sizes were also similar among subgroups, including youth ages 15-24 years, persons using alcohol, and by country.

	for a 1- to 3-month supply at follow-up visits. PEP was provided in situations of gender-based violence or occupational exposure. Community-based visits, HIV self-testing and provider training in patient-centred care were not part of SoC.		Mean follow-up time covered by PrEP/PEP was (47.5%) in the choice group vs. SOC (18.3%); difference=29.2%. 64.9% of follow-up time during periods of HIV risk was covered by PrEP or PEP in the choice group vs. 26.3% in SOC (difference 38.6%).

[1]RR – risk ratio; [2]CI – confidence interval; [3]CHWs – community health workers; [4]DCP – dynamic choice HIV prevention; [5]SOC – standard of care

DISCUSSION

This review highlights that choices are being offered in HIV prevention, treatment, care and support interventions in Africa. The published literature mostly reflects choice in research contexts. The whole spectrum of prevention, treatment, care and support was included 1) to see to what extend is choice being used in HIV interventions, 2) to see where is choice mostly used in the spectrum and, 3) to show the gaps in areas where choice is not being used and so that more studies can be carried out in those areas. Some of the advantages of this approach are it allows us to see that factors surrounding choices in prevention services are different from those surrounding choices in treatment interventions and that the value of choice is different at the two ends of the HIV spectrum.

The findings show that choices vary between individuals and within individuals over time, highlighting the need for services that move away from a "one-size-fits-all" approach. In order to improve quality and access to healthcare, many countries are taking the patient-centred care approach as it provides care that is respectful of, and responsive to, individual patient preferences, needs and values (Camara et al., 2020). The need for a patient-centred approach is supported by our findings as the included studies showed that people changed their minds over time and different subgroups of people made different choices, reinforcing the idea that a one-size-fits-all approach for all patients at all times is not the best idea. Some of the reasons why participants changed their choices of prevention method were safety, convenience, availability, cost to access and user friendliness of the options provided (Montgomery et al., 2019).

Providing multiple options and offering informed choices may be complicated for service delivery, however in the 11 studies included, only seven provided clear descriptions of how the choice was offered and the implementation considerations around offering choices in HIV prevention, treatment or support services. Shared-decision making, whereby the provider has to discuss with the patient what options are available at the health facility, benefits and risks of each option and then making a choice based on patients' beliefs, has helped to uncomplicate service delivery by addressing the cost and safety of involving patients in their care.

Some studies did not clearly specify who was offering the choices to participants, how information was provided to inform the choice, and how much time was taken. Although choices are routinely offered in health care, in high burden settings it may be complex to offer an informed choice. One multilevel analysis (Tsega et al., 2022) assessing the pooled prevalence of informed choice of contraceptive methods in Sub-Saharan Africa showed that informed choice low with 49.47% pooled prevalence (95%CI: 44.33, 54.62%). Qualitative data from South Africa found that

postpartum women were given biased advice regarding contraception by healthcare workers or were given injectable contraceptives without full informed consent (Towriss et al., 2019). Therefore, further research is needed to inform how informed choice can be offered in routine HIV care in a way that is feasible for providers and gives patients valuable options.

This review only found three studies which included direct comparison of a choice and non-choice group. In all three studies, including choice improved outcomes of retention and coverage suggesting that choice seems to be a promising approach and has the potential to improve outcomes (Zolkefli, 2017). However, all the studies presented, limited data are provided on the implementation of choice. Some of the comparison studies in this review highlighted that some subgroups benefited more from the choice intervention than others, including high risk groups such as mobile populations and men who have sex with men (Radebe et al., 2019; Ayieko et al., 2023). Differentiated service delivery models are now widely implemented and offer some flexibility to patients, however these models are frequently only available to stable patients (Huber et al., 2021; Okere et al., 2021). Populations considered high risk groups may benefit greatly from including choice and flexibility in their care.

