A systematic review of the assessment of out-of-pocket payment removal policies in reducing the economic burden caused by direct and indirect costs of HIV service utilization in South Africa

A mini dissertation submitted in partial fulfilment of the requirements for the degree.

Master of Public Health in Health Economics

By

Student: Hlombekazi Sybil Majokweni

(MJKHLO001)

Supervisor: Professor Edina Sinanovic

Health Economics Unit and Division

School of Public Health and Family Medicine

University of Cape Town

November 2022

PREAMBLE

PLAGIARISM DECLARATION

I, *Hlombekazi Sybil Majokweni*, hereby declare that the work on this dissertation is based on my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

I empower the university to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signature: Signed by candidate

Date: 08 November 2022

DEDICATION

This project is dedicated to my father and my late mother.

It is for policymakers and health care workers to always consider the basic needs and health rights of the people we aim to serve.

ABSTRACT

Background: The call for universal health coverage (UHC) has led to some policy introductions such as the removal of out-of-pocket payments (OOPs) in the form of user fees at point of care in primary health facilities in South Africa. The cost of healthcare for patients is not only a barrier to access and utilisation but can also lead to catastrophic spending and impoverishment. For people living with HIV (PLWH), health expenses can threaten their financial wellbeing due to HIV treatment requiring multiple health visits and other health-related costs. We examine how the UHC policy of user fee removal has contributed to reducing the economic burden of HIV/AIDS for PLWH and their households.

Methods: Searches were conducted on Africa Wide, CINAHL, EconLit, Health Source, PsycInfo, PubMed and Web of Science. We included quantitative and qualitative articles that reported costs of HIV service utilization or reported impoverishment and catastrophic health expenditure (CHE) as part of their outcomes. We reviewed and extracted data that would assist in answering the review question and reported on the total cost of utilization and its impact on PLWH.

Results: We found 12 eligible articles. The reviewed data showed that PLWH spent a substantial amount of money on transport, additional care such as private doctors, traditional healers, and special food showing that user fee removal alone is insufficient for financial protection. People borrowed money, took interest bearing loans and sold assets to cover healthcare expenses. PLWH experienced CHE across various thresholds, and people in the rural areas had more odds of CHE compared to those in urban areas. Additional care outside of the public health system and transport were drivers of CHE and impoverishment.

Conclusion: The UHC policy of user fee removal at point of care has been beneficial in reducing the economic burden of HIV/AIDS service utilization for people living in close proximity to the primary healthcare facilities and those who receive care in well-resourced facilities. However, the same cannot be said about those who have to travel long distances to health facilities and are forced to seek additional care for their health needs to be sufficiently met.

ACKNOWLEDGEMENTS

I am grateful to my supervisor, Professor Edina Sinanovic for her expertise, guidance, and support throughout the review process.

Ms Namhla Madini at the Bongani Mayosi Health Sciences Library for her assistance and input in search strategy development and reference management. My line manager and colleagues for their understanding and giving me time to work on my thesis. Thank you to my family and friends who availed themselves to advise and encourage me when I needed strength.

To God, and the power that exists within me to empower and sustain me, be the glory!

Table of Contents

Tables and Figures

Tables

Figures

List of Abbreviations

UHC	Universal Health Coverage
WHO	World Health Organization
LMIC	Low-and middle – income countries
OOP	Out-of-pocket payments
HIV	Human immunodeficiency virus
ART	Antiretroviral treatment
CHE	Catastrophic Health Expenditure
TB	Tuberculosis
PLWH	People living with HIV
NGOs	Non-governmental Organizations

PART A: RESEARCH PROTOCOL

INTRODUCTION

The World Health Organization (WHO) advocates for universal health coverage (UHC) which is defined as a system that advocates for equal health access for all individuals and communities without suffering financial hardship (World Health Organization, 2021). Guided by this framework, low- and middle-income countries (LMICs) developed health finance systems in a bid to attain UHC. Due to the latter, several reforms have been proposed, one of which was the abolishment of out-of-pocket payments (OOPs) in the form of direct payments at the point of care (Kutzin, 2013). The reform has been mainly driven by the notion that barriers to health access were mainly financial, especially OOPs at the point of care (Watson, et al., 2016). Out-of-pocket payments for health are defined as payments made directly to healthcare provider by the clients at the point of care (Nyarko, et al., 2021).

Background to the study

Prior to the period of OOPs abolishment, the World Bank was in favour of user fees, as they deemed to generate funds for health, reduce the demand on services because people would only utilize services when in need, and fees paid in urban communities could be used to subsidize those in disadvantaged communities (Yates, 2009). Contrary to these expectations, evidence indicated that introduction of OOPs negatively affected the poor and increased inequality in healthcare (Honda, 2006). At the 2013 World Health Assembly, the World Bank's president addressed the issue of user fees at point of care as a cause of financial hardship for the poor and called on governments to find other health financing means that do not lead to impoverishment (The World Bank, 2013). Global research shows that an estimated 100 million people from 25 million households are driven into poverty due to OOP healthcare expenditure, and in LMICs there was a significant increase in household healthcare expenditure between the year 2000 and 2017 (Borde, et al., 2022). Countries in Sub-Saharan Africa were among those who had implemented user fees at point of care but after the universal health coverage call, some would eventually consider policies of removal particularly due to their cause of low health service utilization and poor health outcomes (Ejughemre, 2013).

South Africa is among many of the countries in Sub-Saharan Africa that abolished user fees at the point of care through provision of free health care at the primary care level to increase accessibility and utilization of services (Coovadia, et al., 2009). At the dawn of democracy in 1994, the user fee policy was abolished at primary health facilities for children under the age of six, the elderly population, and pregnant mothers, and in 1996 the policy of no OOPs in the form of user fees at point of care was extended to all primary health care facilities (Koch, 2012). In 2006, Zambia followed and abolished user fees at point of care in public primary health facilities in rural districts with the aim of reducing the financial burden caused by these payments on poor populations (Kaonga, et al., 2019). In 2001, the Ugandan government also abolished OOPs at public health facilities with the objective of improving access to the poor because they could not afford to pay the required costs (Orem, et al., 2011). Lesotho removed OOPs at primary healthcare level in 2008 while reducing them at other levels of care which improved utilization and health outcomes among poor people (The World Bank, 2021). Kenya went through a process similar to South Africa where OOPs removal occurred in stages with the concern of how they affected service utilization among the poor, and in 2013, the government eventually decided on complete removal of OOPs for all services at public health facilities (Dennis, et al., 2020).

Human immunodeficiency virus (HIV)

The period of OOPs removal coincided with a time when the world was also faced with the HIV/AIDS epidemic. The human immunodeficiency virus (HIV) is an infection that attacks the body's immune system and people diagnosed with this virus are required to start antiretroviral treatment (ART) (World Health Organization, 2022). The course of ART is monitored with assessment of CD4 count to check the patient's immune system, and the amount of the virus in the blood is checked through measuring of the viral load (World Health Organization, 2022). HIV cannot be cured, and this makes it a chronic illness that requires lifetime regular use of ART and frequent clinic visits to ensure that people live longer healthier lives (World Health Organization, 2022). In 2001, Sub-Saharan Africa had an estimated 28.5 million people living with HIV, which was the highest prevalence in the world at the time (UNAIDS, 2001). The World Health Organization found that the burden of HIV/AIDS could be reduced through improved access to HIV services and increased adherence to antiretroviral treatment (World Health Organization, 2005). Countries were then advised to provide free

HIV services at the point of care (World Health Organization, 2005). ART is effective and improves one's health status when a patient is adherent, which means taking the correct prescribed dosage at the right time and includes the requirement for patients to present themselves at the clinic to ensure they receive enough medication (Peltzer & Pengpid, 2013).

In 2003, the South African National Department of Health (NDoH) started providing free antiretroviral treatment (ART) to people living with HIV at public health facilities in a bid to increase adherence and access among the poor (Rosen, et al., 2007). However, it remains a challenge for people on ART to be adherent when there are competing costs between household costs of food and the cost of accessing care, so they end up foregoing food to access care, or default on their treatment to pay for food (Weiser, et al., 2010). Therefore, despite the removal of user fees, and the introduction of free HIV services provision, HIV patients still incur other costs which include transport to access health facilities, purchasing of recommended supplements and other additional health improvement services (Rosen, et al., 2007). In addition to these costs, the opportunity cost of time spent seeking care continues to be a challenge for the poor (Mudzengi, et al., 2017; Wagner, et al., 2016). The costs associated with seeking and accessing care leads to accumulation of debt to cover household expenses, and loss of income while spending long hours at the clinic (Chimbindi, et al., 2015; Koch & Setshegetso, 2020).

Economic burden

The policy of user fee removal covered the principles of UHC on access to healthcare, but the attempt of financial protection from impoverishment and catastrophic health expenditure (CHE) still requires further consideration. For this review, economic burden refers to impoverishment, which is defined as "household asset depletion and income loss which leads to household consumption needs falling below household needs", and catastrophic health expenditure which is "when OOPs exceed or are equal to a prescribed threshold of household expenditure" (Russell, 2004:147; Njagi, et al., 2018:2). It is worth noting that CHE is not a consequence of high health care costs, but a case of households driven into impoverishment because of health care costs (Kimani & Maina, 2015).

On the economic burden of illness focusing on HIV/AIDS, Tuberculosis (TB) and malaria, evidence suggest that poor health service delivery and indirect costs associated with these diseases leads to high costs, and poor households are driven into impoverishment (Russell,

2004). This does not only affect Sub-Saharan Africa, in other parts of the world such as Nepal, households of PLWH are also driven into impoverishment and apply coping strategies such as selling their farms, depleting family savings, and taking children out of school (Poudel, et al., 2017). A review of literature on understanding variations in catastrophic health expenditure in Sub-Saharan African countries found that patients receiving HIV/ART treatment were amongst those who rated the highest in CHE and some of the factors that contributed to such were household economic status, socio-demographic factors, and geographical location (Njagi, et al., 2018). Mudzengi et al. (2017) found that people living with HIV and TB are at risk of catastrophic costs, and integration of HIV and TB services alone is not enough to offer financial protection.

Furthermore, a review on equity in utilization of antiretroviral therapy for people living with HIV (PLWH) showed that people in poorer households in Sub-Saharan Africa had limited access to ART due to barriers that include economic factors (Tromp, et al., 2014). A cross-sectional study on financial burdens of HIV and chronic disease on people living with HIV in Cote d'Ivoire found that OOP spending on transportation was high even though ART is free, and the cost is much higher for those who have HIV and other chronic illnesses (Stelmach, et al., 2021). Similarly, in South Africa, transport fees were found to be the highest expense for people living with HIV when seeking care at the clinic such that, reducing distance travelled by bringing services closer was recommended to reduce financial distress caused by health costs (Chimbindi, et al., 2015).

Justification

In light of current knowledge on cost, access and utilization of HIV services, few studies have explored how the removal of user fees has reduced the financial burden of the cost of services utilization for people living with HIV (PLWH). Studies that have assessed the impact of user fee removal policies mainly focus on service utilization with less consideration of the financial protection it should offer those who are burdened by the costs (Ridde, et al., 2015). This review intends to address this gap and draws focus on the impact of user fees removal on the economic burden caused by HIV service utilization in South Africa. South Africa was selected because it is within the Sub-Saharan region which continues to have the greatest HIV burden

globally since 1990, and the national government runs the largest ART programme in the world with over 3million people on ART (Kyu, 2021; Meyer-Rath, et al., 2017).

Secondly, the country is among those that introduced the no user fee policy at point of care, it was also reported among the top five countries with the highest new HIV infections in the world in 2022, and HIV/AIDS is the leading cause of morbidity and mortality in this region (World Population Review, 2022; Dwyer-Lindgren, et al., 2019).

The review focuses on people living with HIV because of the critical connection between HIV/AIDS and poverty (ILO Programme on HIV/AIDS and the World of Work, 2005). This is important to consider because user fee removal policies were aimed at increasing access and utilization among the poor, and the HIV treatment programme requires more service utilization due to co-infections which results to more expenditure by those infected (Onwujekwe, et al., 2016). Lastly, studies on the impact of user fee removal on economic burden reduction have been carried out at national level but no systematic review has been done to assess and report the impact of user fee removal on the cost of HIV services utilization in South Africa from the patient's perspective.

The findings of this review should provide broader understanding for policies that seek to address the economic burden caused by health care utilisation for people living with HIV, which was not fully considered by the policy of removal of user fees at the point of care. The review also seeks to contribute to existing literature that evaluates the cost of HIV service utilization trends since the free primary health care policy was introduced, and to provide evidence for HIV programmes.

STUDY AIMS AND OBJECTIVES

This study will take the systematic literature review approach. This approach is a structured process used to examine, compare, and synthesize relevant evidence to answer specific research questions (Brannon, et al., 2014). The review will assess published literature on the cost of HIV services utilization in South Africa, and impoverishment as a result of HIV care costs for people living with HIV from 2004 – 2021. The study uses this as the period of consideration because it is during this time that the South Africa national government had

removed user fees at point of care and had also introduced free HIV services in public health facilities.

Within this context, the review will address the following research question:

Did the removal of user fees at point of care at primary health facilities reduce the economic burden caused by the cost of health service utilization for people living with HIV in South Africa?

Aim

This study aims to assess available evidence on the financial impact of removal of OOPs at point of care on the cost of healthcare utilization for people living with HIV (PLWH).

Objectives

The aim will be unpacked through addressing the following objectives:

- To assess the total cost of HIV services utilization by people living with HIV since the removal of OOPs at point of care
- To demonstrate the extent to which costs associated with HIV care are driving PLWH to impoverishment or catastrophic health expenditure

METHODS

The review will be carried out by following research plan that has been developed, drawing from guidelines for systematic reviews in the health care field (Tawfik, et al., 2019). We will also follow the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines to present the process and findings of the review (Arya, et al., 2021). First, a preliminary search on the subject will be done. Then, the eligibility criteria for studies that will be included and excluded based on the research question that the review seeks to answer will be developed. The next step will be to identify relevant databases. The health economics discipline under which the review is to be carried out will guide the selection of relevant databases that are to be used to search for relevant articles. We developed a search strategy according to the Population, Intervention, Comparator and Outcome (PICO)

structure as detailed below. This will be followed by conducting database searches and article screening. We outline the process below.

Table 1: Study Flow

PHASE I
1. Conduct a preliminary search 2. Formulate eligibility criteria 3. Identify relevant databases 4. Build a search strategy 5. Develop a data management plan
PHASE II
1. Search databases 2. Export to EndNote and Rayyan 3. Titles and Abstracts screening 4. Full text reading 5. Article selection and elimination
PHASE III
1. Data extraction to Excel 2. Data checking 3. Data synthesis and analysis
PHASE IV
1. Report writing 2. Dissemination of findings

Eligibility Criteria

Inclusion

The review will include all articles and literature published in English that report on the HIV service utilization costs in South Africa from a patient perspective from 2004 -2021. Studies must report direct and/ or indirect costs incurred by PLWH using services at primary healthcare level, and/or report CHE or impoverishment due to HIV services utilization.

Exclusion

Studies that were conducted prior to 2004, not reported in English, conducted outside of South Africa, are not disease specific (lump diseases together), report macroeconomic impact of HIV service utilization, report costs from a provider perspective, report costs primarily incurred due to hospital service utilization, and do not have full text will not be included.

Population

The review will include studies that have a population of people living with HIV and receiving HIV care or antiretroviral treatment in primary health facilities.

Intervention

The review will consider studies that focused on costs and financial impact after the country had implemented the no user fee at point of care and free ART/HIV services policy in primary health facilities.

Outcome

The outcome measure will be whether the no user fee policy has reduced the economic burden caused by cost of HIV service utilization through absence of impoverishment as per the review's definition of impoverishment or the total cost of HIV services utilization is below the World Health Organization's 10 – 25% threshold for households which is used to determine catastrophic health expenditure (Hailemichael, et al., 2019).

Study Setting

Studies that focus on costs incurred from primary health care and other services from a patient's perspective across all provinces in South Africa will be included, studies that primarily focus and report on costs incurred from hospital inpatient services will not be included.

Information sources

The search for articles will be done over a range of databases that include PubMed, EconLit, CINAHL, Africa-Wide Information, Health Source – Consumer Edition, PsycInfo and Web of Science. The search will start with a general search on Google Scholar to estimate volume of published literature on this subject and to conduct keyword identification. This will be followed by selection of search terms developed from the commonly used Population, Intervention, Comparator and Outcome (PICO) structure to design literature search strategies which will be used across different databases (Cooper, et al., 2018).

Search Strategy

The first set of terms of the search strategy will be informed by the population of interest which is people living with HIV and on antiretroviral treatment.

The second set of terms will be developed from the intervention aspect which is the removal of out-of-pocket payments from primary healthcare facilities at point of care to increase access and utilization.

The third set will be developed to include the economic burden shown by impoverishment and catastrophic health expenditure as an outcome.

Lastly, the South Africa filter will be used to find studies that focus on this geographic location since it has been selected for review within the years 2004 -2021. MeSH Terms, keywords and Boolean operators will be used to maximize the search on different databases. Table 2 below provides a provisional strategy that will be used.

Table 2: Search Strategy

Search #	**Search Terms**
#1	[(HIV OR AIDS OR "People living with HIV" OR Human Immunodeficiency Virus OR Acquired Immunodeficiency Syndrome) OR (ART OR antiretroviral treatment OR antiretroviral therapy OR Highly Active Antiretroviral therapy OR HAART)]
#2	[Healthcare cost* OR health expenditure OR out-of-pocket payment*]
#3	[Economic burden OR financial distress OR household burden OR Catastrophic expenditure OR Impoverishment OR financial burden OR "cost of illness" OR financial stress OR financial pressure* OR financial toxicity* OR financial challenge* OR financial hardship* OR economic hardship*]

#4	[(HIV OR AIDS OR "People living with HIV" OR Human Immunodeficiency Virus OR Acquired Immunodeficiency Syndrome) OR (ART OR antiretroviral treatment OR antiretroviral therapy OR Highly Active Antiretroviral therapy OR HAART) AND (Healthcare cost* OR health expenditure OR out-of-pocket payment*) AND (Economic burden OR financial distress OR household burden OR Catastrophic expenditure OR Impoverishment OR financial burden OR "cost of illness" OR financial stress OR financial pressure* OR financial toxicity* OR financial challenge* OR financial hardship* OR economic hardship*)].
CINAHL Subject Headings	(MH Human Immunodeficiency Virus), (MH HIV-Positive Persons), (MH Acquired Immunodeficiency Syndrome), (MH Antiretroviral Therapy, Highly Active), (MH Health Care Costs), (MH Financial stress).
PubMed MeSH Terms	HIV OR Acquired Immunodeficiency Syndrome [MeSH], Antiretroviral therapy, Highly Active [MeSH], Health Care Costs OR Health expenditures [MeSH], Financial stress OR cost of illness [MeSH].

Process documentation

The search process will be documented to ensure that reviewers are informed on the steps that will be followed in conducting the search, identifying, and selecting studies for review (Cooper, et al., 2018).

Data management

The articles found will be saved in EndNote which is a reference manager software used to manage and organize large numbers of references in systematic reviews (Lorenzetti & Ghali, 2013). The software will be used to identify and remove duplicates and manage selected articles. The references found from the different electronic databases will be exported to Rayyan for Title and Abstract screening and later full-text screening which is a web-based tool

used for reference screening in systematic reviews (Kellermeyer, et al., 2018). The articles will be saved in this tool and in a folder in Google Drive that is accessible to stakeholders interested in viewing articles used in the review.

Study selection

The selection process will be guided by the research question we seek to answer and the study objectives. The eligibility criteria stated in the search strategy will be used to identify and select the relevant articles. Selection will start with removing duplicates on EndNote, which will be followed by title and abstract screening on Rayyan by two reviewers working independently and blinded from each other's article selection. Full-text screening will then be done on selected articles using the same procedure that are relevant to ensure they meet study-specific objectives. Data containing study characteristics as detailed in Table 2 and specific variables that are used to determine economic burden as covered in Figure 1 will be extracted from articles using a Microsoft Excel spreadsheet which will be piloted before extraction. In the case that the reviewers have difficulties in selection of studies and data extraction, an independent researcher experienced in systematic reviews will be consulted.

Data collection process

A data collection form has been developed, guided by the Cochrane Consumers and Communication data extraction template (Cochrane Consumers and Communication, 2022). The items are presented in Table 2 below and will be used for data extraction, and to create a clear report or summary on characteristics of selected studies.

Table 3: Items for extraction

Source document information	Study characteristics
Author, year of publication	Type of study
Title	Year study conducted
	Study Population
	Geographic location (province), healthcare setting (primary healthcare level, secondary or tertiary level)
	Setting (primary healthcare facility, hospital)

	Economic perspective (patient, provider or societal)
	Primary objectives
	Types of costs reported
	Currency of costs

Data analysis and synthesis

The review focused on the total cost of healthcare utilization for PLWH receiving free ART services at primary healthcare facilities since the removal of user fees to find out whether these costs place them at risk of impoverishment or CHE. The total cost of healthcare utilization refers to the total of both direct and indirect costs incurred for all HIV-related services. Direct costs refer to cost paid to health provider or at the health facility, while indirect costs include transport to health facility, health supplements, HIV-related services and money spent on HIV related treatment. The outcome will be explored through assessment of whether the total costs of service utilization lead to impoverishment, which will be determined by whether households were driven into debt, household asset depletion and household consumption falling below household needs, and catastrophic health expenditure incidence.