One key concept of patient-centred care is patient activation whereby patients' confidence, skill and knowledge are used to address their health care needs (Hibbard & Greene, 2013). Most studies did not address this except for (Ayieko et al., 2023) where patients were given a travel pack with 14-day ART supply and assistance to get refills at out-of-community clinics by the mobility coordinator as these patients had the skill and knowledge to manage their conditions while they were mobile. Patient empowerment, which is a more active involvement of the patient, has been noted to be a promising route to continue engaging PLHIV in care (Wilson et al., 2018). These mobile patients were further empowered by staying in contact with the mobility coordinator over the phone. Patient empowerment has been shown to lead to improved health seeking behaviours by creating active patients (Leonard, 2014) and better outcomes in health (Chen et al., 2016).

These results should be considered with the following limitations in mind. We only reviewed published literature in PubMed and may have missed publications from other sources. Particularly routine HIV care choices may not be in the published literature. Further research exploring grey literature, program guidelines and talking to providers is necessary to better understand how choice is being incorporated in routine HIV services. Search strategy used was narrow thus missing a number of articles that could have been found. Using the search string "NOT discrete choice experiment" might have unintentionally excluded papers that described a discrete choice experiment followed by implementation of choice. There was a large amount of heterogeneity in

the included studies and their reported outcomes so it was not possible to conduct a pooled analysis of the association between choice and health outcomes. Not all included results (only 3 out of 11 studies) were assessed for risk of bias, therefore this study does not strictly conform to the criteria for a systematic review. The results described were based on what was available in the papers and additional data were not requested from authors. The included studies presented several limitations including small sample sizes, a lack of participant blindness and in some included studies it is not very clear what proportion of patients chose an offered intervention option. A multicomponent intervention was also a challenge in some studies, making it difficult to parse out individual component effects. Self-reported outcomes in some studies were always subject to social desirability and recall bias. Lastly, this review was limited to articles written in English, there might be other studies in other languages which also focused on patient choice in HIV interventions.

CONCLUSION

In conclusion, this review has shown that patient choice is being offered in a wide range of HIV preventative services and is allowing people to select what they need when needed. Patient choices are increasingly important in designing intervention programs that are patient centered. More research is required to understand the impact of choice and how patient choice can be sustainably implemented in more HIV treatment, care and support services in high-burden and low-resource settings.

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Author contributions UCT librarians developed the initial search strategy and completed the initial search, DK and TP completed data extraction for the selected articles and TP updated the search; DK completed the synthesis of the results and wrote the manuscript with guidance from TP and PM.

Conflict of interest The authors have no conflicts of interest to declare.

Data Availability Electronic search using search terms was done on PubMed to identify the included studies.

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PART D: APPENDICES

Appendix A

PRISMA-P 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Page 1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Page 3
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Page 25
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 26
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Page 28
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Page 26
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Page 26
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Page 28
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Page 28
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Page 29
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Page 30
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Page 30
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	n/a
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Page 57
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	n/a
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Page 51-55
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	n/a
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	n/a
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	n/a
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	Page 66
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	n/a
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Page 46
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Page 46
Study characteristics	17	Cite each included study and present its characteristics.	Page 47
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Page 56
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Page 57
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	n/a
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	n/a
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	n/a
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	n/a
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	n/a
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	n/a
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Page 60
	23b	Discuss any limitations of the evidence included in the review.	Page 60
	23c	Discuss any limitations of the review processes used.	Page 60
	23d	Discuss implications of the results for practice, policy, and future research.	Page 60
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	nil
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	nil
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	nil
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Page 60
Competing interests	26	Declare any competing interests of review authors.	Page 61
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Page 30

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

Appendix B

Supplementary Table 1. Results of the Methodological Evaluation using the Down and Black checklist

Article Citation	Reporting Score (Out of 11)	External Validity Score (Out of 3)	Bias Score (out of 7)	Confounding Variable Score (Out of 6)	Effect Size Score (Out of 1)	Total Score (Out of 28)
Ayieko et al. (2023)	10	3	5	6	1	25
Kakande et al. (2023)	8	3	5	5	1	22
Koss et al. (2023)	8	3	5	6	1	23

Methodological Evaluation

The methodological quality of each paper was evaluated by each reviewer independently, with the help of the modified Downs and Black (1998) checklist (see Appendix B). The reviewers discussed any disparities in the scores and reached total agreement for each study.

The inter-rater agreement was determined by calculating the intraclass correlation coefficient (ICC) using R studio (2021). The ICC is a measure of the reliability or consistency of measurements taken by different raters. Values range from zero to one and higher values mean level of agreement among the raters is high. The ICC (A,1) value was 0.696 (95% CI: -0.025 to 0.989, $p < .001$), showing that the two independent reviewers were in agreement at higher level.

Appendix C

Modified Downs and Black (1998) Checklist

Item	Criteria	Range			Total
	Reporting				0
1	Is the hypothesis/aim/objective of the study clearly described?	yes (1)	no (0)	-	
2	Are the main outcomes to be measured clearly described in the Introduction or Methods section?	yes (1)	no (0)	-	
3	Are the characteristics of the patients included in the study clearly described?	yes (1)	no (0)	-	
4	Are the interventions of interest clearly described?	yes (1)	no (0)	-	
5	Are the distributions of principal confounders in each group of subjects to be compared clearly described?	yes (2)	partial (1)	no (0)	
6	Are the main findings of the study clearly described?	yes (1)	no (0)	-	
7	Does the study provide estimates of the random variability in the data for the main outcomes?	yes (1)	no (0)	-	
8	Have all important adverse events that may be a consequence of the intervention been reported?	yes (1)	no (0)	-	
9	Have the characteristics of patients lost to follow-up been described?	yes (1)	no (0)	-	
10	Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?	yes (1)	no (0)	-	
	External Validity				0
11	Were the subjects asked to participate in the study representative of the entire population from which they were recruited?	yes (1)	no (0)	u (0)	
12	Were those subjects who were prepared to participate representative of the entire population from which they were recruited?	yes (1)	no (0)	u (0)	
13	Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?	yes (1)	no (0)	u (0)	
	Internal Validity - Bias				0
14	Was an attempt made to blind study subjects to the intervention they have received?	yes (1)	no (0)	u (0)	
15	Was an attempt made to blind those measuring the main outcomes of the intervention?	yes (1)	no (0)	u (0)	
16	If any of the results of the study were based on "data dredging", was this made clear?	yes (1)	no (0)	u (0)	
17	In trials and cohort studies, do the analyses adjust for different lengths of followup of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls?	yes (1)	no (0)	u (0)	
18	Were the statistical tests used to assess the main outcomes appropriate?	yes (1)	no (0)	u (0)	
19	Was compliance with the intervention/s reliable?	yes (1)	no (0)	u (0)	
20	Were the main outcome measures used accurate (valid and reliable)?	yes (1)	no (0)	u (0)	
	Internal validity – confounding (selection bias)				0
21	Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?	yes (1)	no (0)	u (0)	
22	Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?	yes (1)	no (0)	u (0)	
23	Were study subjects randomized to intervention groups?	yes (1)	no (0)	u (0)	
24	Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?	yes (1)	no (0)	u (0)	
25	Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?	yes (1)	no (0)	u (0)	
26	Were losses of patients to follow-up taken into account?	yes (1)	no (0)	u (0)	
27	Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?	present (1)	not (0)	-	
	DOWNS & BLACK OVERALL TOTAL				0

Appendix D

UCT Waiver of Ethical Approval

School of Public Health
Departement Openbare Gesondheid
Isikolo Sempilo Yoluntu

UNIVERSITY OF CAPE TOWN
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15 January 2024

STUDENT NUMBER: KNGDES001

Dear Dr Desire Kanganga,

Please be advised that this protocol has been reviewed by the School of Public Health Departmental Research Committee (DRC), agreeing that the study does not require Human Research Ethics Committee (HREC) approval.

Title: Patient choice in HIV prevention, treatment, care and support interventions in Africa: a systematic review

Please upload this to Peoplesoft in the 'Copy of Ethics Approval Letter' section when you do your Intent to Submit.