Risk of bias

We will use the tools such as Rayyan mentioned above to reduce selection bias by using two reviewers who will work independently and be blinded to each other's article selections. Conflicts between the two reviewers will be resolved by discussion and advice from a third party who is experienced in systematic reviews. We will also use the STROBE Checklist which includes components of assessing bias by checking whether studies have described efforts to address potential bias, have reported any potential bias and magnitude of bias and declared funding which according to the Cochrane Review could lead to reporting bias (Cushieri, 2019).

Dissemination of findings

The dissemination of findings will be done through production of a manuscript for submission to a peer-reviewed journal and a policy brief to be submitted for consideration to government and non-governmental organizations (NGOs). As mentioned earlier, the review should inform policy and provide evidence for HIV programmes. The report will be available for advocacy

groups, health practitioners and other stakeholders interested in the financing of and providing social support for people living with HIV.

Possible difficulties and solutions

We anticipate challenges and difficulties finding the studies that meet the eligibility criteria. In the case that a limited number of articles are found through the electronic database search, the reviewer will conduct an extra search on other platforms for more studies. Where articles meet inclusion criteria but have missing data or items for extraction, information will be obtained from study authors if they are contactable.

Strengths and limitations

The strength of the review is that it will cover studies conducted in both rural and urban settings which is important for generalizability across different settings in LMICs that have a similar geographic context. It is also cost-effective because the collection of data requires minimum financial resources. The review acknowledges as a limitation the inclusion of studies that focus on PLWH as population of interest and will miss those that report costs of HIV service utilization presented together with other diseases such as TB and malaria. This might lead to less studies available for the review and in this case, we will seek advice from another researcher. Notes on grounds for such exclusion will be documented and reported in consultation with the second reviewer.

Framework of analysis

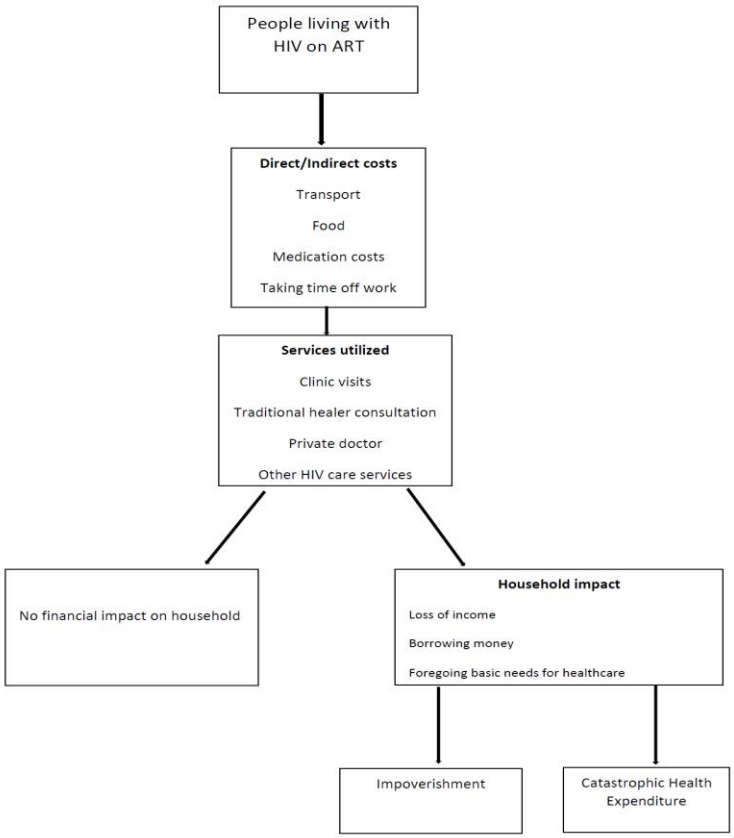


Figure 1: *Framework for analysis* *(adapted from NCCID variables for economic burden of disease)*

The framework is adapted from the National Collaborating Centre for Infectious Diseases (NCCID) variables used to determine economic burden of disease and considers the direct and indirect costs that go into healthcare service utilization by PLWH (National Collaborating Centre for Infectious Diseases, 2016). For some, the costs lead to reduction of household basic needs consumption, while others lose income when taking time off work to utilize services. Some households utilize services and are impacted but not to the extent of falling into impoverishment or catastrophic expenditure, others are not impacted and suffer no financial distress due to these costs, then others are driven into either impoverishment or catastrophic health expenditure.

Expected Results

The results of the review will show how much on average is spent by PLWH on their care since the removal of out-of-pocket payments at point of care in primary health facilities, this includes the free provision of ART. We also expect to see whether the total amount spent on

these services leads to household economic burden in the form of impoverishment or catastrophic health expenditure or it does not cause any financial distress to the household. Where results show that the total costs of HIV care leads to impoverishment or CHE, then it will be an indication that the removal of user fees at point of care does not offer financial protection to people living with HIV and more needs to be done. The results will be presented in summary tables and other formats.

ETHICAL CONSIDERATIONS

The Declaration of Helsinki place duty on researchers to protect human subjects while conducting research and submit research protocols to ethics committees for guidance and approval before research take place (World Medical Association, 2013). Systematic reviews do not involve direct contact with research subjects and do not collect private and confidential identifiable information from participants but, their evolution into influential material for policy decisions requires that they are conducted in an ethically appropriate manner (Suri, 2020).

Study Approval

This review will seek approval from the University of Cape Town School of Public Health and Family Medicine Departmental Research Committee. On the basis that the review does not involve human subjects, approval from the University of Cape Town Human Research Ethics Committee is not required.

Data collection and extraction

While ethics approval is not required, it is important that data collection and extraction is done in an ethically appropriate manner (Suri, 2020). The authors of selected studies will be acknowledged in the reference list and quoted within text where necessary. Vergnes, et al., (2010) suggest that reviewers should include summaries on ethical considerations of the selected studies. The study will aim to use quality assessment tools that ensure all appropriate processes to conduct research have been followed by selected studies.

Good practices in systematic reviews

Reliability

One of the ways to ensure rigor in systematic reviews is to have a reproducible and transparent search strategy to strengthen reliability (Batten & Brackett, 2021). The search strategy will be documented, and a clear report outlining the process will be produced should other researchers want to conduct the same search under the same conditions to produce the same result.

Duplication

The search to identify reviews that exist on the same subject is recognized as the first step before reviewers conduct a review to avoid duplication (Moher, 2013). A preliminary search will be done to identify any reviews similar to the proposed review. Where similar reviews have been conducted, the proposed review will fill the gaps that exist without duplicating what has already been covered.

Conflict of interest

There are no conflicts of interest known for the proposed review at the moment. This is a self-funded independent review with no external funding and sponsors. The reviewer will report any conflicts of interest that come up during the process of the review.

Study Timeline **(Feb – Dec 2022)**

ACTIVITY	FEB	MARCH	APRIL	MAY	JUNE	JULY	AUG	SEP	OCT	NOV	DEC
1. Protocol											
2. Literature Review											
3. Data extraction											
4. Data analysis and synthesis											
5. Writing up findings											
6. Intention to submit											

References

Batten, J. & Brackett, A., 2021. Ensuring the rigor in systematic reviews: Part 3, the value of research. *Heart and Lung,* 50(2), pp. 220 - 222.

Borde, M. T., Kabthymer, R. H., Shaka, M. F. & Abate, S. M., 2022. The burden of household out-of-pocket healthcare expenditures in Ethiopia: a systematic review and meta-analysis. *International Journal for Equity in Health,* Volume 21.

Brannon, P. M., Taylor, C. L. & Coates, P. M., 2014. Use and applications of systematic reviews in public health nutrition. *Annual Review of Nutrition,* Volume 34, pp. 401-419.

Chimbindi, N. et al., 2015. Time and Money: the true cost of health care utilization for patients receiving free HIV/TB care and treatment in rural KZN. *Journal of Acquired Immune Deficiency Syndromes,* 70(2), pp. 52 - 60.

Cochrane Consumers and Communication, 2022. *Consumers and Communication Group resources for authors.* [Online]
Available at: https://cccrg.cochrane.org/author-resources
[Accessed 27 May 2022].

Cooper, C. et al., 2018. Defining the process to literature searching in systematic reviews: a literature review of guidance and supporting studies. *BMC Medical Research Methodology,* Volume 85.

Coovadia, H. et al., 2009. The health and health system of South Africa: historical roots of current public health challenges. *The Lancet,* pp. 817 - 834.

Dennis, M. L. et al., 2020. Examining user fee reductions in public primary healthcare facilities in Kenya, 1997–2012: effects on the use and content of antenatal care. *International Journal of Equity in Health,* 19(35).

Dwyer-Lindgren, L., Cork, M. & Sligar, A. e. a., 2019. Mapping HIV prevalencein sub-Saharan Africa between 2000 and 2017. *Nature,* Volume 570, pp. 198 - 193.

Ejughemre, U. J., 2013. The Impacts of User Fees on Health Services in Sub-Saharan African Countries: A Ctirical Analysis of the Evidence. *American Journal of Public Health Research,* 1(7), pp. 196 - 202.

Hailemichael, Y. et al., 2019. Catastrophic health expenditure and impoverishment in households of persons with depression: a cross-sectional, comparative study in rural Ethiopia. *BMC Public Health,* Volume 19.

Honda, A., 2006. *User Fees Policy and Equitable Access to Health Care Services in Low- and Middle-Income Countries ―with the Case of Madagascar,* Tokyo: Institute for International Cooperation.

ILO Programme on HIV/AIDS and the World of Work, 2005. *HIV/AIDS and poverty: the critical connection ,* Geneva: International Labour Office.

Kangudie, D. M. et al., 2019. Effective integration of sexual reproductive health and HIV prevention, treatment, and care services across sub-Saharan Africa: where is the evidence for program implementation?. *Reproductive Health,* 16(1).

Kaonga, O., Banda, C. & F, M., 2019. Hardship financing of out-of-pocket paymemts in the context of free healthcare in Zambia. *PLoS ONE,* 14(4).

Kimani, D. & Maina, T., 2015. *Catastrophic Health Expenditures and Impoverishment in Kenya,* Nairobi: University of Nairobi.

Koch, S. F., 2012. *The abolotion of User Fees and the Demand for Health Care - Re-evaluating the Impact,* Cape Town: Economic Research Southern Africa.

Koch, S. F. & Setshegetso, N., 2020. Catastrophic health expenditures arising from out-of-pocket payments: Evidence from South African income and expenditure surveys. *PLoS ONE,* Volume 15.

Kutzin, J., 2013. *Health financing for universal health coverage and health system peformance: concepts and implications for policy,* Geneva: World Health Organization.

Kyu, H. H., 2021. Global, regional, and national sex-specific burden and control of the HIV epidemic, 1990–2019, for 204 countries and territories: the Global Burden of Diseases Study 2019. *The Lancet,* 8(10), pp. 633 - 651.

Lemphane, M. S. S. & Rantekoa, M., 2017. *Increasing adult ART uptake under Test and Treat in Lesotho through ART initiation at the village health post level,* s.l.: USAID.

Lorenzetti, D. L. & Ghali, W. A., 2013. Reference management software for systematic reviews and meta-analyses: an exploration of usage and usability. *BMC Medical Research Methodology,* Volume 13.

Meyer-Rath, G. et al., 2017. Changing the South African national antiretroviral therapy guidelines: The role of cost modelling. *PLoS ONE,* 12(10).

Meyer-Rath, G. et al., 2017. Changing the South African national antiretroviral therapy guidelines: The role of cost modelling. *PLoS ONE,* Volume 12.

Moher, D., 2013. The problem of duplicate systematic reviews. *BMJ Clinical Research,* Volume 347.

Moyo, S. et al., 2018. Equity of antiretroviral treatment use in high HIV burden countries: Analyses of data from nationally-representative surveys in Kenya and South Africa. *PLoS ONE,* 13(8).

Mudzengi, D. et al., 2017. The patient costs of care for those with TB and HIV: a cross-sectional study from South Africa. *Health Policy and Planning,* Volume 32, pp. 48-56.

Njagi, P., Arsenijevic, J. & Groot, W., 2018. Understanding variations in catastrophic health expenditure, its underlying determinants and impoverishment in Sub-Saharan African conutries: a scoping review. *Systematic Reviews Journal,* Volume 7, p. 136.

Nyarko, D.-K. A., Agyepong, I. A., Enyimayew, N. & Gilson, L., 2021. A Narrative Synthesis Review of Out-of-Pocket Payments for Health Services Under Insurance Regimes: A Policy Implementation Gap Hindering Universal Health Coverage in Sub-Saharan Africa. *International Journal of Health Policy and Management,* 10(7), pp. 443 - 461.

Onwujekwe, O. E. et al., 2016. Examining geographic and socio-economic differences in outpatient and inpatient consumer expenditures for treating HIV/AIDS in Nigeria. *Journal of the International AIDS Society,* Volume 19.

Orem, J. N. et al., 2011. Abolition of user fees: the Uganda paradox. *Health Policy and Planning,* Volume 26, pp. 41 - 51.

Peltzer, K. & Pengpid, S., 2013. Socioeconomic Factors in Adherence to HIV Therapy in Low- and Middle-income countries. *Journal of Health, Population and Nutrition,* 31(2), pp. 150-170.

Poudel, A. N., Newlands, D. & Simkhada, P., 2017. The economic burden of HIV/AIDS on individuals and households in Nepal: a quantitative study. *BMC Health Services Research,* Volume 17.

Ridde, V. et al., 2015. The impact of user fee removal policies on household out-of-pocket spending: evidence against the inverse equity hypothesis from a population based study in Burkina Faso. *European Journal of Health Economics,* Volume 16, pp. 55-64.

Rosen, S., Ketlhapile, M., Sanne, I. & DeSilva, M. B., 2007. Cost to patients of obtaining treatment for HIV/AIDS in South Africa. *South African Medical Journal,* 97(7), pp. 524-529.

Russell, S., 2004. The economic burden of illness for households in developing countries: A review of studies focusing on Malaria, Tuberculosis, and Human ImmunoDeficiency Virus/Acquired ImmunoDeficiency Syndrome. *America Journal of Tropical Medicine and Hygiene,* Volume 71, pp. 147 - 155.

Stelmach, R. D. et al., 2021. Financial burdens of HIV and chronic disease on people living with HIV in Coˆte d'Ivoire: A cross-sectional out-of-pocket expenditure study. *PLoS ONE,* 16(7).

Suri, H., 2020. Ethical Considerations of Conducting Systematic Reviews in Educational Research. In: O. Zawchi-Richter, et al. eds. *Systematic Reviews in Educational Research.* Wiesbaden: Springer VS, pp. 41-54.

Tawfik, M. G. et al., 2019. A step by step guide for conducting a systematic review and meta-analysis with simulation data. *Tropical Medicine and Health,* Volume 47.

The World Bank, 2013. *World Bank Group President Jim Yong Kim's Speech at World Health Assembly: Poverty, Health and the Human Future,* Geneva: The World Bank.

The World Bank, 2021. *The World Bank in Africa.* [Online]
Available at: https://www.worldbank.org/en/region/afr/overview#1
[Accessed 28 March 2022].

The World Bank, 2021. *The World Bank in Africa.* [Online]
Available at: https://www.worldbank.org/en/region/afr/overview#1
[Accessed 24 March 2022].

Tromp, N. et al., 2014. Equity in utilization of antiretroviral therapy for HIV - infected people in South Africa: a systematic review. *International Journal for Equity in Health,* 60(13).

UNAIDS, 2001. *Report on the global HIV/AIDS epidemic,* Geneva: UNAIDS.

UNAIDS, 2021. *Global HIV and AIDS Statistics Fact Sheet.* [Online]
Available at: https://www.unaids.org/en/resources/fact-sheet
[Accessed 24 March 2022].

UNDP, 2013. *UNDP in Sub Saharan Africa; Supporting A Region On The Move,* New York: UNDP.

Vergnes, J.-N.et al., 2010. Ethics in sytematic reviews. *Journal of Medical Ethics,* 36(12).

Vu, L. et al., 2016. Annual cost of antiretroviral therapy among three service delivery models in Uganda. *Journal of the International AIDS Society,* 19(4).

Wagner, R. G. et al., 2016. Health care utilization and outpatient, out-of-pocket costs for active convulsive epilepsy in rural northeastern South Africa: a cross-sectional Survey. *BMC Health Services Research,* Volume 16.

Watson, S. et al., 2016. The impact of user fees on health services utilization and infectious disease diagnoses in Neno District, Malawi: a longitudinal, quasi-experimental study. *BMC Health Services Research,* Volume 16, p. 595.

Weiser, S. D. et al., 2010. Food Insecurity as a Barrier to Sustained Antiretroviral Therapy Adherence in Uganda. *PLoS ONE,* 5(4).

World Health Organization, 2005. *WHO Discussion Paper: The practice of charging user fees at the point fo service delivery for HIV/AIDS treatment and care,* s.l.: World Health Organization.

World Health Organization, 2017. *Zambia HIV Country Profile: 2016,* Geneva: World Health Organization.

World Health Organization, 2021. *World Health Organization.* [Online]
Available at: https://www.who.int/health-topics/universal-health-coverage#tab=tab_1
[Accessed 7 November 2021].

World Health Organization, 2022. *Health Topics/ HIV/AIDS.* [Online]
Available at: https://www.who.int/health-topics/hiv-aids#tab=tab_1
[Accessed 23 April 2022].

World Medical Association, 2013. *World Medical Association Declaration of Helsinki,* Ferney Voltaire: JAMA.

World Population Review, 2022. *HIV rates by country.* [Online]
Available at: https://worldpopulationreview.com/country-rankings/hiv-rates-by-country
[Accessed 23 March 2022].

Yates, R., 2009. Universal health care and the removal of user fees. *The Lancet,* Volume 373, pp. 2078 - 2081.

PART B: LITERATURE REVIEW

INTRODUCTION

Health systems across the globe have been prioritizing HIV/AIDS prevention and treatment since it was first discovered in the early 1980s. In the early 2000s, the global estimate was 36 million people living with HIV, over 20 million had died, and sub-Saharan Africa was the most affected region with almost 25,3 million people infected (Piot, et al., 2001). The 2005 geographic global distribution of HIV infection rate showed that sub-Saharan Africa had the highest infections with over 25 million people infected, south and South-East Asia had 7,6 million people infected, and Latin America, Eastern Europe, North America were just above 1 million and other parts of the world reporting below 1 million (Karim, et al., 2007). HIV is currently recognized as a chronic illness that is treated and managed with antiretroviral treatment (ART) which is administered immediately after positive diagnosis with strict prescription guidelines and adherence requirements to ensure treatment effectiveness (Phanuphak, et al., 2020). The HIV/AIDS epidemic has caused devastating economic impact in both high income and low- and middle-income countries (Piot, et al., 2001). This has made it a global health concern that requires pooling of resources to prevent and manage the spread (Piot, et al., 2001). The economic impact of HIV/AIDS is first felt at the household level where income is spent on healthcare, then the household foregoes basic needs for healthcare costs, this leads to ill-health which results to loss of income, and then sale of assets and school dropout follows (Ijumba, 2011).

Over the years, governments have allocated a large share of their health budgets to HIV services to increase availability and accessibility. It is reported that, low- and middle-income countries spent over $221 billion for HIV/AIDS services through domestic and donor funding between 2000 and 2016, and $19 billion was spent in 2018 (Avancena & Hutton, 2020). Despite the different strategies and funding made available to ensure the cost burden does not fall on individuals and households, there are indirect costs associated with seeking care and treating HIV that push households into further poverty (Pouden, et al., 2015). This challenge hinders progress of various countries to achieve universal health coverage (UHC), which is a policy objective of the World Health Organization (WHO) for equal access to quality healthcare for all without suffering financial hardship (World Health Organization, 2021). The experience has not been the same across all countries and different socioeconomic groups.

The extent of economic impact on the health system and financial distress experienced by people living with HIV depends on whether countries have funds and resources to efficiently provide required services (Beck, et al., 2001). The HIV infection demographics show a critical connection between HIV and poverty, with evidence of high infection rates in low-middle-income countries (LMICs) when compared to the low rate of infection in high-income countries (Karim, et al., 2007). Most LMICs have budget constraints and households contribute more than half of health expenditure through out-of-pocket payments in the form of both direct and indirect costs which places an economic burden on them (Pouden, et al., 2015; Assebe, et al., 2020). The removal of user fees at point of care by various countries was meant to, among other reasons, reduce the cost burden for the poor, yet PLWH are still suffering financial hardship due to service utilization costs (Souteyrand, et al., 2008).

South Africa is one of the LMICs in Sub-Saharan Africa (SSA) with a high HIV burden and runs the largest ART programme in the world (Bekker, et al., 2014). Studies have been conducted in the country at a local and national level to understand the extent to which health service utilization costs from a patient perspective affects the financial well-being of people living with HIV. However, no systematic reviews have been done to understand the impact of user fee removal at point of care for PLWH. The body of evidence produced by such a review can be used to inform policy that can help address the challenge of HIV service utilization costs and how they can be averted to provide financial risk protection. Using evidence from South Africa, a country with a high HIV prevalence, and the largest ART programme, to understand the total cost of HIV care and its determinants, will assist governments to make informed decisions for policies and interventions that can address the economic burden caused by HIV service utilization on individuals and households and therefore increase opportunity to achieve their UHC goals.

OBJECTIVES OF LITERATURE REVIEW

The focus of this section is to:

- Provide an account of the factors that led to removal of user fees at point of care
- Show how the economic burden of disease is determined.

- Present what is already known about the total cost of HIV service utilization from the patient perspective across different countries.
- Highlight gaps in research that can be filled by this review.
- Present evidence on the economic burden caused by HIV services utilization on households.
- Examine available evidence on South Africa's financing mechanism for HIV/AIDS since user fee removal at point of care and whether it reduces financial distress on households as an aim to achieve universal health coverage.
- Present other issues discovered and need to be considered for future research and policy development with regards to HIV/AIDS and financial hardship.

LITERATURE SEARCH STRATEGY

The search strategy for literature was developed in line with the objectives of this section. Google Scholar, Pubmed and EBSCO Host were used to find literature on the global burden of HIV but focusing on countries with a high prevalence, health financing mechanisms, impoverishment, and catastrophic health expenditure. The keywords used were "HIV/AIDS", "health financing mechanisms", "universal health coverage", "user fees" and "catastrophic health expenditure". In some instances, the keywords were combined with Boolean operators such as 'AND' to optimize the search. We included articles that focused on HIV/AIDS cost of service utilization from a patient perspective and economic burden on individuals and households. We excluded literature that was not published in English and did not focus on HIV/AIDS and financing mechanisms.

SUMMARY AND INTERPRETATION OF LITERATURE

Systematic reviews and determining economic burden of disease

Systematic reviews have become an important part of decision-making for policymakers due to their approach of comprehensive examination of evidence done on specific subjects. Defined as a structured process used to examine, compare, and synthesize relevant evidence to answer specific research questions (Brannon, et al., 2014), systematic reviews have been found to be useful and reliable in examining the effectiveness of health interventions and in informing policy development and decisions (Dobbins, et al., 2004). Petticrew (2009) in the

World Health Organization (WHO) bulletin encourages the use of systematic reviews of different study designs for public health questions over prioritizing one specific design such as randomized control trials (RCTs) alone as it would reduce the volume of available evidence. He further states that using different designs and methodologies are beneficial because public health issues are not evaluated in one single method and most importantly, some policy interventions have never been evaluated using RCTS therefore systematic reviews on this subject would have no evidence (Petticrew, 2009). In this regard, Pearson, et al. (2015) present the emergence of mixed-methods in systematic reviews where researchers use evidence from qualitative and quantitative traditions covering the same subject or topic of interest. Furthermore, they recognize that policymakers using systematic reviews as evidence for decision-making would find difficulty in making decisions if they have to search through a number of reviews under the same topic. Therefore, reviews focusing on public health policies may be more successful and useful if they follow the mixed-methods approach in the review process.

The economic burden of HIV/AIDS has been studied using different designs and methods but quantitative methods has been the most utilized due to cost evaluations. Adedigba, et al. (2009) study on assessing the economic burden in Nigeria used a cross-sectional design applying quantitative methods, Ritchwood, et al. (2017) on trends in health expenditure among PLWH in the USA also used quantitative methods, and Bachmann & Booysen (2004) used quantitative methods to examine the relationship between HIV/AIDS, income and expenditure in South Africa. However, Goudge, et al. (2009) on their study on illness related impoverishment in South Africa used quantitative and qualitative methods to assess the link between costs and impoverishment. Eze, et al. (2022) systematic review on catastrophic health expenditure in Sub-Saharan Africa used quantitative methods to estimate incidence of CHE in SSA. However, Njagi, et al. (2018) used both quantitative and qualitative methods because impoverishment was one of the outcomes and is at times reported through qualitative methods.

Published systematic reviews including those determining CHE have reported limitations such as the different CHE thresholds used by different studies, the heterogeneity of the data collected as difficult to pool because it varies by disease, studies use different time-points and stages of illness, and also use either household or individual income as determinants of

expenditure (Jahan, et al., 2016; Eze, et al., 2022; Njagi, et al., 2018; Russell, 2004). This review focuses on HIV/AIDS and includes studies that used different study designs and applied quantitative methods or qualitative methods so to capture all available eligible evidence published on the economic burden caused by the disease and to satisfactorily answer the review question.

Universal Health Coverage and User Fees

The World Health Organisation (WHO) called for country health systems to move towards universal health coverage (UHC), which means all persons should have equal access to quality healthcare without the risk of financial hardship (World Health Organization, 2021). To meet the UHC principle of access without financial hardship, countries introduced policies of the removal of out-of-pocket payments (OOPs) in the form of user fees at point of care based on the 2013 World Health Assembly's report that user fees lead to catastrophic expenditure for the poor (Kutzin, 2013; The World Bank, 2013). User fees were initially introduced to prevent or reduce unnecessary demand on health services because people did not pay for them, and fees collected in more advantaged communities were used to subsidize poor communities to improve quality and increase utilization (Ejughemre, 2013). User fee removal was not without contestation, and on whether to retain or remove user fees, James, et al. (2006) report that proponents of user fees argued that the fees were not the only barrier for lack of access and poor utilization and removing them would negatively impact the quality of services. The opponents suggested that a broader health benefits package that addressed other barriers would be more appropriate (James, et al., 2006).

Some countries removed user fees from all health services and countries such as South Africa removed them at primary healthcare level, Kenya and Lesotho removed them in stages at primary healthcare level first and reduced them at secondary and tertiary levels (Kaonga, et al., 2019; Orem, et al., 2011; Dennis, et al., 2020). Interestingly, an assessment of user fees impact on access to health services in LMICs found that introduction and increase of user fees reduced utilization but, utilization also increased when user fees were increased to improve quality of services (Lagarde & Palmer, 2011). The removal of user fee policy met the principle of access to service to some extent, but the aspect of financial protection needs further discussion. According to Ahmed, et al. (2021) on their assessment of the incidence of CHE and impoverishment from OOPs, an estimated 150 million people in the world experience CHE

and 100 million are pushed into poverty because of these payments, and the majority live in LMICs.

Conceptual Framework: Determining the economic burden of HIV/AIDS

The National Collaborating Centre for Infectious Diseases (NCCID) suggests that the approach to measuring the economic burden of diseases should be focused on financial costs of the illness for individuals, households, healthcare systems and societies (National Collaborating Centre for Infectious Diseases, 2016). The approach further outlines that variables to be considered are direct costs in the form of medical visits to doctors, in-patient and outpatient hospital care, medications, medical tests and disease prevention methods, and the variable of indirect costs which includes loss of income due to ill-health, absence from work due to health-related factors or premature death (National Collaborating Centre for Infectious Diseases, 2016). A study on the economic burden of HIV in Nepal used this approach from a household perspective and focused on direct costs in the form of money spent seeking care and productivity costs representing indirect costs (Poudel, et al., 2017). Adedigba, et al. (2009) on their study on the economic burden of HIV/AIDS on households in Nigeria used money spent on HIV-related care, loss of savings and funeral costs. On the economic burden of illness for households in developing countries, Russell (2004) used the direct costs in the form of medical costs but included transport as a direct but non-medical cost. He also measured indirect costs in the form of time lost by the person seeking care, the caregiver and other economically active individuals in the household (Russell, 2004). In this review, catastrophic health expenditure and impoverishment are indicative of the economic burden caused by HIV/AIDS.

Catastrophic Health Expenditure and Impoverishment

The occurrence of financial hardship is assessed through catastrophic health expenditure (CHE) which is defined as health expenditure exceeding a specified threshold of the household total income (Wagstaff, 2008). Another approach views it as expenditure that exceeds the total amount a household spends on basic needs such as food and shelter (Cylus, et al., 2018). Studies use different thresholds between 10% and 40% to measure CHE, and studies assessing CHE in Sub-Saharan Africa and specifically in HIV patients have used the 10% threshold (Ngcamphalala & Ataguba, 2018; Njagi, et al., 2018; Wagstaff, et al., 2017). The review will use the 10% threshold to determine CHE.

CHE is also used as an indicator to measure progress on financial protection as a UHC component by health systems and can be observed in low- and middle-income countries (LMICs) and high-income countries (HIC) but reported higher in LMICs (Grepin, et al., 2020; Njagi, et al., 2018). In high income countries, Portugal was found to be one of the countries with the highest incidence of CHE, but this was amongst the poorest population, a confirmation of evidence on the poor being the most affected (Quintal, 2019; The World Bank, 2013).

Impoverishment is used to identify the occurrence of financial hardship which is when OOPs push non-poor households who are above the poverty line to below the poverty line and the already poor into further poverty (Ngcamphalala & Ataguba, 2018; Hailemichael, et al., 2019). A literature review on the economic burden of illness in developing countries determined impoverishment by assessing whether health expenditure led to households foregoing basic needs and applying coping mechanisms such as borrowing money and sale of household assets (Russell, 2004).

The link between user fee policies and HIV/AIDS

The connection between free HIV/AIDS services at point of care and the removal of user fees at primary health care level is that both are components of UHC to ensure that those who need healthcare can access it without suffering financial hardship, and both components have been prioritized as part of the United Nations Sustainable Development Goals (World Health Organization, 2020). Importantly, based on the global burden of HIV/AIDS and the resources required for its treatment, its effect on UHC cannot be ignored (Michel, et al., 2020). The cost of HIV/AIDS services is well researched but the impact of financial protection mechanisms from the economic burden caused by HIV service utilization costs needs further investigation.

Studies have found that the highest CHE is reported amongst PLWH, and this is concerning due to the number of visits they are required to attend at healthcare facilities (Eze, et al., 2022; Njagi, et al., 2018). PLWH utilize services more especially in countries where immediate ART initiation policies have not been implemented and patients go through a CD4 count staging process which requires clinic visits for blood tests, results, and then determination of ART initiation and pharmacy refill frequency (Heffernan, et al., 2016). The removal of user fees at point of care is in line with the WHO call for provision of free ART to increase coverage, but this strategy seems to be lacking in preventing the financial hardship caused by multiple

clinic visits (World Health Organization, 2005; Bousmah, et al., 2021). Research has been done on the effectiveness of decentralizing HIV services to protect households from CHE as it brings services closer and reduces transport costs, but limited research is found on the overall impact of user fee removal to protect HIV/AIDS households from CHE and impoverishment (Boyer, et al., 2011).

There is a global concern that OOPs at point of care by patients has dropped but the health expenditure as a share of household income has not decreased (Wagstaff, et al., 2017). Therefore, it is important for further research to consider that removal of OOPs at point of care alone does not offer financial protection and gather evidence that will contribute towards policies that address other healthcare costs driving households to CHE and impoverishment.

HIV/AIDS: An overview

Treatment and prevention

In 2016, the international community set a development agenda through the Sustainable Development Goals (SDGs) and committed to ending epidemics such as HIV/AIDS by 2030 (Harries, et al., 2016). Improvements in managing HIV have been made but barriers such as limited access to services continue to cause ART non-adherence and the reality of achieving this goal is questionable. Prior to this period, the UNAIDS introduced the 90-90-90 strategy with the aim of having 90% of people with HIV to be diagnosed and know their status, 90% of the diagnosed to be initiated on ART and 90% of those on ART to be virally suppressed by 2020 (De Kock, et al., 2021). This was complemented by the WHO Universal Test and Treat (UTT) strategy which would fast track the 90-90-90 targets at the time by ensuring that all people that test positive for HIV are immediately initiated on ART (Sanders, et al., 2021). Countries such as Botswana have achieved this target and the campaign has increased ART coverage across the globe, with high income countries taking the lead due to enough resource capacity for service provision (Bekker, et al., 2018). The initiation and provision of ART to all people living with HIV is a costly exercise for governments and requires large budgets for programmes and interventions (Lieberman, et al., 2009).

The global financing mechanisms for HIV/AIDS

International solidarity and resource mobilization through various strategies has been of help to LMICs such as those in the sub-Saharan Africa region where there is a high prevalence of HIV but limited budgets to provide the services needed (Bekker, et al., 2018). The establishment of the Global Fund, the President's Emergency Plan for AIDS Relief (PEPFAR) and the Bill and Melinda Gates Foundation have been instrumental in provision of financial assistance and capacitating countries struggling with the fight against HIV/AIDS reporting a record of over $17 billion expenditure on HIV programmes by 2016 (Bekker, et al., 2018; Cohen, 2008).

The Global Fund and PEPFAR are funded by countries and development organizations who are part of the global community that is affected by the global economic crises and as a result, over the years international funding has decreased and this raised questions of sustainability in this method of HIV financing (Suthar, et al., 2017; Bekker, et al., 2018). To find sustainable ways of financing programmes to prevent and treat HIV, countries must look inward and consider maximising efforts through different financing mechanisms which in some instances lead to a larger proportion of contributions made by individuals and households (Assebe, et al., 2020). Due to the nature of HIV/AIDS being a lifetime illness, it is crucial to study and understand the lifetime financial burden carried by PLWH so to develop policy that will alleviate this burden and protect people from impoverishment (Kumarasamy, et al., 2007).

HIV/AIDS policy priorities

Epidemiology focused policy

The primary focus of HIV/AIDS policy and programmes has been on the clinical aspect of the disease which is the prioritization of increased ART coverage to manage existing cases and prevent new infections and high mortality rates, less attention is given to the threat of impoverishment caused by HIV services utilization (Kumarasamy, et al., 2007). As one of the countries with the highest number of HIV cases in Asia, India started looking at the impoverishing effect of HIV/AIDS and found that PLWH sell their assets to cover cost of medication and pay for travel costs to the clinic (Kumarasamy, et al., 2007). Similarly, Adedigba, et al. (2009) studied the impact of HIV and service utilization on households in Nigeria and found that households spend their family savings on health care, and

opportunities of income-generation are reduced when other household members must look after the sick. There is a need for further research for policy development that will look beyond service provision and the direct costs of care for PLWH and address the economic burden on households associated with indirect costs (Russell, 2004).

Services integration policy

Recommendations of HIV/AIDS services integration alongside other non-communicable diseases to save costs and increase coverage have been made, with South Africa, Kenya, Nigeria, and Russia integrating their HIV/AIDS services with other diseases screening, reproductive health, and substance use services (Bekker, et al., 2018). HIV/AIDS has been integrated with illnesses such as Tuberculosis (TB) which is a co-infection and the leading cause of death among people living with HIV (Bekker, et al., 2014). Evidence in Brazil shows that PLWH and TB are at higher risk of catastrophic health expenditure due to indirect costs with time and income loss being the higher cost components and lead to treatment dropout and death (De Siqueira Filha, et al., 2018). The trend of studying the diseases together has been justified by arguments of the intimate link and service integration of the two (Assebe, et al., 2020; Sadoh & Oviawe, 2007). The integration of HIV/AIDS and TB services has led to more evidence available on the economic burden of HIV/AIDS and TB being studied together and has led to limited focus on the economic burden of HIV/AIDS alone, which has created a gap on the evidence of economic burden carried by those living with HIV but without TB as a co-infection.

Global differences on the economic impact of HIV/AIDS care

HIV/AIDS in high income countries

The economic impact of HIV/AIDS is not a challenge faced by poor regions only, but it is felt across the world at different levels, even though households feel greater impact (Piot, et al., 2001). Evidence on trends in healthcare expenditure among people living with HIV/AIDS in the United States of America (USA) shows that in 2017 there were almost 1.2 million people living with HIV and the population demographics indicated that these were minority groups of the poor and less educated, and compared to people not living with HIV, they had higher health expenditures due to direct costs such as prescription medications which then leads to a higher financial burden (Ritchwood, et al., 2017). This can be attributed to the country's HIV

financing mechanisms that have strict eligibility criteria which limit access to care and do not cover all costs related to HIV services (Kates, et al., 2021).

Review of literature on France, Italy, Germany, Spain, and the United Kingdom (UK) shows a different challenge, that even with low HIV prevalence, the cost of HIV treatment in these countries has great economic impact on their health systems and individuals who are not infected (Trapero-Bertran & Oliva-Moreno, 2014). The authors found that this is a result of more contributions made towards health financing mechanisms due to the extended number of years of life that ART has afforded PLWH (Trapero-Bertran & Oliva-Moreno, 2014). This is a factor worth noting because of the financial contributions that most high-income countries continue to make towards free ART provision programmes in LMICs.

Russia has the highest HIV prevalence in Eastern Europe due to drug injecting users, and the concern of the economic impact of HIV is different to what is seen in LMICs, their concern is the increased mortality rate among the economically active age group that leads to a decline in the workforce contributing to health insurance and the country's economic growth (Smith, et al., 2011). Trapero-Bertran and Oliva-Moreno (2014) have identified a knowledge gap that exists on the cost of HIV/AIDS in these countries and highlight the need for more research to increase evidence that looks at the overall economic impact of HIV/AIDS which includes household impact and considers costs from the patient's perspective.

HIV/AIDS in Sub-Saharan Africa

According to the WHO, the highest HIV/AIDS prevalence is in Sub-Saharan Africa (SSA) which is the region made up of 54 countries in the south of the Sahara Desert on the African continent (Lange, 2019). Kharsany & Karim (2016) studied the current status, challenges and opportunities of HIV/AIDS in Sub-Saharan Africa and found a decline in new infections since the introduction of ART but rated South Africa, Nigeria, Uganda, Mozambique and Kenya with most new infections compared to the rest of the region. An estimated 70% of the poorest people in the world who live on less than 1USD per day are in SSA, and this confirms the correlation mentioned earlier on HIV/AIDS and poverty (Mbirimtengereji, 2007). Using Demographic and Health Surveys from 27 countries, Vollmer, et al. (2017) indicated that a high HIV/AIDS prevalence can be seen in adults of 49 years and above due to ART which has increased life expectancy.

High infection rates are reported among young women between 15 – 24 years which is a direct consequence of sexual relations through sex trade, polygamy, and teenage marriages with men in their late 20s and 30s (Karim & Baxter, 2019; Mbirimtengereji, 2007). This age group forms about 30% of the total population in the region and is a combination of people who are still financially dependant on parents or guardians and those largely affected by the high unemployment rate in the region (Fox, et al., 2016). In response to the WHO policy recommendation of increased ART coverage, countries such as Uganda, Zambia, South Africa and Kenya removed user fees on HIV services at point of care with the belief that costs were a barrier to treatment adherence (World Health Organization, 2005). A cohort study on household economic impact of HIV in South Africa shows that this policy increased utilization of HIV services but it overlooked the household economic burden of illness for PLWH (Bachman & Booysen, 2003). In Cote d'Ivoire, a cross-sectional survey on financial burden of morbidity in HIV-infected adults taking ART shows that while ARVs and CD4 count tests are free at point of service, poor households still face catastrophic health expenditure due to other drug purchases not related to routine tests and ARVs (Arnousse, et al., 2010).

On subsidized HIV/AIDS treatment in Nigeria, Etiaba, et al. (2016) found that household costs not related to ART but still within HIV care lead to catastrophic expenditure and further recommend service decentralization policies and subsidization to be extended to other areas of HIV care to reduce costs. A cluster randomized trial on Differentiated Service Delivery (DSD) models in Lesotho, a country with the second highest HIV prevalence in the world, found that moving services closer to the people and reducing level of interactions by multi-month dispensing of ART prevents financial distress because it reduces money spent by patients on travel and loss of income due to time spent away from work (Nichols, et al., 2021). Nyabyonga-Orem, et al. (2008) assessment on the impact of HIV/AIDS on household welfare in Uganda, in relation to the Poverty Eradication Action Plan, found that 77% of households of PLWH missed work, 59% lost all sources of income due to HIV/AIDS related illness and 80% households used savings to care for a family member which then led to financial hardship.

Evidence from a cross-sectional study on barriers to initiation of ART in Zambia suggests that removal of user fees at point of care has increased ART adherence but the reduction of actual costs associated with seeking care beyond removal of clinic fees needs to be considered to encourage ART initiation among those reluctant to start (Fox, et al., 2010). Tarvene, et al.

(2021) assessed the impact of universal health coverage on reducing out-of-pocket expenditure for people living with HIV in Senegal and found that health expenditure for PLWH is still high even though certain services are provided for free, and they recommended free transport provision due to high transport fees, a finding similar to a study in Malawi (Pinto, et al., 2013).

Systematic reviews on the economic impact of HIV/AIDS in Sub-Saharan Africa are rarely disease specific and often pool TB, malaria, and other chronic illnesses together or study HIV/AIDS under TB as the main subject (Eze, et al., 2022; Njagi, et al., 2018), a trend that could be influenced by the global policy and research agenda of integrating HIV and non-communicable diseases (NCD) as a cost saving strategy for health systems, PLWH and the general population (Vorkoper, et al., 2018). The common finding of these reviews is that catastrophic health expenditure is higher in PLWH and those with TB than those with other diseases (Eze, et al., 2022; Njagi, et al., 2018). Research conducted in South Africa on reduction of costs for PLWH through HIV and TB service integration shows that this is beneficial but the lack of proper implementation of service integration may not succesfully help in cost saving for patients (Mudzengi, et al., 2017).