Kind regards,

Patience Nyakato
Co-Chair: Departmental Research Committee School of Public Health

Appendix E

Second Search

("Choice Behavior"[Mesh] OR choice OR preference OR option* OR alternative* OR self-selection OR "self selection")
AND ("HIV"[Mesh] OR HIV OR "human immunodeficiency virus")
AND ("Antiretroviral Therapy, Highly Active"[Mesh] OR ART OR antiretroviral OR Therap* OR treatment* OR intervention* OR "Primary Prevention"[Mesh] OR "Pre-Exposure Prophylaxis"[Mesh] OR prevention* OR "pre exposure" OR pre-exposure OR prophylaxis OR support OR care)
AND ("public health" OR "primary health" OR "community health" OR "primary care" OR ("Public Health"[Mesh]) OR "Primary Health Care"[Mesh]) AND ("Africa"[Mesh] OR "Africa South of the Sahara"[Mesh] OR Africa* OR Algeria* OR Angola* OR Benin OR Botswana OR "Burkina Faso" OR Burkina OR Burundi OR "Cabo Verde" OR Cameroon OR Cameroun OR "Canary Island*" OR "Cape Verde" OR "Central African Republic" OR CAR OR Chad OR Comoros OR Congo OR "Cote d'Ivoire" OR "Democratic Republic of Congo" OR Djibouti OR Egypt OR Eritrea OR eSwatini OR Ethiopia OR Gabon OR Gambia OR Ghana OR Guinea OR Guinea- Bissau OR "Ivory Coast" OR Jamahiriya OR Kenya OR Lesotho OR Liberia OR Libya OR Madagascar OR Malawi OR Mali OR Mauritania OR Mauritius OR Mayotte OR Morocco OR Mozambique OR Namibia OR Niger OR Nigeria OR Principe OR Reunion OR Rwanda OR "Saint Helena" OR "Sao Tome" OR Senegal OR Seychelles OR "Sierra Leone" OR Somalia OR "St Helena" OR Sudan OR Swaziland OR Tanzania OR Togo OR Tunisia OR Uganda OR "Western Sahara" OR Zaire OR Zambia OR Zimbabwe OR sub-saharan or "sub Saharan")

The information source is MEDLINE and the platform/service provider used to search the particular database is PubMed); all planned limits (date – from 2010/1/1 - 2023/12/8 & language – English); and the number of records retrieved by the search - 3,968 results.

Search conducted on 17/06/2024

Appendix F

Summary Table of Limitations

Author, year	Methodological concerns
Adams, 2017	There is no comparison with non-choice group. Interview data were captured by open-ended survey response, and not recorded, which may have limited verbatim responses thus limiting generalization and interpretation of the results. no comparison with non-choice, no descriptive of how choice was offered….
Foster, 2010	This study did not measure the impact of the medicine companion on outcomes. Direct observation of therapy was not stressed in this model of support. There is no comparison with non-choice group.
Gorman, 2015	This study did not provide details on who gave the participants the choice or how the choice was provided. There is no comparison with non-choice group.
Kabami, 2023	Short duration of follow-up, reliance on self-report and recall bias. There is no comparison with non-choice group.
Liu, 2021	There is no comparison with non-choice group. The study focuses on the Central Chronic Medicines Dispensing and Distribution expansion but does not assess whether or how the program contributed to patient-level clinical outcomes and pursuit of the 95-95-95 benchmarks. It is not very clear what proportion of patients chose health facility fast lane, independent pharmacies or community clubs when the study started in 2016.
Montgomery, 2019	Product preference and self-reported use data may have been subject to social desirability bias. There is no comparison with non-choice group.
Odoyo-June, 2019	There is no comparison with non-choice group. The uptake of the ShangRing is based on clients who came for Voluntary Medical Male Circumcision at the sites monitoring adverse reactions to the ring. Reasons for not choosing ShangRing were not recorded. Results for those who chose the standard of care was not recorded and explained.

Radebe, 2019	Small sample size, was used which limits our ability to generalise findings to the entire population of men who have sex with me in South Africa. Self-reported outcomes are always subject to social desirability and recall bias. No other details or results about how the choice was implemented were provided. There is no comparison with non-choice group.