The economic burden of HIV/AIDS in South Africa

South Africa has the highest HIV prevalence in the world with an estimated 8.2 million people living with HIV which is 13,7% of the total population and it is the leading cause of death in the country (Statistics South Africa, 2021; Bachmann & Booysen, 2004). In 2004, South Africa rolled out the national ART programme to all PLWH at primary health level (Johnson, 2012). In line with universal test and treat (UTT), and close to reaching the 90-90-90 target, in 2017, 84.8% of the people with HIV knew their status, 70,7% of those who knew their status were on ART and 87.4% of those on ART were virally suppressed (Marinda, et al., 2020). South Africa's history of racial segregation resulted in many black poor people forced to live in communities with poor quality or no health services provision compared to White, Indian, and Coloured people who had access to good quality services (Coovadia, et al., 2009). HIV/AIDS is more prevalent among poor black people due to lack of education on prevention and infection, lack of good health services in communities, and engaging in high-risk sexual activities for financial reward (Tladi, 2006).

Affected population characteristics

The average household is dependent on a single income provider, and poor households depend on the social grant (Collins & Leibbrandt, 2007). Research on social grants as safety net for HIV/AIDS affected households was found to be a good strategy in poverty alleviation but not so effective for poverty eradication (Collins & Leibbrandt, 2007; Booysen, 2004). On characteristics of patients receiving treatment for HIV/AIDS at public and non-governmental sites in South Africa, Rosen, et al. (2008) found that the average age of women was 34 years and 37 years for men, 26% had formal employment and 21% were informally employed with 40% living in informal housing. More results showed that those living in rural settings were unemployed or less likey to be employed (Rosen, et al., 2008).

Household income as determinant of CHE and impoverishment

Sections above show that household income level plays a role in the level of economic impact felt due to HIV/AIDS service utilization. Higher income households are found to be unlikely to experience CHE compared to middle and low income households due to their ability to pay for services (Njagi, et al., 2018). Some research shows that HIV/AIDS impoverishes households because the population that is assessed is already poor and if the population was not poor, perhaps the result would be different (Steinert, et al., 2017). Contrary to this, Carter, et al. (2007) stated that in some instances, already poor households do not experience financial distress due to HIV/AIDS care costs because there is no income that can be affected. However, according to Koch & Setshegetso (2020), the case of the 'unaffected' poor households needs to be carefully considered because they are affected but not in monetary terms and they are missing from these analyses because the cost of service utilization has become so unaffordable for them that they have no access and therefore not included in impact research. In their systematic review, Eze, et al. (2022) reported this factor as a limitation.

Factors that drive households to CHE and Impoverishment

Direct and indirect costs

According to McIntyre, et al. (2006), the presence of chronic illness such as HIV/AIDS in households increases the economic burden because of medical expenses, loss of income due to illness, transport costs, other healthcare related costs and death of people who are the sole providers in their households. Studies in rural and urban settings in South Africa confirm this assertion and show the impoverishing effect of HIV/AIDS on households and link it to the

direct and indirect costs incurred during time of illness and death, and suggest targeted programmes to mitigate some aspects of HIV/AIDS costs (Steinert, et al., 2017; Booysen, 2004). Evidence on the full extent of HIV and AIDS household experience from KwaZulu-Natal, a province with the highest HIV prevalence in South Africa, shows that households struggled to recover from funeral costs, travel costs to health facilities, how to cope when they had to provide food, and send children to school due to increasing household size because of number of orphaned children (Hosegood, et al., 2007).

Transport costs

Further review of literature shows that most health expenditure for PLWH goes to transport costs while seeking care and it contributes to treatment non-adherence and risk of death (Miller, et al., 2010; Mee, et al., 2014; Probst, et al., 2016). Goudge, et al. (2009) show that even with free health services at point of care, 51% of the household health expenditure goes to transport which is determined by proximity to health facilities. People who live far from the facility such as those in rural areas travel a longer distance than those in urban areas where health facilities are closer to the people (Goudge, et al., 2009). McLaren, et al. (2014) found that 90% of the people in South Africa live within 7km from their nearest health facilities and 14% of Black people live more than 5km away from their nearest facility. Discussions have been held on the hidden costs of HIV, including transport cost as an agenda item and it was suggested that people on ART should receive free transport to health facilities but this had limited success due to increased stigma (Meyer-Rath & Richter, 2007). Rosen, et al. (2007) estimated the cost of patients obtaining treatment for HIV/AIDS and found that on average, patients had at least six visits to the clinic in a year and the highest transport cost was R75, and total cost per visit including other expenses was R120. This is four times above the World Bank's international poverty line of 1.90USD per day, and in 2021, an estimated 16.7 million South African's lived below this poverty line (Galal, 2021).

Loss of income

Loss of income is identified as one of the key factors that contribute to the household economic burden caused by HIV/AIDS especially in cases where the only or highest income earner in the household falls ill and loses work or dies (Collins & Leibbrandt, 2007). South African labour laws allow for formally employed people to take time for sick leave which means their income on days they are unwell is unaffected, but those who are paid for days

worked means that they have no income when ill or collecting medication from clinic (Rosen, et al., 2007). Carter, et al. (2007) shows that death can push already poor households into further poverty in the case where they have to cover funeral costs and are unable to recover from that but, it is also evident that households below the poverty line experience less financial distress during such shocks than those slightly above the poverty line because there was no significant income prior to illness or death. In some instances, household members caring for the ill lose income, but Bachman & Booysen (2003) found that the high rate of unemployment in South Africa means this is a rare occurrence in households. Research on lessons from the Covid19 pandemic for HIV/AIDS show strategies that required less physical interaction and facility based delivery of services, and the authors suggest that these can be adopted as policy to reduce the number of visits for HIV patients to reduce transport costs and prevent loss of income due to missed days of work (Boyd, et al., 2021).

Healthcare pluralism: a mix of private, traditional and public health services

The use of traditional healers and purchase of more healthy food and supplements suggested by health practitioners has been reported (Chimbindi, et al., 2015; Rosen, et al., 2007). Seeking alternative or additional treatment also contributes to how much is spent by households on healthcare, and research on medical pluralism shows that PLWH in rural areas use a combination of the public healthcare system and local traditional healers (Chimbindi, et al., 2015; Moshabela, et al., 2011). Further evidence shows that even with provision of free healthcare at primary health facilities, low-income households still prefer to use private sector services when they are able to pay due to poor quality and long waiting hours in the public sector which then increases their household health expenditure (Govender, et al., 2021).

Social protection for households

Existing evidence on one of the government's strategies which is the Disability Grant (DG) for PLWH who are unable to work due to mental or physical illness caused by HIV/AIDS shows that it assists in prevention of CHE and impoverishment, but the eligibility criteria and the administrative process of the grant is complicated (Govender, et al., 2015). It is reported that eligibility for the DG can only be authorized or confirmed through medical assessments done by specific doctors, a limited human resource that the health system is unable to provide for every health facility, and eligibility requires reassessment every six months period to confirm

that the patient is still unwell and unable to work (Govender, et al., 2015). On the perceived benefit of the DG, Woolgar and Mayers (2014) found that people who are dependent on the grant understood that it is a temporary measure and once they are deemed well, they no longer meet eligibility criteria as beneficiaries, so they stop taking their ART to ensure they continue receiving financial support, and this offset the purpose of the grant to facilitate treatment adherence. This intervention is beneficial, but it carries a certain level of risk for the health outcomes. On social protection in the context of HIV/AIDS, Veenstra (2006) argues that social incentives such as the DG lack success and instead have led to PLWH with the burden of prioritizing money over health, and therefore more social protection interventions across different sectors are needed to address these challenges.

The literature presented in sections above details the focus of strategies and policies on provision of free ART to manage mortality and prevent new infections, and the evidence also demonstrates the different costs incurred while seeking free treatment which serve as a barrier to access and push households into poverty (Chimbindi, et al., 2015; Rosen, et al., 2007). Furthermore, considering all the factors mentioned, it is also important to note that the aim for the removal of user fees or the introduction of free primary healthcare at point of care was to increase access among the poor, but evidence shows that there is still a significant cost burden on households which leads to catastrophic health expenditure and impoverishment (Coovadia, et al., 2009; Koch & Setshegetso, 2020).

HIV/AIDS Financing in South Africa

South Africa is among many of the countries that abolished OOPs at the point of care through provision of free health care at the primary care level to increase accessibility and utilization of services (Coovadia, et al., 2009). However, the abolishment of OOPs at the point of care was not universal at the outset. At the dawn of democracy in 1994, the OOP policy was abolished at primary health facilities for children under the age of six, the elderly population, and pregnant mothers, and in 1996 the policy of no OOPs at point of care was extended to all primary health care facilities (Koch, 2012). No fees would be paid by patients seeking care at public primary health care facilities and a fee of R50 would be paid by those who bypass the primary health facilities and seek outpatient services at public hospitals (Health Systems Trust, 1996).

Free HIV/AIDS care is provided by primary health facilities where no fees are paid but prior to this, ART was only provided by hospitals to patients with 200 cells CD4 count due to treatment guidelines (Burger, et al., 2022). Abaerei et al. (2017) reported that since the policy changes in 1994 on free healthcare at point of use, utilization in the public health sector remained low, with economic barriers cited as one of the issues that influenced this outcome. However, utilization increased when the government introduced free ART to all who are eligible due to the number of PLWH that had also increased because for a while, people could not access treatment (Burger, et al., 2022). As mentioned in above sections, despite government's approach to increasing coverage through free HIV/AIDS services, households still suffer financial hardship (Goudge, et al., 2009; Coovadia, et al., 2009; Koch & Setshegetso, 2020).

South Africa's public health system is financed through general tax revenue and direct OOPs, while the private sector is financed through medical aid contributions and OOPs (Ataguba & McIntyre, 2018). Consistent with findings by Govender, et al. (2021), McIntyre (2012) points out that part of the population that accounts for the OOPs made in the private sector is not necessarily from high- or middle-income households making co-payments to providers but includes low-income households who are not satisfied with the public sector service and decide to seek and pay for care in the private sector.

According to South Africa's health financing profile of 2016, 84% of the population which includes informal sector employees, unemployed people and the poor are uninsured and depends on government funded public health services which is often unreliable with shortage of specialist care, while 16% is covered by health insurance and serviced by the private sector (Michel, et al., 2020; Health Policy Project, 2016). Importantly, PLWH who are unable to afford private healthcare receive care from the public sector which is funded by government and financed through general tax revenue and donor funds (Health Policy Project, 2016). Ataguba (2021) states an important consideration, that general tax revenue is also generated from household income in the form of direct taxes such as personal income tax and indirect taxes such as value added tax (VAT) and fuel levy.

Policy documents on the current HIV financing structure show that the National Department of Health (NDoH) spent more than R14 billion on HIV in the 2015/2016 budget period and was projected to spend R20 – R30 billion in the 2018/2019 period, raising concerns on the sustainability of such spending and how it can be maintained in the time of slow economic

growth and decreasing donor funding (Chaitkin, et al., 2016). However, Blecher, et al. (2016) and Michel, et al. (2020) believe that spending and investing now on interventions will have greater impact in the future and lead to a healthy population that can contribute to economic growth, and this will ultimately reduce total spending.

Financing reforms: National Health Insurance (NHI) and HIV/AIDS

The evidence presented shows that the current health financing system does not provide financial risk protection to all, and the introduction of the National Health Insurance (NHI) intends to address this including the unequal distribution of health services (Murphy & Moosa, 2021). The South African government is moving towards UHC by introducing this system which is *"designed to pool funds to provide access to quality affordable personal health services for all South Africans based on their health needs, irrespective of their socio-economic status"* (Department of Health, 2017: 3). The NHI brings all South Africans under one healthcare system to receive equal services according to health needs and not income (Michel, et al., 2020).

While the NHI bridges the gap between the rich and the poor in healthcare, the financial protection it offers is through cutting out OOPs without compromising service quality (Ataguba, 2021), but this approach is similar to user fee removal as it also focuses on direct cost elimination at point of care. However, the NHI promises to provide good quality services including specialist care which helps everyone including PLWH avoid the cost of spending on private healthcare services to receive good quality and specialist care (Department of Health, 2017; Govender, et al., 2021). In addition, this health financing reform is consistent with the idea of introducing a health benefits package instead of user fee removal as suggested by user fee removal opponents (James, et al., 2006), and further demonstrates that user fee removal alone has been inadequate in offering financial protection.

Limitations of current research in South Africa

Steinert, et al., (2017), pointed out a limitation of their research study, they reported that the population studied on the financial impact of HIV/AIDS was already poor and therefore findings would reflect further impoverishment but this may not be true for other income groups. Similar to this limitation, Bachmann & Booysen (2004) hold the view that study designs on the impact of HIV/AIDS do not have a long enough follow-up period to properly study the change caused by HIV/AIDS over time in the household, and there is lack of

comparison groups with which the impact can be studied. This amplifies the importance of systematic reviews to pool evidence from different study designs and perspectives to show the true economic impact of HIV/AIDS services utilization.

CONCLUSION

The cost of healthcare is one of the most prioritized factors to achieve universal health coverage. It is also a priority for all governments to ensure that access to health as a human right is not denied due to lack of affordability. From the literature examined it is clear that there is a continuous process of policy development to remove costs as a barrier to healthcare access and utilization. The removal of user fees at different levels of care is an indication of government's commitment to ensure that all people can access care, and it has proven to be beneficial in increasing access and utilization but whether this policy direction offers complete financial protection is yet to be confirmed.

It has also been established that poor people especially in LMICs such as South Africa are mostly affected by the cost of care, and this is made worse by the fact that these countries have high burden of diseases. Without reducing the impact of economic burden caused by other diseases, the literature shows that HIV/AIDS service access has been prioritized but the focus has been more epidemiological and less on the cost implication for households while accessing ART. Evidently, the HIV/AIDS treatment design which requires multiple clinic visits is what sets its utilization costs apart from other chronic illnesses. This has been highlighted in the various studies showing high transport costs due to multiple clinic visits, and geographic distance to facility as a major factor that drives households to catastrophic health expenditure (CHE) and impoverishment.

There is a need for more research on the economic burden caused by HIV/AIDS in South Africa. While research is often guided by specific agendas and available funds, research that will inform policy that specifically targets the impoverishing effect of the disease should be considered. The study designs and methodologies used to examine the economic burden also need to be carefully considered. Factors such as appropriate follow-up periods to measure impact, and representative populations would be beneficial in producing wide-ranging results.

The factors identified as causes of CHE and impoverishment give policy direction and will help decision makers in policy development for financial protection. What has emerged from the literature review to consider for future research is the difference in how households in high-income countries and low-and middle-income countries have felt or experienced the economic burden of HIV/AIDS and how this shapes the global agenda on financial protection policies and who they aim to protect. The findings from this review could help decision makers reflect on what has been done, how previous and current policies have been effective and what areas should be considered going forward in order to improve financial protection.

References

Abaerei, A. A., Ncayiyana, J. & Levin, J., 2017. Healthcare utilization and associated factors in Gauteng province, South Africa. *Global Health Action,* 10(1).

Adedigba, M. A. et al., 2009. The economic burden of HIV and AIDS on households in Nigeria. *African Journal of AIDS Research,* Volume 8, pp. 107-114.

Ahmed, S. et al., 2021. Assessing the incidence of catastrophic health expenditure and impoverishment from out-of-pocket payments and their determinants in Bangladesh: evidence from the nationwide Household Income and Expenditure Survey 2016. *International Health ,* 14(1), pp. 84-96.

Arnousse, B. et al., 2010. The Financial Burden of Morbidity in HIV-Infected Adults on Antiretroviral Therapy in Côte d'Ivoire. *PLoS ONE,* 5(6).

Arya, S., Kaji, A. H. & Boermeerster, M. A., 2021. PRISMA Reporting Guidelines for Meta-analyses and Systematic Reviews. *JAMA Surgery,* 156(8), pp. 789-790.

Assebe, L. F. et al., 2020. Financial burden of HIV and TB among patients in Ethiopia: a cross-sectional survey. *BMJ Open Access,* Volume 10.

Ataguba, J. E., 2021. The Impact of Financing Health Services on Income Inequality in an Unequal Society: The Case of South Africa. *Applied Health Economics and Health Policy,* Volume 19, pp. 721-733.

Ataguba, J. E.-O. & McIntyre, D., 2018. The incidence of health financing in South Africa: findings from a recent data set. *Health Economics Policy and Law,* Volume 13, pp. 68-91.

Avancena, A. L. & Hutton, D. W., 2020. Optimization Models for HIV/AIDS Resource Allocation: A Systematic Review. *Value in Health,* 23(11), pp. 1509 - 1521.

Bachman, M. O. & Booysen, F. L., 2003. Health and economic impact of HIV/AIDS on South African households: a cohort study. *BMC Public Health,* 14(3).

Bachmann, M. & Booysen, F., 2004. Relationships between HIV/AIDS, income and expenditure over time in deprived South African households. *AIDS Care,* 16(7), pp. 817-826.

Bachmann, M. & Booysen, F., 2004. Relationships between HIV/AIDS, income and expenditure over time in deprived South African households. *AIDS Care,* 16(7), pp. 817-826.

Batten, J. & Brackett, A., 2021. Ensuring the rigor in systematic reviews: Part 3, the value of research. *Heart and Lung,* 50(2), pp. 220 - 222.

Beck, E. J., Miners, A. H. & Tolley, K., 2001. The Cost of HIV Treatment and Care: A Global Review. *Pharmaeconomics,* 19(1), pp. 13 - 39.

Bekker, L.-G., Alleyne, G. & Beyrer, C., 2018. Advancing global health and strengthening the HIV response in the era of the Sustainable Development Goals: the International AIDS Society—Lancet Commission. *The Lancet Commissions,* 392(10144), pp. 312-358.

Bekker, L.-G.et al., 2014. Provision of antiretroviral therapy in South Africa: the nuts and bolts. *Antiviral Therapy,* Volume 19, pp. 105-116.

Blecher, M. S. et al., 2016. HIV and AIDS financing in South Africa: sustainability and fiscal space. *South African Health Review,* 2016(1).

Booysen, F., 2004. Social grants as safety net for HIV/AIDS-affected households in South Africa. *SAHARA-J: Journal of Social Aspects of HIV/AIDS,* 1(1), pp. 45-56.

Booysen, F. l. R., 2004. Income and poverty dynamics in HIV/AIDS-affected households in the Free State Province of South Africa. *South African Journal of Economics,* 72(3), pp. 522-545.

Borde, M. T., Kabthymer, R. H., Shaka, M. F. & Abate, S. M., 2022. The burden of household out-of-pocket healthcare expenditures in Ethiopia: a systematic review and meta-analysis. *International Journal for Equity in Health,* Volume 21.

Bousmah, M.-a.-Q., Nishimwe, M. L. K. C. & Boyer, S., 2021. Free access to antiretroviral treatment and protection against the risk of catastrophic health expenditure in people living with HIV: evidence from Cameroon. *BMC Health Services,* Volume 21.

Boyd, A. T. et al., 2021. Expanding access to HIV services during the COVID-19 pandemic—Nigeria, 2020. *AIDS Research and Therapy,* 18(62).

Boyer, S. et al., 2011. Does HIV Services Decentralization Protect against the Risk of Catastrophic Health Expenditures? Some Lessons from Cameroon. *Health Services Research,* Volume 46, pp. 2029-2056.

Brannon, P. M., Taylor, C. L. & Coates, P. M., 2014. Use and applications of systematic reviews in public health nutrition. *Annual Review of Nutrition,* Volume 34, pp. 401-419.

Burger, C., Burger, R. & van Doorslaer, E., 2022. The health impact of free access to antiretroviral therapy in South Africa. *Social Science and Medicine,* Volume 299.

Carter, M. R., May, J., Aguero, J. & Ravindranath, S., 2007. The economic impacts of premature adult mortality: panel data evidence from KwaZulu-Natal, South Africa. *AIDS,* 21(7), pp. 67-73.

Chaitkin, M. et al., 2016. *HIV Financing Integration in South Africa: Policy Scenarios and Feasibility Analysis,* s.l.: UNAIDS.

Chimbindi, N. et al., 2015. Time and Money: the true cost of health care utilization for patients receiving free HIV/TB care and treatment in rural KZN. *Journal of Acquired Immune Deficiency Syndromes,* 70(2), pp. 52 - 60.

Cleary, S. M., Birch, S., Moshabela, M. & Schneider, H., 2012. Unequal access to ART: exploratory results from rural and urban case studies of ART use. *Sexually Transmitted Infections,* Volume 88, pp. 141-146.

Cochrane Consumers and Communication, 2022. *Consumers and Communication Group resources for authors.* [Online]

Available at: https://cccrg.cochrane.org/author-resources
[Accessed 27 May 2022].

Cohen, J., 2008. The Great Funding Surge. *Science,* 321(5888), pp. 512-519.

Collins, D. L. & Leibbrandt, M., 2007. The financial impact of HIV/AIDS on poor households in South Africa. *AIDS,* Volume 21, pp. 75-81.

Cooper, C. et al., 2018. Defining the process to literature searching in systematic reviews: a literature review of guidance and supporting studies. *BMC Medical Research Methodology,* Volume 85.

Coovadia, H. et al., 2009. The health and health system of South Africa: historical roots of current public health challenges. *The Lancet,* 374(9692), pp. 817-834.

Coovadia, H. et al., 2009. The health and health system of South Africa: historical roots of current public health challenges. *The Lancet,* pp. 817 - 834.

Cushieri, S., 2019. The STROBE Guidelines. *Saudi Journal of Anesthesia,* Volume 13, pp. 31-34.

Cylus, J., Thomson, S. & Evetovits, T., 2018. *Catastrophic health spending in Europe: equity and policy implications of different calculation methods,* s.l.: World Health Organization.

Dalton, J., Booth, A., Noyes, J. & Sowden, A. J., 2017. Potential value of systematic reviews of qualitative evidence in informing user-centered health and social care: findings from a descriptive overview. *Journal of Clinical Epidemiology,* Volume 88, pp. 37-46.

De Kock, K. M., Jaffe, H. W. & Curran, J. W., 2021. Reflections on 40 Years of AIDS. *Emerging Infectious Diseases,* 27(6), pp. 1553-1560.

De Siqueira Filha, N. T. et al., 2018. The economic burden of tuberculosis and latent tuberculosis in people living with HIV in Brazil: a cost study from the patient perspective. *Public Health,* Volume 158, pp. 31-36.

Dennis, M. L. et al., 2020. Examining user fee reductions in public primary healthcare facilities in Kenya, 1997–2012: effects on the use and content of antenatal care. *International Journal of Equity in Health,* 19(35).

Department of Health, 2017. *NATIONAL HEALTH INSURANCE FOR SOUTH AFRICA: Towards Universal Health Coverage,* Cape Town: Parliamentary Monitoring Group.

Dobbins, M., Thomas, H., O'Brien, M. A. & Duggan, M., 2004. Use of systematic reviews in the development of new provincial public health policies in Ontario. *International Journal of Technology Assessment in Health Care,* 20(4), pp. 399-404.

Dwyer-Lindgren, L., Cork, M. & Sligar, A. e. a., 2019. Mapping HIV prevalencein sub-Saharan Africa between 2000 and 2017. *Nature,* Volume 570, pp. 198 - 193.

Ejughemre, J. U., 2013. The Impacts of User Fees on Health Services in Sub-Saharan African Countries: A Ctirical Analysis of the Evidence. *American Journal of Public Health Research,* 1(8), pp. 196-202.

Ejughemre, U. J., 2013. The Impacts of User Fees on Health Services in Sub-Saharan African Countries: A Ctirical Analysis of the Evidence. *American Journal of Public Health Research,* 1(7), pp. 196 - 202.

Etiaba, E. et al., 2016. What Is the Economic Burden of Subsidized HIV/AIDS Treatment Services on Patients in Nigeria and Is This Burden Catastrophic to Households?. *PLoS ONE,* 11(12).

Eze, P., Lawani, L. O., Agu, U. J. & Acharya, Y., 2022. Catastrophic health expenditure in sub-Saharan Africa: systematic review and meta-analysis. *Bulletin of the World Health Organization,* 100(5), pp. 337-351.

Fox, L., Senbet, L. W. & Simbanegavi, W., 2016. Youth Employment in Sub-Saharan Africa: Challenges, Constraints and Opportunities. *Journal of African Economics,* Volume 25, pp. 3-15.

Fox, M. P. et al., 2010. Barriers to initiation of antiretroviral treatment in rural and urban areas of Zambia: a cross-sectional study of cost, stigma, and perceptions about ART. *Journal of the International AIDS Society,* 13(1), p. 8.

Galal, S., 2021. *Statista.* [Online]
Available at: https://www.statista.com/statistics/1127838/national-poverty-line-in-south-africa/#:~:text=As%20of%202021%2C%20an%20individual,per%20month%20was%20considered%20poor.
[Accessed 02 August 2022].

Goudge, J. et al., 2009. The household costs of health care in rural South Africa with free public primary care and hospital exemptions for the poor. *Tropical Medicine and International Health,* 14(4), pp. 458-467.

Goudge, J. et al., 2009. Illness-related impoverishment in rural South Africa: Why does social protection work for some households but not others?. *Journal of International Development,* 21(2), pp. 231-251.

Govender, K. et al., 2021. Primary healthcare seeking behaviour of low-income patients across the public and private health sectors in South Africa. *BMC Public Health,* Volume 21.

Govender, V. et al., 2015. Disability Grant: a precarious lifeline for HIV/AIDS patients in South Africa. *BMC Health Services Research,* Volume 15.

Grepin, K. A., Irwin, B. R. & Trakinsky, B. S., 2020. On the Measurement of Financial Protection: An Assessment of the Usefulness of the Catastrophic Health Expenditure Indicator to Monitor Progress Towards Universal Health Coverage. *Health Systems and Reform,* 6(1).

Hailemichael, Y. et al., 2019. Catastrophic health expenditure and impoverishment in households of persons with depression: a cross-sectional, comparative study in rural Ethiopia. *BMC Public Health,* Volume 19.

Hailemichael, Y. et al., 2019. Catastrophic health expenditure and impoverishment in households of persons with depression: a cross-sectional, comparative study in rural Ethiopia. *BMC Public Health,* Volume 19.

Harries, A. D. et al., 2016. Ending the HIV/AIDS epidemic in low- and middle-income countries by 2030: is it possible?. *F1000Research,* Volume 5.

Health Policy Project, 2016. *Health Financing Profile South Africa,* Washington: Health Financing Project.

Health Systems Trust, 1996. *South African Health Review,* Durban: Health Systems Trust and Henry J Kaiser Family Foundation.

Heffernan, A. et al., 2016. Impact and Cost-Effectiveness of Point-Of-Care CD4 Testing on the HIV Epidemic in South Africa. *PLoS ONE,* 11(7).

Hoffmann, C. J. et al., 2018. Value stream mapping to characterize value and waste associated with accessing HIV care in South Africa. *PLoS ONE,* 13(7).

Honda, A., 2006. *User Fees Policy and Equitable Access to Health Care Services in Low- and Middle-Income Countries —with the Case of Madagascar,* Tokyo: Institute for International Cooperation.

Hosegood, V. et al., 2007. Revealing the full extent of households' experiences of HIV and AIDS in rural South Africa. *Social Science and Medicine,* 65(6), pp. 1249-1259.

Ijumba, N., 2011. *Impact of HIV/AIDS on Education and Poverty,* Geneva: Unted Nations.

ILO Programme on HIV/AIDS and the World of Work, 2005. *HIV/AIDS and poverty: the critical connection ,* Geneva: International Labour Office.

Jahan, N., Naveed, S., Zeshan, M. & Tahir, M. A., 2016. How to Conduct a Systematic Review: A Narrative Literature Review. *Cuerus Journal of Medical Science,* 8(11), p. 864.

James, C. D. et al., 2006. To retain or remove user fees?: reflections on the current debate in low- and middle-income countries. *Applied Health Economics and Health Policy,* Volume 5, pp. 137-153.

Johnson, L. F., 2012. Access to Antiretroviral Treatment in South Africa, 2004 - 2011. *South African Journal of HIV Medicine,* 13(1).

Kangudie, D. M. et al., 2019. Effective integration of sexual reproductive health and HIV prevention, treatment, and care services across sub-Saharan Africa: where is the evidence for program implementation?. *Reproductive Health,* 16(1).

Kaonga, O., Banda, C. & F, M., 2019. Hardship financing of out-of-pocket paymemts in the context of free healthcare in Zambia. *PLoS ONE,* 14(4).

Karim, S. S. A. & Baxter, C., 2019. HIV incidence rates in adolescent girls and young women in sub-Saharan Africa. *The Lancet,* 7(11), pp. 470-471.

Karim, S. S. A., Karim, Q. A., Gouws, E. & Baxter, C., 2007. Global Epidemiology of HIV-AIDS. *Infectious Disease Clinics of North America,* 21(1), pp. 1-17.

Kates, J. et al., 2021. Insurance coverage and financing landscape for HIV treatment and prevention in the USA. *The Lancet,* 397(10279), pp. 1127-1138.

Kellermeyer, L., Harnke, B. & Knight, S., 2018. Covidence and Rayyan. *Journal of the Medical Library Association,* Volume 106, pp. 580-583.

Kharsany, A. B. & Karim, Q. A., 2016. HIV Infection and AIDS in Sub-Saharan Africa: Current Status, Challenges and Opportunities. *The Open AIDS Journal,* Volume 10, pp. 34-38.

Kimani, D. & Maina, T., 2015. *Catastrophic Health Expenditures and Impoverishment in Kenya,* Nairobi: University of Nairobi.

Koch, S. F., 2012. *The abolotion of User Fees and the Demand for Health Care - Re-evaluating the Impact,* Cape Town: Economic Research Southern Africa.

Koch, S. F. & Setshegetso, N., 2020. Catastrophic health expenditures arising from out-of-pocket payments: Evidence from South African income and expenditure surveys. *PLoS ONE,* Volume 15.

Koch, S. F. & Setshegetso, N., 2020. Catastrophic health expenditures arising from out-of-pocket payments: Evidence from South African income and expenditure surveys. *PLoS ONE,* 15(8).

Kumarasamy, N., Venkatesh, K. K., Mayer, K. H. & Freedberg, K., 2007. Financial burden of health services for people with HIV/AIDS in India. *Indian Journal of Medical Research,* Volume 126, pp. 509-517.

Kutzin, J., 2013. *Health financing for universal health coverage and health system peformance: concepts and implications for policy,* Geneva: World Health Organization.

Kyu, H. H., 2021. Global, regional, and national sex-specific burden and control of the HIV epidemic, 1990–2019, for 204 countries and territories: the Global Burden of Diseases Study 2019. *The Lancet,* 8(10), pp. 633 - 651.

Lagarde, M. & Palmer, N., 2011. The Impact of User Fees on Access to Health Services in Low- and Middle-Income Countries. *Cochrane Database of Systematic Reviews,* Issue 4.

Lange, K., 2019. *Young Initiative on Foreign Affairs and International Relations.* [Online] Available at: https://ifair.eu/2019/06/22/the-sub-saharan-africa-region/ [Accessed 18 July 2022].

Lemphane, M. S. S. & Rantekoa, M., 2017. *Increasing adult ART uptake under Test and Treat in Lesotho through ART initiation at the village health post level,* s.l.: USAID.

Lieberman, S. et al., 2009. International Health Financing and the Response to AIDS. *Journal of Acquired Immuno Deficiency Syndromme,* Volume 52, pp. 38-44.

Lines, M. & Suleman, F., 2017. Patients' perceptions of a rural decentralised anti-retroviral therapy management and its impact on direct out-of-pocket spending.. *African Health Sciences,* 17(3).

Lorenzetti, D. L. & Ghali, W. A., 2013. Reference management software for systematic reviews and meta-analyses: an exploration of usage and usability. *BMC Medical Research Methodology,* Volume 13.

Mafune, R. V., Lebese, R. T. & Nemathaga, L. H., 2017. Challenges faced by caregivers of children on antiretroviral therapy at Mutale Municipality selected healthcare facilities, Vhembe District, Limpopo Province. *AOSIS,* 40(1).

Marinda, E. et al., 2020. Towards achieving the 90–90–90 HIV targets: results from the south African 2017 national HIV survey. *BMC Public Health,* Volume 20.

Mayosi, B. M. et al., 2012. Health in South Africa: changes and challenges since 2009. *The Lancet,* Volume 380, pp. 2029-2043.

Mbirimtengereji, N. D., 2007. Is HIV/AIDS Epidemic Outcome of Poverty in Sub-Saharan Africa?. *Croatian Medical Journal,* Volume 48, pp. 605-617.

McIntyre, D., 2012. *Health service financing for universal coverage in east and southern Africa,* Harare: Equinet.

McIntyre, D., Thiede, M., Dahlgren, G. & Whitehead, M., 2006. What are the economic consequences for households of illness and of paying for health care in low- and middle-income country contexts?. *Social Science and Medicine,* 62(4), pp. 858-865.

McLaren, Z. L., Ardington, C. & Leibbrandt, M., 2014. Distance decay and persistent health care disparities in South Africa. *BMC Health Services Research,* Volume 14.

Mee, P. et al., 2014. Determinants of the risk of dying of HIV/AIDS in a rural South African community over the period of the decentralised roll-out of antiretroviral therapy: a longitudinal study. *Global Health Action,* 7(1).

Meyer-Rath, G. et al., 2017. Changing the South African national antiretroviral therapy guidelines: The role of cost modelling. *PLoS ONE,* 12(10).

Meyer-Rath, G. et al., 2017. Changing the South African national antiretroviral therapy guidelines: The role of cost modelling. *PLoS ONE,* Volume 12.

Meyer-Rath, G. & Richter, M., 2007. User Fees, Transport Costs, and the Ethics of Exemption: How Free is Free ART?. *The South African Journal of HIV Medicine,* 8(2), pp. 52-56.

Michel, J. et al., 2020. Universal health coverage financing in South Africa: wishes vs reality. *Journal of Global Health Reports,* Volume 4.

Miller, C. M., Ketlhapile, M., Rybasack-Smith, H. & Rosen, S., 2010. Why are antiretroviral treatment patients lost to follow-up?A qualitative study from South Africa. *Tropical Medicine and International Health,* 15(1), pp. 48-54.

Moher, D., 2013. The problem of duplicate systematic reviews. *BMJ Clinical Research,* Volume 347.

Moshabela, M. et al., 2011. Patterns and Implications of Medical Pluralism Among HIV/AIDS Patients in Rural South Africa. *AIDS and Behaviour,* 15(4), pp. 842-852.

Moyo, S. et al., 2018. Equity of antiretroviral treatment use in high HIV burden countries: Analyses of data from nationally-representative surveys in Kenya and South Africa. *PLoS ONE,* 13(8).

Mudzengi, D. et al., 2017. The patient costs of care for those with TB and HIV: a cross-sectional study from South Africa. *Health Policy and Planning,* Volume 32, pp. 48-56.

Mudzengi, D. et al., 2017. The patient costs of care for those with TB and HIV: a cross-sectional study from South Africa. *Health Policy and Planning,* Volume 32, pp. 48-56.

Mudzengi, D. et al., 2017. The patient costs of care for those with TB and HIV: a cross-sectional study from South Africa. *Health Policy and Planning,* Volume 32.

Murphy, S. D. & Moosa, S., 2021. The views of public service managers on the implementation of National Health Insurance in primary care: a case of Johannesburg Health District, Gauteng Province, Republic of South Africa. *BMC Health Services Research,* Volume 21.

National Collaborating Centre for Infectious Diseases, 2016. *More than just numbers: Exploring the concept of "burden of disease",* Winnipeg: NCCID.

Negin, J. et al., 2017. Health expenditure and catastrophic spending among older adults living with HIV. *Global Public Health,* 12(10), pp. 1282-1296.

Ngcamphalala, C. & Ataguba, J. E., 2018. An assessment of financial catastrophe and impoverishment from out-of-pocket health care payments in Swaziland. *Global Health Action,* 11(1).

Nichols, B. E. et al., 2021. Economic evaluation of differentiated service delivery models for HIV treatment in Lesotho: costs to providers and patients. *Journal of the International AIDS Society,* 24(4).

Njagi, P., Arsenijevic, J. & Groot, W., 2018. Understanding variations in catastrophic health expenditure, its underlying determinants and impoverishment in Sub-Saharan African conutries: a scoping review. *Systematic Reviews Journal,* Volume 7, p. 136.

Njagi, P., Arsenijevic, J. & Groot, W., 2018. Understanding variations in catastrophic health expenditure, its underlying determinants and impoverishment in Sub-Saharan African countries: a scoping review. *Systematic Reviews,* Volume 7.

Nyabyonga-Orem, J. et al., 2008. Effect of HIV/AIDS on household welfare in Uganda rural communities: a review. *East African Medical Journal,* 85(4), pp. 187-196.

Nyarko, D.-K. A., Agyepong, I. A., Enyimayew, N. & Gilson, L., 2021. A Narrative Synthesis Review of Out-of-Pocket Payments for Health Services Under Insurance Regimes: A Policy Implementation Gap Hindering Universal Health Coverage in Sub-Saharan Africa. *International Journal of Health Policy and Management,* 10(7), pp. 443 - 461.

Onwujekwe, O. E. et al., 2016. Examining geographic and socio-economic differences in outpatient and inpatient consumer expenditures for treating HIV/AIDS in Nigeria. *Journal of the International AIDS Society,* Volume 19.

Orem, J. N. et al., 2011. Abolition of user fees: the Uganda paradox. *Health Policy and Planning,* Volume 26, pp. 41 - 51.

Pearson, A. et al., 2015. A mixed-methods approach to systematic reviews. *International Journal of Evidence-Based Healthcare,* 13(3), pp. 121-131.

Peltzer, K. & Pengpid, S., 2013. Socioeconomic Factors in Adherence to HIV Therapy in Low- and Middle-income countries. *Journal of Health, Population and Nutrition,* 31(2), pp. 150-170.

Petticrew, M., 2009. Systematic reviews in public health: old chestnuts and new challenges. *Bulletin of the World Health Organization,* 87(3), p. 163.

Phanuphak, N., Gulick & M, R., 2020. HIV treatment and prevention 2019: current standards of care. *Current Opinion in HIV and AIDS,* 15(1), pp. 4-12.

Pillai, N. et al., 2019. Patient costs incurred by people living with HIV/AIDS prior to ART initiation in primary healthcare facilities in Gauteng, South Africa. *PLoS ONE,* 14(2).

Pinto, A. D. et al., 2013. Patient costs associated with accessing HIV/AIDS care in Malawi. *Journal of the International AIDS Society,* 16(1).

Piot, P. et al., 2001. *The global impact of HIV/AIDS,* Geneva: Joint United Nations Programme on HIV/AIDS (UNAIDS).

Poudel, A. N., Newlands, D. & Simkhada, P., 2017. The economic burden of HIV/AIDS on individuals and households in Nepal: a quantitative study. *BMC Health Services Research,* Volume 17.

Poudel, N. A., Newlands, D. & Simkhada, P., 2017. The economic burden of HIV/AIDS on individuals and households in Nepal: a quantitative study. *BMC Health Services Research,* Volume 70.

Pouden, A. N., Newlands, D. & Simkhada, P., 2015. Economic Burden of HIV/AIDS Upon Households in Nepal: A Critical Review. *Nepal Journal of Epidemiology,* 5(3), pp. 502-510.

Probst, C., Parry, C. D. & Rehm, J., 2016. Socio-economic differences in HIV/AIDS mortality in South Africa. *Tropical Medicine and International Health,* 21(7), pp. 846-855.

Quintal, C., 2019. Evolution of catastrophic health expenditure in a high income country: incidence versus inequalities. *International Journal for Equity in Health,* Volume 18.

Ridde, V. et al., 2015. The impact of user fee removal policies on household out-of-pocket spending: evidence against the inverse equity hypothesis from a population based study in Burkina Faso. *European Journal of Health Economics,* Volume 16, pp. 55-64.

Ritchwood, T. D., Bishu, K. G. & Egede, L. E., 2017. Trends in healthcare expenditure among people living with HIV/AIDS in the United States: evidence from 10 Years of nationally representative data. *International Journal of Equity for Health,* Volume 16.

Rosen, S., Kethlapile, M., Sanne, I. & DeSilva, B. M., 2007. Cost to patients of obtaining treatment for HIV/AIDS in South Africa. *South African Medical Journal,* 97(7), pp. 524-529.

Rosen, S., Ketlhapile, M., Sanne, I. & Bachman DeSilva, 2008. Characteristics of Patients AccessingCare and Treatment for HIV/AIDS atPublic and Nongovernmental Sites in South Africa. *Journal of International Association of Physicians in AIDS Care,* 7(4), pp. 200-207.

Rosen, S., Ketlhapile, M., Sanne, I. & DeSilva, M. B., 2007. Cost to patients of obtaining treatment for HIV/AIDS in South Africa. *South African Medical Journal,* 97(7), pp. 524-529.

Russell, S., 2004. The Economic Burden of Illness for Households in Developing Countries: A Review of Studies Focusing on Malaria, Tuberculosis, and Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome. *American Journal of Tropical Medicine and Hygiene,* Volume 71, pp. 147-155.

Russell, S., 2004. The economic burden of illness for households in developing countries: A review of studies focusing on Malaria, Tuberculosis, and Human ImmunoDeficiency Virus/Acquired ImmunoDeficiency Syndrome. *America Journal of Tropical Medicine and Hygiene,* Volume 71, pp. 147 - 155.

Sadoh, W. E. & Oviawe, O., 2007. HIV/Tuberculosis Coinfection in a Subsidized HIV Treatment Program. *Journal of the National Medical Association,* 99(6), pp. 627-631.

Sanders, E. J., Agutu, C. A. & Graham, S. M., 2021. Multiple HIV testing strategies are necessary to end AIDS. *AIDS,* Volume 35, pp. 2039-2041.

Smith, J., Ahmed, K. & Whiteside, A., 2011. Why HIV/AIDS should be treated as exceptional: arguments from sub-Saharan Africa and Eastern Europe. *African Journal of AIDS Research,* Volume 10, pp. 345-356.

Souteyrand, Y. P. et al., 2008. Free care at the point of service delivery: a key component for reaching universal access to HIV/AIDS treatment in developing countries. *AIDS,* Volume 22, pp. 161-168.

Statistics South Africa, 2021. *Mid-year Population Estimates,* Pretoria: Statistics South Africa.

Steinert, J. I., Cluver, L., Melendez-Torrez, G. & Romero, R. H., 2017. Relationships between poverty and AIDS Illness in South Africa: an investigation of urban and rural households in KwaZulu-Natal. *Global Public Health,* 12(9), pp. 1183-1199.

Stelmach, R. D. et al., 2021. Financial burdens of HIV and chronic disease on people living with HIV in Coˆte d'Ivoire: A cross-sectional out-of-pocket expenditure study. *PLoS ONE,* 16(7).

Suri, H., 2020. Ethical Considerations of Conducting Systematic Reviews in Educational Research. In: O. Zawchi-Richter, et al. eds. *Systematic Reviews in Educational Research.* Wiesbaden: Springer VS, pp. 41-54.

Suthar, A. B. et al., 2017. Performance-based financing for improving HIV/AIDS service delivery: a systematic review. *BMC Health Services,* Volume 17.

Tarvene, B. et al., 2021. Does universal health coverage reduce out-of-pocket expenditures for medical consultations for people living with HIV in Senegal? An exploratory cross-sectional study. *BMJ Open,* 11(7).

Tawfik, M. G. et al., 2019. A step by step guide for conducting a systematic review and meta-analysis with simulation data. *Tropical Medicine and Health,* Volume 47.

The World Bank, 2013. *World Bank Group President Jim Yong Kim's Speech at World Health Assembly: Poverty, Health and the Human Future,* Geneva: The World Bank.

The World Bank, 2021. *The World Bank in Africa.* [Online]
Available at: https://www.worldbank.org/en/region/afr/overview#1
[Accessed 28 March 2022].

The World Bank, 2021. *The World Bank in Africa.* [Online]
Available at: https://www.worldbank.org/en/region/afr/overview#1
[Accessed 24 March 2022].

Tladi, L. S., 2006. Poverty and HIV/AIDS in South Africa: an empirical contribution. *SAHARA J: Journal of Social Aspects of HIV/AIDS,* 3(1), pp. 369-381.

Trapero-Bertran, M. & Oliva-Moreno, J., 2014. Economic impact of HIV/AIDS: a systematic review in five European countries. *Health Economics Review,* Volume 4.

Tromp, N. et al., 2014. Equity in utilization of antiretroviral therapy for HIV - infected people in South Africa: a systematic review. *International Journal for Equity in Health,* 60(13).

UNAIDS, 2001. *Report on the global HIV/AIDS epidemic,* Geneva: UNAIDS.

UNAIDS, 2021. *Global HIV and AIDS Statistics Fact Sheet.* [Online]
Available at: https://www.unaids.org/en/resources/fact-sheet
[Accessed 24 March 2022].

UNDP, 2013. *UNDP in Sub Saharan Africa; Supporting A Region On The Move,* New York: UNDP.

Veenstra, N., 2006. Social Protection in a Context of HIV/AIDS: A Closer Look at South Africa. *Social Dynamics,* 32(2), pp. 111-135.

Vergnes, J.-N.et al., 2010. Ethics in sytematic reviews. *Journal of Medical Ethics,* 36(12).

Vollmer, S. et al., 2017. The HIV Epidemic in Sub-Saharan Africa is Aging: Evidence from the Demographic and Health Surveys in Sub-Saharan Africa. *AIDS and Behaviour,* Volume 21, pp. 101-113.

Vorkoper, S. et al., 2018. Building on the HIV chronic care platform to address noncommunicable diseases in sub-Saharan Africa: a research agenda. *AIDS,* Volume 32, pp. 107-113.

Vu, L. et al., 2016. Annual cost of antiretroviral therapy among three service delivery models in Uganda. *Journal of the International AIDS Society,* 19(4).

Wagner, R. G. et al., 2016. Health care utilization and outpatient, out-of-pocket costs for active convulsive epilepsy in rural northeastern South Africa: a cross-sectional Survey. *BMC Health Services Research,* Volume 16.

Wagstaff, A., 2008. *Measuring Financial Protection in Health,* Washington: The World Bank.

Wagstaff, A. et al., 2017. Progress on catastrophic health spending in 133 countries: a retrospective observational study. *The Lancet Global Health,* Volume 6, pp. 169-179.

Watson, S. et al., 2016. The impact of user fees on health services utilization and infectious disease diagnoses in Neno District, Malawi: a longitudinal, quasi-experimental study. *BMC Health Services Research,* Volume 16, p. 595.

Weiser, S. D. et al., 2010. Food Insecurity as a Barrier to Sustained Antiretroviral Therapy Adherence in Uganda. *PLoS ONE,* 5(4).

Woolgar, H. L. & Mayers, P. M., 2014. The Perceived Benefit of the Disability Grant for Persons Living With HIV in an Informal Settlement Community in the Western Cape, South Africa. *Journal of the Association of Nurses in AIDS Care,* 25(6), pp. 589-602.

World Health Organization, 2005. *WHO Discussion Paper: The practice of charging user fees at the point fo service delivery for HIV/AIDS treatment and care,* s.l.: World Health Organization.

World Health Organization, 2017. *Zambia HIV Country Profile: 2016,* Geneva: World Health Organization.

World Health Organization, 2018. *South Africa: Country Cooperation Strategy at a glance,* Geneva: World Health Organization.

World Health Organization, 2020. *Financial protection and the Sustainable Development Goals,* Copenhagen: World Health Organization Regional Office for Europe.

World Health Organization, 2021. *World Health Organization.* [Online]
Available at: https://www.who.int/health-topics/universal-health-coverage#tab=tab_1
[Accessed 7 November 2021].

World Health Organization, 2022. *Health Topics/ HIV/AIDS.* [Online]
Available at: https://www.who.int/health-topics/hiv-aids#tab=tab_1
[Accessed 23 April 2022].

World Medical Association, 2013. *World Medical Association Declaration of Helsinki,* Ferney Voltaire: JAMA.

World Population Review, 2022. *HIV rates by country.* [Online]
Available at: https://worldpopulationreview.com/country-rankings/hiv-rates-by-country
[Accessed 23 March 2022].

Wouters, E. et al., 2010. Who is accessing public-sector anti-retroviral treatment in the Free State, South Africa? An exploratory study of the first three years of programme implementation. *BMC Public Health,* Volume 10.

Xu, K., Evans, D. B., Carrin, G. & Aguila-Rivera, A. M., 2005. *Designing Health Financing Systems to Reduce Catastrophic Health Expenditure,* Geneva: World Health Organization.

Yates, R., 2009. Universal health care and the removal of user fees. *The Lancet,* Volume 373, pp. 2078 - 2081.

PART C: MANUSCRIPT

Proposed Journal: BMC Health Services Research

The assessment of out-of-pocket payment removal policies in reducing the economic burden caused by the cost of HIV service utilization in South Africa: A systematic review.

ABSTRACT

Background: The call for universal health coverage (UHC) has led to some policy introductions such as the removal of out-of-pocket payments (OOPs) in the form of user fees at point of care in primary health facilities in South Africa. The cost of healthcare for patients is not only a barrier to access and utilisation but can also lead to catastrophic spending and impoverishment. For people living with HIV (PLWH), health expenses can threaten their financial wellbeing due to HIV treatment requiring multiple health visits and other health-related costs. We examine how the UHC policy of user fee removal has contributed to reducing the economic burden of HIV/AIDS for PLWH and their households.

Methods: Searches were conducted on Africa Wide, CINAHL, EconLit, Health Source, PsycInfo, PubMed and Web of Science. We included quantitative and qualitative articles that reported costs of HIV service utilization or reported impoverishment and CHE as part of their outcomes. We reviewed and extracted data that would assist in answering the review question and reported on the total cost of utilization and its impact on PLWH.

Results: We found 12 eligible articles. The reviewed data showed that PLWH spent a substantial amount of money on transport, additional care such as private doctors, traditional healers, and special food showing that user fee removal alone is insufficient for financial protection. People borrowed money, took interest bearing loans and sold assets to cover healthcare expenses. PLWH experienced CHE across various thresholds, and people in the rural areas had more odds of CHE compared to those in urban areas. Additional care outside of the public health system and transport were drivers of CHE and impoverishment.

Conclusion: The UHC policy of user fee removal at point of care has been beneficial in reducing the economic burden of HIV/AIDS service utilization for people living in close proximity to the primary healthcare facilities and those who receive care in well-resourced facilities. However, the same cannot be said about those who have to travel long distances to

health facilities and are forced to seek additional care for their health needs to be sufficiently met.

Keywords: HIV/AIDS, user fees, catastrophic health expenditure, impoverishment, South Africa

BACKGROUND

The call for universal health coverage (UHC) by the World Health Organization (WHO) has assisted in magnifying the importance of providing free healthcare to those in need and as such, the removal of out-of-pocket payments in the form of user fees at point of care by different countries has succeeded in mitigating challenges of access and utilization for those in need. What seems to be lacking are policies that ensure increased access and utilization without financial distress. We focus on South Africa due to the HIV/AIDS prevalence and because the country runs the largest ART programme in the world (Bekker, et al., 2014). South Africa has implemented policies that ensure that all people who need services have access without paying for them. Of interest is the access to and utilization of services by people living with HIV (PLWH) who are often required to frequently visit their clinics as a measure of adherence through pharmacy refills and CD4 count and viral load monitoring (Eze, et al., 2022; Njagi, et al., 2018). The disadvantage is that clinics do not operate on weekends or public holidays and the expectation is to take time off work and other income generating activities or family responsibilities. This has led to loss of income while having to pay for transport and other costs related to access and utilization (McIntyre, et al., 2006).

The public health system is overwhelmed due to multiple burdens of disease, and many are left unsatisfied with the services they receive and turn to other providers where they end up paying more. Moreover, HIV/AIDS education is still lacking in rural communities and people reach out to traditional healers instead of the healthcare services, where they pay unregulated fees for traditional medicine and services (Moshabela, et al., 2011). This has been reported to lead to catastrophic expenditure in poor households. Income plays a role in determining whether households are impoverished or suffer catastrophic expenditure due to healthcare expenses, and literature shows that HIV/AIDS demographics tend to reflect a population that is poor and unemployed (Tladi, 2006; Collins & Leibbrandt, 2007). Therefore,

we examine how the removal of OOPs has been beneficial in reducing the economic burden of HIV/AIDS on households and PLWH.

The aim of this review is to assess the removal of OOPs in the form of user fees at the point of care as sufficient in reducing or preventing the economic burden they cause combined with other costs, by reviewing literature looking at the total cost of HIV service utilization including direct and indirect costs. These costs are reported as per visit and as monthly expenses. We further examine whether the cost of HIV services utilization leads to impoverishment and CHE, which is indicative of whether the policy has been effective in protecting households from financial risk. The review uses quantitative methods to present, aggregate costs of care and determine CHE, and qualitative methods to present and provide depth to the causes of CHE and impoverishment.

METHODS

We conducted a systematic review on the economic burden caused by HIV service utilization as a measure of effectiveness of the removal of OOPs at point of care at primary healthcare level for people living with HIV in South Africa. We conducted a search within seven electronic databases: Africa Wide, CINAHL, EconLit, Health Source, PsycInfo, PubMed and Web of Science. The search strategy was the same across all electronic databases but included subject headings for CINAHL and MeSH Terms for PubMed. The search was not filtered to South Africa as we found that applying this filter excluded other articles published on this subject based on data collected in South Africa.

Search Strategy

We used the following search strategy across all databases between 25 May 2022 and 19 September 2022:

[((HIV OR AIDS OR “People living with HIV” OR Human Immunodeficiency Virus OR Acquired Immunodeficiency Syndrome) OR (ART OR antiretroviral treatment OR antiretroviral therapy OR Highly Active Antiretroviral therapy OR HAART)) AND (Healthcare cost* OR health expenditure OR out-of-pocket payment*) AND (Economic burden OR financial distress OR household burden OR Catastrophic expenditure OR Impoverishment OR financial burden OR

"cost of illness" OR financial stress OR financial pressure* OR financial toxicity* OR financial challenge* OR financial hardship* OR economic hardship*)].

The following subject headings were used for CINAHL: (MH Human Immunodeficiency Virus), (MH HIV-Positive Persons), (MH Acquired Immunodeficiency Syndrome), (MH Antiretroviral Therapy, Highly Active), (MH Health Care Costs), (MH Financial stress).

The following MeSH terms were used in PubMed: HIV OR Acquired Immunodeficiency Syndrome [MeSH], Antiretroviral therapy, Highly Active [MeSH], Health Care Costs OR Health expenditures [MeSH], Financial stress OR cost of illness [MeSH].

Inclusion

Initially, the inclusion criteria aimed to include articles published between 2004 and 2018 but, during the search we found that this limited evidence volume, and we included articles published between 2004 and 2021. We included both qualitative and quantitative studies that were conducted in South Africa, they reported direct and/ or indirect costs incurred by patients who were receiving care at primary healthcare level and were published in English.

Exclusion

We excluded studies that (i) were not conducted in South Africa or did not include data from South Africa, (ii) were not disease (HIV) specific and reported economic burden on all chronic illnesses, (iii) reported costs from a provider perspective, (iv) were primarily focused on hospital inpatient stay, (v) had objectives that were not aligned with the primary objective of the review such as focusing on macroeconomic economic burden instead of individual or household burden, (vi) did not include any of variables of interest (costs of HIV service utilization, CHE or impoverishment) which are required to answer the review question, (vii) were conducted prior to 2004 which is before the free HIV care at primary health facilities policy was introduced, (viii) had no full-text available and (ix) were commentary or discussion papers.

Selection process

The references found in the electronic databases were managed in EndNote where duplicates were checked and manually removed (Lorenzetti & Ghali, 2013). Secondly, references were exported to Rayyan to perform Title, Abstract and Full-Text screening. Rayyan detected duplicates which were then resolved and manually deleted. Two reviewers who worked

independently and were blinded to each other's selections conducted the Title and Abstract screening to minimize risk of bias (Kellermeyer, et al., 2018). References selected at this stage were moved to full-text screening stage following the same procedure of two independent reviewers blinded from each other's selections. Conflicts at both stages of screening were resolved through discussion by the two reviewers with reference to inclusion and exclusion criteria and review outcome. The PRISMA 2020 flow diagram details the number of all articles found, duplicates removed, articles screened, articles included, and those excluded with reasons.

Quality of the articles included was assessed using the Strengthening the Reporting of Observational studies in Epidemiology (STROBE) guidelines (Cushieri, 2019). This guideline was created to ensure adequate and quality reporting for observational studies and to assess the strengths and weaknesses to assist in establishing eligibility for inclusion in systematic reviews (Cushieri, 2019). We used the 22-item checklist version that combines cohort, cross-sectional, and case-control studies covering key components of title and abstract, introduction, methods, results, and discussion. We answered checklist items with 'Yes' where studies reported fully or partially what is required and 'Not reported' (NR) where studies did not report as stated in the guideline. A full version of the STROBE checklist can be found in *Appendix 1* of this document where all checklist question and items are explained in detail.

Data management

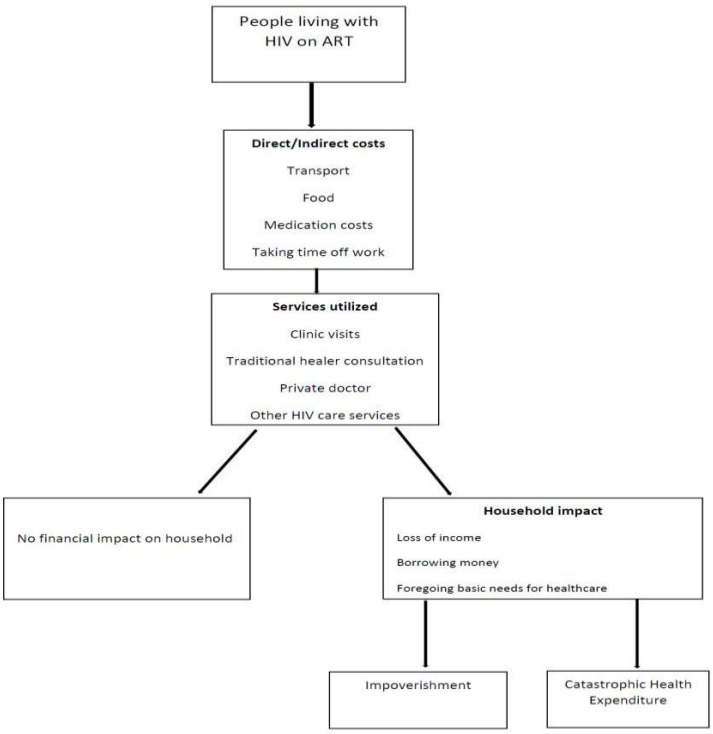
We stored articles that were included in Rayyan (Kellermeyer, et al., 2018), and Google Drive where they could be accessed by reviewers at any time when questions came up.

Data extraction

Using Microsoft Excel, we extracted data on study characteristics as listed in the extraction tool *in Table 2.* We further extracted data on total costs of utilization to meet the first objective of the study, then we extracted direct and indirect costs incurred by households for all HIV care related services guided by the framework of analysis in *Figure 1,* based on the NCCID approach to measure economic burden of disease (National Collaborating Centre for Infectious Diseases, 2016). We also extracted CHE results and the various thresholds used by

the studies. As a measure of impoverishment, we extracted data reporting coping mechanisms applied by households to cover costs and to cope after paying for healthcare.

Figure 1: Framework of analysis *(adapted from NCCID variables for economic burden of disease)*



Data synthesis and analysis

We used a mixed-methods approach because the economic burden of disease is assessed and reported using quantitative and qualitative methods and articles found were of the two methods. We analysed the quantitative data and qualitative data separately and results were organized and reported by cost items and outcomes. The framework of analysis *(Figure 1)* was used to determine which cost items should be included in determining the total cost of care. Where costs were reported in USD, we converted to ZAR (Rands) using The Economist's Index rate of the year the study was published where studies did not specify the year of exchange rate used. After costs had been converted from USD to the ZAR currency; we adjusted for inflation with 2022 as target year because this is the year the review was conducted and reported. We used the Consumer Price Index (CPI) formula for adjustment (Turner, et al., 2019). Dunn, et al. (2016) suggest using the CPI when comparing consumer out of pocket spending on health care services across time. The South Africa CPI across different

study years and 2022 was extracted from the Organization for Economic Co-operation and Development (OECD) data webpage (Organization for Economic Co-operation and Development, 2023).

Different studies reported total costs of care per visit, others as monthly costs and others as annual costs. We grouped those that reported the total costs per visit to determine the mean per visit, then we grouped those that reported per month costs to determine the per month mean. The annual costs were reported as they were without calculating the mean.

We combined traditional healers and private doctor costs into one because two studies reported them as one variable. Then we also reported private doctors and traditional healers separately because other studies did not combine costs. The same was done with special foods and medicine where we also combined into one variable because three studies reported them as such, then also split them to accurately report for studies that did not combine these variables. We combined public hospital outpatient and clinic fees into one variable. We excluded clinic fees where it was clearly stated that the clinic charged a fee, but we included the item where it was stated that the facility was a no fee facility, yet patients paid. Time was converted into hours where studies reported more than 60-minutes to simplify reporting. Costs that were reported as overall per visit or monthly costs were not included in the individual cost items but were reported under per visit/monthly costs.

CHE was reported according to how it was observed by the different studies, and this gave variation of observed CHE for PLWH across different thresholds. For studies that did not report CHE but provided the monthly total cost of healthcare and income, CHE was determined using the 10% of health expenditure exceeding the household income. We could not determine CHE for studies that did not include data on total health expenditure and household income. Impoverishment was reported according to how studies reported it, using variables of borrowing money or sale of assets.

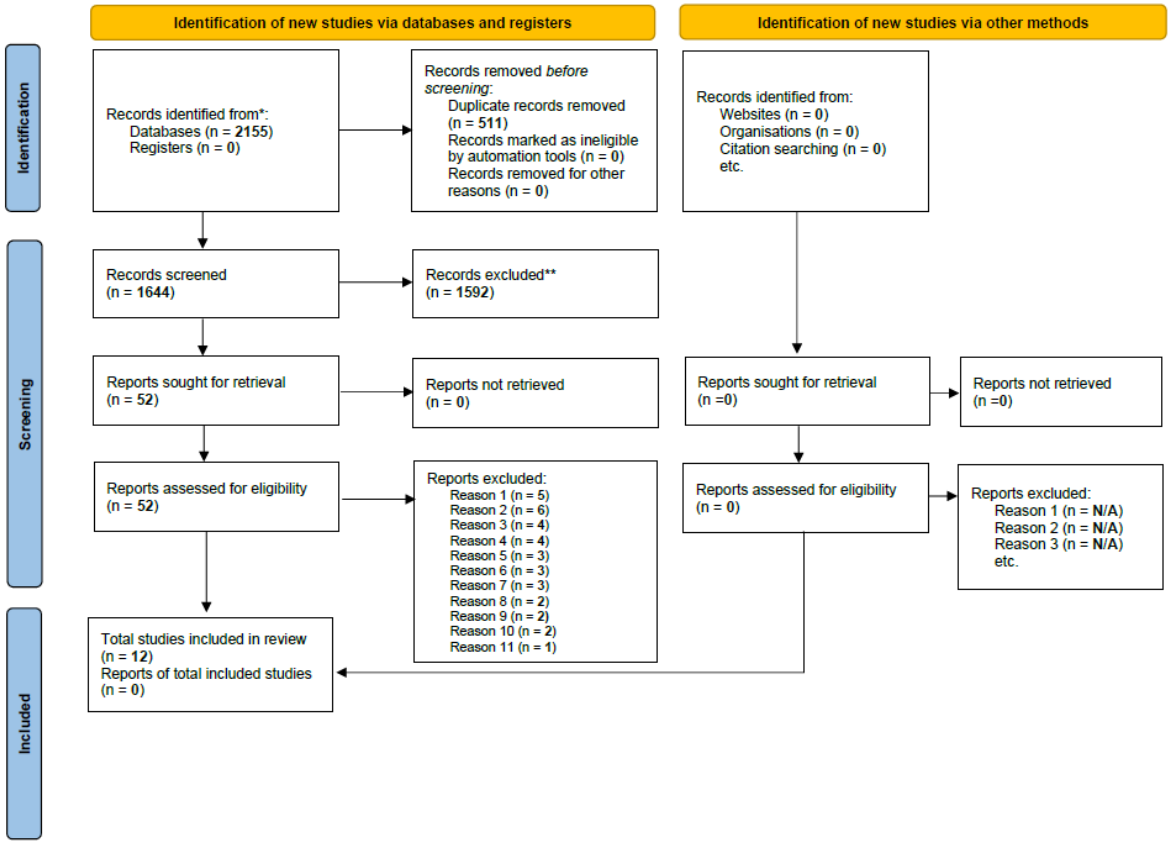
RESULTS

We identified 2155 articles from seven databases. 511 duplicates were removed prior to Title and Abstract screening. After screening of Title and Abstract, we excluded 1592 articles because they did not cover costs on HIV/AIDS, were not conducted in South Africa, were

conducted before 2004, did not report costs from the patient perspective and had no variables aligned with the review objectives. 52 articles met eligibility for full-text screening and 12 remained for final inclusion.

We excluded 40 articles for the following reasons: they were not HIV-specific but pooled HIV/AIDS data with other non-communicable diseases or chronic illnesses (5), study objectives were not aligned with thesis question because they focused on determinants of HIV/AIDS or reported costs that were not HIV care related (6), gave an international account of the economic burden of disease or HIV/AIDS with no specific data on South Africa (4), did not report any data on impact of cost or utilization (4), reported from the provider perspective (3), were published prior to the review period of 2004 (3), reported the macroeconomic impact of HIV/AIDS without specific data on households/individuals (3). Two studies were excluded because no full-text documents were available, another two were commentary papers, one was a duplicate of another study, and lastly, one was an ongoing study report. A summary of the search and inclusion/exclusion can be seen in the PRISMA diagram in *Figure 2* below.

Figure 2: *Prisma 2020 flow diagram for search results*



During quality assessment of the studies, of the twelve studies assessed, *Table 4* shows that two studies did not report nine out of the 22-item checklist, these are marked in orange. One was a qualitative study and was therefore not a perfect fit for the checklist, while the other was a cohort study reflecting poor reporting according to the guideline. Three studies did not report three items out of the 22-item checklist, and these are marked in yellow. Nine studies described efforts to address potential bias, eleven declared funding and reported on limitations that include potential bias. No studies were excluded from the review because they did not obtain the full score, this is based on the premise that; studies that poorly report their methods are not necessarily poor in quality (Dalton, et al., 2017).

A summary of included studies can be found in *Table 5* with characteristics such as author, year, year of study, treatment phase (pre-ART or ART), province, the population of study, healthcare level, study objectives, and type of costs. The studies included were conducted in seven out of the nine provinces of South Africa, with a mix of rural and urban settings, and one study was based on national data.

Table 4: **STROBE Checklist**

Item No.	*Bachmann & Booysen, 2004*	*Chimbindi, et al., 2015*	*Cleary, et al., 2012*	*Hoffmann, et al., 2018*	*Lines & Sulman, 2017*	*Mafune, et al., 2017*	*Moshabela, et al., 2012*	*Mudzengi, et al., 2017*	*Negin, et al., 2017*	*Pillai, et al., 2019*	*Rosen, et al., 2007*	*Wouters, et al., 2010*
1	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
3	Yes	Yes	Yes	Yes	Yes	Yes	NR	Yes	Yes	Yes	NR	NR
4	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
5	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
6	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
7	Yes	Yes	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	NR	Yes
8	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
9	Yes	Yes	Yes	Yes	Yes	NR	Yes	Yes	NR	NR	Yes	Yes
10	NR	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NR	Yes
11	Yes	Yes	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	NR	Yes
12	Yes	Yes	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	NR	Yes
13	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
14	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
15	Yes	Yes	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	Yes
16	Yes	Yes	Yes	NR	Yes	NA	Yes	Yes	Yes	Yes	NR	Yes
17	NR	NR	Yes	NR	NR	NA	NR	NR	NR	Yes	NR	NR
18	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
19	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NR	Yes
20	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
21	NR	Yes	Yes	Yes	Yes	Yes	NR	NR	NR	NR	NR	Yes
22	Yes	Yes	Yes	Yes	NR	Yes	Yes	Yes	Yes	Yes	Yes	Yes

*NA= Not Applicable, *NR= Not reported

***Table 5*: Summary of study characteristics**

Item	Author	Year of study	Treatment phase	Population	Province	Healthcare level	Economic perspective	Objectives	Type of costs
1	Bachmann & Booysen, 2004	2001	ART	202 Households with HIV-infected member, 202 neighbouring unaffected households	Free State	PHC	Patient	To estimate the differences in income and expenditure between affected and unaffected households, adjusted for baseline differences, as indicators of the economic impact of HIV/AIDS on households.	Transport, consultation fees, hospital, medicine
2	Chimbindi, et al., 2015	2010	Pre-ART and ART	200 HIV- infected patients not yet on ART (pre-ART), 300 ART patients, and 300 TB patients receiving public sector care in rural South Africa	KwaZulu Natal,	PHC	Patient	To provide insight into the true costs of healthcare seeking for public sector patients.	Transport, private doctor, traditional healer, food, medicine, hospital/clinic fees, time
3	Cleary, et al., 2012	2012	ART	A representative sample of 1267 ART users were interviewed within 12 ART facilities across the four settings	Mpumalanga, Gauteng, Western Cape and KwaZulu Natal	PHC and secondary level	Patient	To assess barriers along three dimensions: availability, affordability and acceptability.	Transport, private doctor, traditional healer, special food, medicine, time, childcare, accommodation, other providers
4	Hoffmann, et al., 2018	2016	ART	15 adults with HIV from a hospital discharge study.	North-West,	PHC	Patient	To quantify time spent on each component of a clinic visit while receiving care following a hospital admission in South Africa.	Transport, food, loss of income, time
5	Lines & Sulman, 2017	2014	ART	117 patients from five different primary health care collection points and a hospital anti-retroviral clinic.	Eastern Cape,	PHC and secondary level	Patient	To ascertain the perceptions and satisfaction of patients in terms of the decentralised anti-retroviral policy and the direct out-of-pocket expenses of patients accessing this care in a rural setting.	Transport
6	Mafune, et al., 2017	2013-2014	ART	16 caregivers of children between 0-15 years who are on ART	Limpopo	PHC	Patient	To explore and describe the challenges faced by caregivers of children on ART at Mutale Municipality, Vhembe District, Limpopo Province.	Transport, time

7	Moshabela, et al., 2012	2008-2009	ART	1266 patients taking ART in two rural and two urban sub-districts.	Mpumalanga, Gauteng, Western Cape and KwaZulu Natal	PHC and secondary level	Patient	To investigate factors associated with patterns of plural healthcare usage among patients taking ART in diverse South African settings.	Private specialist, hospital, traditional healer
8	Mudzengi, et al., 2017	2013	ART	454 participants with TB or HIV or both in public primary health care clinics in Ekurhuleni North Sub-District, South Africa.	Gauteng	PHC	Patient	To comprehensively describe the post diagnosis care-seeking behaviour, patient costs incurred, and coping strategies adopted by people living with TB and/or HIV and their households, in order to identify the potential benefits of integrated care.	Transport, special food, caregiver, loss of income, time, other facility
9	Negin, et al., 2017	2007-2008	ART	147 HIV-positive and 2725 HIV-negative respondents aged 50+ years in the SAGE South Africa Wave 1 dataset	All nine provinces	PHC and secondary level	Patient	To use nationally representative data to compare the health utilisation and health expenditure patterns of HIV-positive and HIV-negative older adults living in South Africa.	Transport, private doctor/clinic/hospital, traditional healer
10	Pillai, et al., 2019	2013-2014	ART	289 HIV positive patients	Gauteng	PHC	Patient	To quantify costs to patients of accessing HIV care prior to ART initiation.	Travel, private doctor, diagnostic tests, carer, supplements, time
11	Rosen, et al., 2007	2005-2006	ART	1072 patients on ART	Mpumalanga and Gauteng	PHC and secondary level	Patient	To find out how much ART patients in South Africa are spending on their care.	Transport, food, medication, clinic fees, loss of income, time, other medical care
12	Wouters, et al., 2010	2004-2006	ART	912 patients enrolled in the public sector ART programme	Free State	PHC	Patient	To extend the current literature by investigating, in a quantitative manner and using a longitudinal study design, the participants enrolled in the public-sector ART programme in the period 2004-2006 in the Free State Province of South Africa	Transport

Eight healthcare cost items of direct and indirect costs were reported by the studies, and each is discussed below in the summary of findings including how it was reported. In *Table 6* we show a summary of cost items reported and the cost ranges. Eight studies reported the total cost of healthcare utilization, and five did not report the total of the costs but instead reported per item *(Table 7).* Eight studies reported income at household level, and one reported individual income. Table 6 presents eight studies that reported on impoverishment, and four reported CHE and thresholds. We marked NR (not reported) where articles did not report income, total cost of healthcare expenses, observed impoverishment or CHE, or the variables were not included as outcomes. We marked N/A (not applicable) where no CHE thresholds were reported because the study did not include CHE as an outcome. Below we provide a summary of findings.

***Table 6*: Cost items and total costs reported**

Author	Transport	Private doctor + traditional healer	Private doctor only	Traditional healer only	Special food and medicine	Special foods only	Hospital and clinic fees	Income lost	Time
Bachmann & Booysen, 2004	R120.73 incl. all monthly health expenditure	NR	NR	NR	NR	NR	NR	NR	NR
Chimbindi, et al., 2015	R7.87 pre-ART p/m; R58.22 ART p/m	N/A	R47.52 pre-ART p/m; R36.82 ART p/m	R45.79 pre-ART p/m	R132.96 pre-ART p/m; R144.29 ART p/m	N/A	R1.57	NR	3.5 hrs pre-ART per visit; 2.8 hrs ART per visit
Cleary, et al., 2012	R65.57 and R66.95 at rural sites; R16.12 and R12.86 at urban sites	R32.68 and R36.71 at rural sites; R32.59 and 34.60 at urban sites	N/A	N/A	R45.22 and R131.80 at rural sites; R2.79 and R19.34 at urban sites	N/A	NR	NR	23-74 min of travel, 3,5hrs - 4hrs seeing doctor/nurse, 1.6-4hrs collecting medication
Hoffmann, et al., 2018	R26.63 round trip	NR	NR	NR	NR	NR	R26.63 - R102.52	1 person missed 1 workday, 3 people forewent income	4.5hrs travel and waiting at clinic.
Lines & Sulman, 2017	R38.48 at primary clinic; R107.26 hospital-based clinic	NR	NR	NR	NR	NR	NR	NR	NR
Mafune, et al., 2017	Majority reported transport costs as highest contributor to financial burden	NR	NR	NR	NR	NR	NR	NR	Time lost while waiting at clinic contributed to financial burden
Moshabela, et al., 2012	NR	33.8% used services outside public clinic and 18.9% used mix of private providers	N/A	R1933.16	NR	NR	NR	NR	NR

Mudzengi, et al., 2017	R29.33 for patient and guardian	NR	NR	NR	NR	NR	NR	R45.73; R63.08	23.4hrs travel per month for all health visits
Negin, et al., 2017	34% used public and private transport	25% used private outpatient services	N/A	N/A	NR	NR	NR	NR	NR
Pillai, et al., 2019	R94.66 incl other direct non-medical costs	N/A	R25.34	NR	NR	R50.68	NR	NR	R28.80 and R68.57 worth of time spent at clinic
Rosen, et al., 2007	R96.56 for 75% of participants; R120.70 for 10% of participants round trip	NR	NR	NR	R277.61	NR	R53.11	R14 per visit and 4-15% paid for substitute labour	1.5hrs for patient and 2.6 hrs for caregiver per visit
Wouters, et al., 2010	R20.28 single trip	NR	NR	NR	NR	NR	NR	NR	NR
Number of studies reported	**11**	**3**	**2**	**2**	**3**	**1**	**3**	**3**	**7**

Transport

Eleven studies reported transport costs, ranging from the lowest at ZAR7.87 to ZAR107.26 as the highest cost paid based on different treatment stages, one-way or round trips, mode of transportation, geographic setting, and per visit/month/year period. Three studies lumped transport costs together with other cost items which were then not included in the cost range for transport. Chimbindi, et al. (2015) reported pre-ART and ART patient utilization costs and mentioned that transport costs were the largest expense out of all expenses reported, with pre-ART patients paying ZAR7.87, and ART patients paying ZAR58.22 per month. Hoffmann, et al. (2018) reported ZAR26.63 for travel to and from the clinics where out of the 15 participants, 10 used public transport, one used private transport and one walked. Lines & Suleman (2017) reported on patients at a hospital-based primary clinic and primary healthcare clinic in a rural setting, and patients at a hospital-based clinic spent ZAR107.26 while those at the PHC spent R38.48. Rosen, et al. (2007) reported that 75% of the participants paid R96.56 or less for a round trip and 10% paid R120.70 for a round trip. In Cleary, et al., (2012) four urban and rural sites were compared, and food and transport costs were combined with a total of ZAR65.57, ZAR66.95, ZAR16.12 and ZAR12.86. Mudzengi, et al. (2017) reported patient and guardian travel with a total of ZAR29.33 combined. Wouters, et al. (2010) shows that participants incurred a mean of ZAR20.28 for a one-way trip to the facility.

Negin, et al. (2017) does not specify amount spent on transport but shows that 34% (32/81) of the participants who used transport to get to the facility used public transport, a private taxicab or private vehicle. Pillai, et al. (2019) found that 39% of the participants used a taxi and bus, 5% used their own cars and 57% walked, no specific transport costs were reported but they formed part of the direct non-medical cost of ZAR94.66. Similarly, Bachmann & Booysen (2004) reported transport costs as part of the overall monthly health expenditure of ZAR120.73. Mafune, et al. (2017) interviewed caregivers of children on ART and the majority reported transport costs incurred during follow-up visits to the clinic as one of the highest contributors to the financial burden of caring for children on ART.

Medical pluralism: Private doctors and traditional healers

Five studies reported using private doctors and three reported the use of traditional healers with costs ranging between ZAR25.34 and ZAR1933.16. Chimbindi, et al. (2015) reported that pre-ART patients spent ZAR47.52 at a private doctor and ZAR45.79 for a traditional healer, ART patients spent ZAR36.82 on a private doctor. Cleary, et al. (2012) found that participants in the two rural and two urban sites spent ZAR32.68, ZAR36.71, ZAR32.59 and ZAR34.60 for private doctors and traditional healers. Pillai, et al. (2019) reported a cost of ZAR25.34 for a private doctor. Negin, et al. (2017) do not report costs but indicate that in their study of older adults across the country, 25% of people used private outpatient health services. Moshabela, et al. (2011) reported that 33.8% of the participants used other services outside of the PHC, 18.9% of the participants used a mix of medical providers, and further show that although use of traditional healers was low, the highest amount spent on this service was ZAR1933.16.

Medical pluralism: Medicine and special foods

Five studies reported purchase of medicine and special foods starting from ZAR2.79 – ZAR277.61. Chimbindi, et al. (2015) found that pre-ART patients purchased traditional medicine and special foods for ZAR132.96, ART patients spent ZAR144.29. Cleary, et al. (2012) reported that across the four rural and urban settings people spent ZAR45.22, ZAR131.80, ZAR2.79 and ZAR19.34 on special foods and medicine. In their study conducted in Mpumalanga, KwaZulu Natal and Gauteng, Rosen, et al. (2007) reported that people spent

ZAR277.61 on special food and medicine. Pillai, et al. (2019) reported ZAR50.68 spent on special food.

Public clinic and hospital fees

Three studies reported public hospital outpatient and clinic fees. Chimbindi, et al. (2015) reported that there were clinic fees paid by patients which were less than ZAR1.57, but they could not establish what the fees were for because services were provided at no fee. Rosen, et al. (2007) also mention that ART was provided for free at the clinics, but service fees of ZAR53.11 were charged to those who were able to pay. Hoffmann, et al. (2018) report that two participants paid between ZAR26.63 – ZAR102.52 to open a file at the clinic but these costs were not included in overall analysis. The cost range therefore stands at ZAR1.57-ZAR102.52.

Loss of income

Three studies reported on income in the form of money and job loss. Mudzengi, et al. (2017) reported that participants lost income of ZAR45.73 due to time spent seeking care and 3% lost their jobs due to illness. They further report that guardians lost ZAR63.08 in monetary value of time. Rosen, et al. (2007) found that 4-15% of the participants paid for substitute labour when visiting the clinic and 4-16% were losing income, and the overall mean of income lost by participants across all sites was ZAR14 per visit. Hoffmann, et al. (2018) do not specify the cost but found that one participant missed one workday and three people forewent income on day of visit.

Time

While most studies did not quantify time into costs, seven studies reported time as a contributor to cost of healthcare utilization and one study reported time as costs. Chimbindi, et al. (2015) reported that pre-ART patients spent 3.5 hours at the clinic per visit and ART patients spent 2.8 hours. Mudzengi, et al. (2017) found that participants lost 23.4 hours travelling and accessing care across all health providers in a month. Rosen, et al. (2007) measured time in travel time for the clinic visit (1.5hours) and time required for the caretaker (2.6 hours). Pillai, et al. (2019) valued the time spent at the clinic at ZAR28.80 when using

reported income approach and ZAR68.57 using the minimum wage approach. Cleary, et al. (2012) reported time spent travelling and accessing care across four urban and rural sites ranging between 23 – 74 minutes of travel, 3.5 – 4 hours seeing the doctor/nurse and 1.6 – 4 hours collecting ART. Hoffmann, et al., (2018) reported travel and waiting time which was 4.5 hours combined. Mafune, et al. (2017) reported that, time lost while waiting for consultations also contributed to the financial challenges faced by caregivers of children on ART.

Total cost of healthcare utilization

Eight studies reported the total cost of healthcare utilization, but they reported over different periods of one month, a year or according to each visit as shown in *Table 7*. Bachmann & Booysen (2004) reported ZAR395.44 per month, Chimbindi, et al. (2015) reported ZAR258.05 (ART) and ZAR273.78 (pre-ART) per month, Cleary, et al. (2012) reported ZAR51.50, ZAR67.31, ZAR143.48 and ZAR234.40 per month across four different sites, Mudzengi, et al. (2017) reported ZAR605.52 per month. Pillai, et al. (2019) reported ZAR131.18 per month for healthcare expenses. Hoffmann, et al. (2018) reported ZAR62.58 per visit, and Rosen, et al. (2007) reported ZAR231.75 per visit. Finally, ZAR817.84 per year was reported by (Negin, et al., 2017). Based on per month extracted utilization costs, we found that the mean monthly cost for HIV services utilization was ZAR239, and the per visit mean was ZAR146.

***Table 7*: Cost of care and reported income**

Author	USD>ZAR Exchange rate	Total cost of care	Mean (cost of utilization)	HH income
Bachmann & Booysen, 2004	$1USD = 6.71ZAR	R395 (p/m)		R2573 p/m
Chimbindi, et al., 2015		R258 (ART) – R273 (pre-ART) p/m		NR
Cleary, et al., 2012		R51 – R234 in past month		NR
Mudzengi, et al., 2017	$1USD = 9.62ZAR	R605 (p/m)		R788-R2275 p/m
Pillai, et al., 2019	$1USD = 9.66ZAR	R131 (p/m)	R239 p/m	R2082 p/m
Hoffmann, et al., 2018	$1USD = 15ZAR	R62 (p/v)		R3262 p/m
Rosen, et al., 2007		R231 (p/v)	R146 p/v	NR
Negin, et al., 2017		R817 (p/y)		R22501 (p/y)
Lines & Sulman, 2017		NR		R2429 p/m
Mafune, et al., 2017		NR		R536-R1788 p/m
Moshabela, et al., 2012	$1USD = 8.00ZAR	NR		NR
Wouters, et al., 2010		NR		R1979- R4000 p/m

*p/m = per month; *p/v = per visit

Income as determinant of CHE and impoverishment

Nine studies reported on income using estimated income, self-reported income, and ranges between the low and high income in their population as seen in *Table 7* above. Bachmann & Booysen, (2004) reported ZAR2573, Hoffmann, et al. (2018) ZAR3262, Lines & Suleman, (2017) ZAR2429, Mafune, et al. (2017) reported between ZAR536 – ZAR1788, Mudzengi, et al., (2017) reported between ZAR788 – ZAR2275, Negin, et al., (2017) ZAR22501 per year, Pillai, et al. (2019) reported ZAR2082 as per month average for study population, and Wouters, et al. (2010) reported between ZAR1979-ZAR4000 with more than half of the participants receiving social welfare grant. Additionally, Negin, et al. (2017) reported that in the demographics, a greater proportion of HIV households fell into the lowest income group compared to the HIV negative households who were in the higher income group. Lines & Suleman, (2017) reported that only seven out of the 117 participants were employed, and income was sourced from child support or pension grants. In Pillai, et al., (2019), out of the cohort, 41% lived on less than ZAR447 per month which at the time was reported to be below the World Bank poverty threshold, and with 21% receiving a government grant as their primary source of income.

Catastrophic Health Expenditure

Four studies reported CHE as a result of spending on HIV care using different thresholds *(Table 8)*. Cleary, et al. (2012) determined CHE using the more than 10% of household income spent on healthcare. They found that total expenditure was higher in the two rural sites of Hlabisa, and Bushbuckridge compared to the urban sites in Soweto and Mitchells Plain, and this was driven by self-care expenses which included traditional healers, special foods, and as a result, CHE was observed in 50% of participants in Hlabisa. Moshabela, et al. (2011) calculated CHE as mean monthly health expenditure of more than 15% mean monthly expenditure. 34.8% of people who used additional services such as traditional healers and private chemists experienced CHE compared to 6.9% who did not seek additional care outside of their ART programme, and CHE levels were higher in 77.2% of those in the rural settings compared to 22.8% of the urban residents. Mudzengi, et al. (2017) determined CHE using the threshold variation of 5-25% of health expenditure exceeding income and found that more than 70% of

HIV only participants faced CHE at the 5% threshold, but the percentage dropped at higher thresholds. When considering direct costs only (travel, food, and service at other facilities according to their definition) the percentage of participants experiencing CHE was reduced (Mudzengi, et al., 2017). Negin, et al. (2017) used the threshold of household OOP payments being 40% or above the household's capacity to pay. They found that 8.7% of HIV positive participants experienced CHE at 40% and rural households had greater odds of CHE at 30% threshold than those in urban areas (Negin, et al., 2017).

Table 8: **Catastrophic Health Expenditure and Impoverishment**

Author	Impoverishment	CHE	CHE %
Bachmann & Booysen, 2004	Expenditure on medicine, transport, consultation, hospital fees higher in HIV affected households.	NR	N/A
Chimbindi, et al., 2015	36% ART, 29% pre-ART borrowed money (R280 and R278) and sold assets for health costs and were driven into debt.	NR	N/A
Cleary, et al., 2012	36%, 27%, 2%, 12% across all sites sold assets and borrowed money to pay for healthcare.	50% of respondents in rural site incurred catastrophic expenditure.	CHE calculated as HE exceeding 10% of HH expenditure
Hoffmann, et al., 2018	NR	NR	N/A
Lines & Sulman, 2017	Over 70% of the study sample lived below the food poverty line and 93% are poor by definition.	NR	N/A
Mafune, et al., 2017	Caregivers borrowed money, accumulated, and lived in debt due to transport for clinic follow-ups and food.	NR	N/A
Moshabela, et al., 2012	18.7% of the total sample reported having to borrow money (18.7%) and at times sell their belongings (4.9%) in order to finance healthcare.	34.8% of plural healthcare users. CHE was identified in 77.2% of plural healthcare users with rural origin.	CHE calculated as HE 15% more than HH expenditure
Mudzengi, et al., 2017	11% took loans at 22% interest, 2% sold assets	>60% of all participants face catastrophic costs at the 10% threshold. >70% of HIV-only participants experienced catastrophic costs at 5% threshold.	CHE calculated as 5% - 25% HE exceeding HH income
Negin, et al., 2017	NR	8.7% of HIV+ group experienced CHE at a 40% threshold. Rural households having 2.7 times greater odds (95% CI 1.7–4.3) of CHE at 30% compared to urban.	CHE when HH total OOP payments were 40% or more of its capacity to pay.
Pillai, et al., 2019	Some participants (14%) borrowed money in order to cope with pre-ART care costs, with more than half of those who borrowed money (69%) having to pay interest on money borrowed.	NR	N/A

Rosen, et al., 2007	NR	NR	N/A
Wouters, et al., 2010	NR	NR	N/A

*NR Not Reported, *N/A Not Applicable

Impoverishment

Seven studies reported on participants borrowing money, selling assets, and increased expenditure to cover health costs or to cope after paying for health services *(Table 8).* Bachmann & Booysen, (2004) reported that expenditure in HIV affected households increased over time compared to unaffected households. Chimbindi, et al. (2015) found that 36% of ART patients borrowed an amount of ZAR280 and 29% of pre-ART borrowed ZAR278, they also sold household assets and were driven into debt due to health costs. Cleary, et al. (2012) reported that 27.24% in Bushbuckridge, 36.33% in Hlabisa, 1.81% in Soweto and 11.8% in Mitchells Plain sold assets and borrowed money for healthcare expenses. Mafune, et al. (2017) found that caregivers looking after children on ART borrowed money to cover transport costs and lived in debt due to food costs and follow-up visits at the clinic. Moshabela, et al. (2011) findings show that of the total sample, 18.7% reported borrowing money and 4.9% sold their belongings to cover health expenses. Taking loans that bear interest was reported by Mudzengi, et al. (2017) with 11% of people taking loans at 22% interest, and 2% selling their assets. Similarly, 14% in Gauteng borrowed money to cope with pre-ART costs and of this number, 69% had to pay interest on that money (Pillai, et al., 2019).

DISCUSSION

The review set out to assess whether the user fee removal policy is alone sufficient in reducing the likelihood of impoverishment and CHE for people living with HIV by looking at costs incurred in direct and indirect costs for their HIV care. We also assessed how much of their household income and resources are spent on health expenses. Furthermore, we determined how these costs affect their financial well-being through examination of whether they experience CHE and impoverishment or they are unaffected. Through review of the different studies, we found that transport and seeking additional care outside of the public health service drives households to CHE or impoverishment. Moreover, people in rural settings are

reported to be most affected compared to those in urban settings, and in the same breath, the demographics on income show that most people seeking HIV care are unemployed and rely on social welfare grants. Loss of income due to missed days of work is not highly reported because of the high levels of unemployment, but job loss due to illness is a threat to financial well-being.

The results show that the economic burden is evidently caused by costs paid outside of the health facilities, particularly seeking of additional care from other providers in the private sector, and transport costs. While seeking additional care from other providers can be viewed as optional for PLWH, lack of HIV education and awareness, and poor public health service delivery are some of the reasons people choose to seek care from other providers. These factors can be attributed to an overwhelmed public health system that is faced with skills shortages and a quadraple burden of disease (World Health Organization, 2018; Mayosi, et al., 2012). Further investment is required to ensure that patient health needs are sufficiently met to prevent catastrophic spending outside the public health system.

The cost of transport is a challenge that needs to be addressed from both a clinical and health policy perspective as it serves as a barrier to treatment adherence and service utilization, thereby affecting health outcomes. The amount of time spent travelling to facilities shows that people live far from health facilities even though McLaren, et al. (2014) showed that 90% of people in the country live within 7km to their closest health facility. However, the long distance travelled is in line with findings in Goudge, et al. (2009) where people in rural communities are reported to still travel long distance to health facilities.

The loss of income due to time spent seeking care does not appear to be a major contributor to the economic burden for the unemployed, because there is no income affected but it is a cause for concern for those who lose their jobs due to illness. This is consistent with findings by Bachman & Booysen (2003) that people losing income while taking care of the sick or seeking care is a rare occurrence in South Africa because of the high unemployment rate. What also needs further consideration is the amount of time (23.4 hours) spent across all providers in a month which is equivalent to three working days. On the other hand, the unemployed cannot be viewed as unaffected by the time spent seeking care because they do

not suffer financial loss, there are factors such as childcare and other responsibilities they need to forego while seeking care, even though these have no financial benefit.

PLWH do not seem to spend a substantial amount of money on costs at the facility where they receive their HIV care but spend more on additional care due to factors of service quality and access. The total cost of care may seem reasonable but as a share of household income and household expenses, these are significant costs that have been shown to lead to borrowing of money and sale of assets, which is indicative of financial distress.

The strength of this review lies in the timing in which it was conducted as South Africa is in its second implementation phase of the National Health Insurance (NHI) which looks at expansion of benefits and provision of services. The review should be instrumental in providing perspective for policymakers to identify key focus areas that need to be addressed and considered for a benefits package and for strengthening health service delivery in order to achieve universal health coverage, especially for people living with HIV. In the wake of pharmaceutical innovations to improve ART, the findings of the review should be beneficial for considering treatment regimens that do not require patients to make multiple visits to the clinic so to avoid patients dropping out of care because they are unable to afford the travel costs or to take time off work. The inclusion of studies conducted in all nine provinces of the country with a mix of rural and urban settings also strengthens the data presented as it is representative of the population receiving HIV care and is generalizable to countries of similar settings. The use of mixed-methods approach which utilizes both quantitative and qualitative studies validate the review with quantitative methods presenting accurate data in the form of costs and qualitative studies giving depth and understanding of factors that are not captured through quantitative methods.

The review has several limitations. Firstly, the number of articles found were less than anticipated but this is owed to the fact that we strictly focused on HIV only and not people with other co-infections such as TB, and the selection of search terms, even though enough time was spent to develop a good search strategy, may have excluded useful articles. The review could have taken a meta-analysis approach but due to heterogeneity of data this was not possible, perhaps for future reviews looking at cost in the greater population including TB

and HIV/AIDS, this would be possible. Since most health policies on HIV in South Africa are merged or integrated with TB, this may limit the consideration of the review findings for policy. Some of the studies included in the review were conducted before policy changes on HIV treatment such as the UTT were implemented, therefore, costs reported for seeking care while waiting for ART eligibility may be less important in today's context.

CONCLUSION

The cost of healthcare remains a challenge for South Africa and even more so for the poor. It is evident that the challenge is not caused by the costs at point of care, but travel costs and services used to supplement those offered by the public sector. This can be solved by improving service quality and bringing services closer to the people. Factors such as unemployment and low income contribute to the financial distress caused by healthcare costs, and as such, if South Africa is to achieve universal health coverage, multi-sector partnerships and engagement is required.

Conclusively, the review considers the user fee removal policies to have been beneficial in reducing the economic burden for those living in close proximity to health clinics and receive care in well-resourced facilities, but it has no significant benefit for those who still travel long distances and have to turn to other providers for their health needs to be met. Therefore, for future policy to be effective for all target populations, the development process should consider the context and different settings that people live and seek their care in.

DECLARATIONS

Ethics approval and consent to participate

The systematic review did not require any ethics approval because no primary data or interaction with animal or human subjects was required. We sought approval from the Departmental Research Committee of Public Health and School of Family Medicine at the University of Cape Town.

Consent for publication

Not Applicable

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request

Competing interests

The authors declare that they have no competing interests.

Funding

No funding was received to carry out this review.

References

Bachman, M. O. & Booysen, F. L., 2003. Health and economic impact of HIV/AIDS on South African households: a cohort study. *BMC Public Health,* 14(3).

Bachmann, M. & Booysen, F., 2004. Relationships between HIV/AIDS, income and expenditure over time in deprived South African households. *AIDS Care,* 16(7), pp. 817-826.

Bekker, L.-G.et al., 2014. Provision of antiretroviral therapy in South Africa: the nuts and bolts. *Antiviral Therapy,* Volume 19, pp. 105-116.

Chimbindi, N. et al., 2015. Time and Money: The True Costs of Health Care Utilization for Patients Receiving "Free" HIV/Tuberculosis Care and Treatment in Rural KwaZulu-Natal. *Acquired Immune Deficiency Syndromme,* 70(2), pp. 52-60.

Cleary, S. M., Birch, S., Moshabela, M. & Schneider, H., 2012. Unequal access to ART: exploratory results from rural and urban case studies of ART use. *Sexually Transmitted Infections,* Volume 88, pp. 141-146.

Collins, D. L. & Leibbrandt, M., 2007. The financial impact of HIV/AIDS on poor households in South Africa. *AIDS,* Volume 21, pp. 75-81.

Cushieri, S., 2019. The STROBE Guidelines. *Saudi Journal of Anesthesia,* Volume 13, pp. 31-34.

Dalton, J., Booth, A., Noyes, J. & Sowden, A. J., 2017. Potential value of systematic reviews of qualitative evidence in informing user-centered health and social care: findings from a descriptive overview. *Journal of Clinical Epidemiology,* Volume 88, pp. 37-46.

Dunn, A., Grosse, S. D. & Zuvekas, S. H., 2016. Adjusting Health Expenditures for Inflation: A Review of Measures for Health Services Research in the United States. *Health Services Research,* 53(1), pp. 175-196.

Eze, P., Lawani, L. O., Agu, U. J. & Acharya, Y., 2022. Catastrophic health expenditure in sub-Saharan Africa: systematic review and meta-analysis. *Bulletin of the World Health Organization,* 100(5), pp. 337-351.

Goudge, J. et al., 2009. The household costs of health care in rural South Africa with free public primary care and hospital exemptions for the poor. *Tropical Medicine and International Health,* 14(4), pp. 458-467.

Govender, K. et al., 2021. Primary healthcare seeking behaviour of low-income patients across the public and private health sectors in South Africa. *BMC Public Health,* Volume 21.

Hoffmann, C. J. et al., 2018. Value stream mapping to characterize value and waste associated with accessing HIV care in South Africa. *PLoS ONE,* 13(7).

Kellermeyer, L., Harnke, B. & Knight, S., 2018. Covidence and Rayyan. *Journal of the Medical Library Association,* Volume 106, pp. 580-583.

Lines, M. & Suleman, F., 2017. Patients' perceptions of a rural decentralised anti-retroviral therapy management and its impact on direct out-of-pocket spending.. *African Health Sciences,* 17(3).

Lorenzetti, D. L. & Ghali, W. A., 2013. Reference management software for systematic reviews and meta-analyses: an exploration of usage and usability. *BMC Medical Research Methodology,* Volume 13.

Mafune, R. V., Lebese, R. T. & Nemathaga, L. H., 2017. Challenges faced by caregivers of children on antiretroviral therapy at Mutale Municipality selected healthcare facilities, Vhembe District, Limpopo Province. *AOSIS,* 40(1).

Mayosi, B. M. et al., 2012. Health in South Africa: changes and challenges since 2009. *The Lancet,* Volume 380, pp. 2029-2043.

McIntyre, D., Thiede, M., Dahlgren, G. & Whitehead, M., 2006. What are the economic consequences for households of illness and of paying for health care in low- and middle-income country contexts?. *Social Science and Medicine,* 62(4), pp. 858-865.

McLaren, Z. L., Ardington, C. & Leibbrandt, M., 2014. Distance decay and persistent health care disparities in South Africa. *BMC Health Services Research,* Volume 14.

Moshabela, M. et al., 2011. Patterns and Implications of Medical Pluralism Among HIV/AIDS Patients in Rural South Africa. *AIDS and Behaviour,* 15(4), pp. 842-852.

Mudzengi, D. et al., 2017. The patient costs of care for those with TB and HIV: a cross-sectional study from South Africa. *Health Policy and Planning,* Volume 32.

National Collaborating Centre for Infectious Diseases, 2016. *More than just numbers: Exploring the concept of "burden of disease",* Winnipeg: NCCID.

Negin, J. et al., 2017. Health expenditure and catastrophic spending among older adults living with HIV. *Global Public Health,* 12(10), pp. 1282-1296.

Njagi, P., Arsenijevic, J. & Groot, W., 2018. Understanding variations in catastrophic health expenditure, its underlying determinants and impoverishment in Sub-Saharan African countries: a scoping review. *Systematic Reviews,* Volume 7.

Organization for Economic Co-operation and Development, 2023. *OECD.* [Online]
Available at: https://data.oecd.org/price/inflation-cpi.htm
[Accessed 24 April 2023].

Pillai, N. et al., 2019. Patient costs incurred by people living with HIV/AIDS prior to ART initiation in primary healthcare facilities in Gauteng, South Africa. *PLoS ONE,* 14(2).

Rosen, S., Kethlapile, M., Sanne, I. & DeSilva, B. M., 2007. Cost to patients of obtaining treatment for HIV/AIDS in South Africa. *South African Medical Journal,* 97(7), pp. 524-529.

Tladi, L. S., 2006. Poverty and HIV/AIDS in South Africa: an empirical contribution. *SAHARA J: Journal of Social Aspects of HIV/AIDS,* 3(1), pp. 369-381.

Turner, H. C. et al., 2019. Adjusting for Inflation and Currency Changes Within Health Economic Studies. *Vlaue in Health,* 22(9), pp. 1026-1032.

World Health Organization, 2018. *South Africa: Country Cooperation Strategy at a glance,* Geneva: World Health Organization.

Wouters, E. et al., 2010. Who is accessing public-sector anti-retroviral treatment in the Free State, South Africa? An exploratory study of the first three years of programme implementation. *BMC Public Health,* Volume 10.

PART D: POLICY BRIEF

Policy Brief

November 2022

The impact of out-of-pocket removal policies on the economic burden caused by the cost of HIV services in South Africa.

About the study

This is a systematic review is an assessment of the universal health coverage (UHC) policy of out-of-pocket payment removal in the form of user fees at primary healthcare facilities in South Africa. We assessed the role of this policy by reviewing published evidence to establish whether the policy has helped in reducing the economic burden of HIV/AIDS for people living with HIV (PLWH). PLWH were found to be economically burdened by their HIV care costs if they were driven into catastrophic health expenditure (CHE), which refers to spending more than they are able to, or impoverishment, which means they had to forego basic needs such as food or borrow money to cope with healthcare expenses. The review focused on HIV/AIDS due to the prevalence of the disease and the policy gap that exists in addressing the impoverishing effect it has on the population reported to be largely affected. The review further recommends what more can be done to protect them from catastrophic spending and impoverishment.

Introduction

The introduction of no user fee payment at public primary healthcare facilities in South Africa along with free provision of antiretroviral therapy (ART) services has been successful in increasing coverage and service utilization. Despite these policies and strategies, costs incurred outside the point of care have fallen on the individuals and have been found to be catastrophic and leading to impoverishment. This is a direct consequence of poor public health service delivery and geographic location of facilities.

When people are not satisfied with the care they receive at public health facilities, they seek alternative or additional care from the private sector or traditional healers (Govender, et al., 2021). Those who live far from health facilities are forced to travel long distances and pay high transport fees. This makes the no user fee policy less effective in providing financial protection. The South African government has been active in considering the financial ramifications of HIV/AIDS morbidity by introducing the Disability Grant, but strict eligibility criteria and lack of proper administration has led to limited success (Veenstra, 2006). The National Health Insurance (NHI) aims to offer financial protection but more evidence that highlights drivers of CHE and impoverishment should be considered to ensure this mechanism is effective so to achieve UHC.

Methods

We conducted searches across seven databases for published literature on the cost of HIV care utilization since the removal of user fees in 2004 up to 2021 in South Africa. During our initial search we found 2155 articles, after removing duplicates and excluding according to the review's eligibility criteria. We came to 12 articles which were included for final review. Two independent reviewers who were blinded to each other's selection conducted title and abstract screening of articles and full-text screening.

We included qualitative and quantitative studies because CHE is measured and reported using quantitative methods, but impoverishment is also reported using qualitative methods. This approach enabled us to capture as much appropriate and relevant evidence as we could for this review. Data was extracted and analysed using a Microsoft Excel tool that was designed at the beginning of the study. The items for extraction were guided by the National Collaborating Centre for Infectious Diseases (NCCID) approach to determining the economic burden of disease (National Collaborating Centre for Infectious Diseases, 2016).

Key findings

PLWH spend more on transport and additional care from private doctors and traditional healers. On average it costs between ZAR7 and ZAR107 to travel to a health facility depending on how close or far the facility is. The average amount spent on a single visit is ZAR146 and the monthly cost on care is ZAR239. These costs seem modest but based on demographics that reflect poverty and unemployment in the affected population, they can be catastrophic.

The studies included reported monthly income ranging from ZAR536 to ZAR4000, with one study reporting that 41% of the participants in their Eastern Cape study lived on less than ZAR447 per month (Pillai, et al., 2019).

CHE was observed in 50% of the participants in rural Hlabisa (KwaZulu Natal) at the 10% CHE threshold (Cleary, et al., 2012). More than 70% of the participants in Gauteng experienced CHE at a 5% threshold.

Using nationally representative data, CHE was observed in 8.7% participants at a 40% threshold, with participants in rural areas found to be more likely to experience CHE at the 30% threshold compared to those in urban areas (Negin, et al., 2017).

In rural KwaZulu Natal, 36% of participants on ART reported to have borrowed ZAR280 to pay for healthcare costs.

In Mpumalanga (Bushbuckridge) 27.24% and 11.8% in the Western Cape (Mitchells Plain) also borrowed money, with 11% in Gauteng taking loans at 22% interest to cover their healthcare costs (Chimbindi, et al., 2015; Mudzengi, et al., 2017).

Conclusion

The findings of the review show that the removal of user fees at the point of care and free provision of ART services alone are not sufficient protect all PLWH from impoverishment and catastrophic expenditure. It is also evident that for everyone to benefit and the policy to have more impact, investment to improve the public health system to ensure that it delivers appropriate, accessible, and acceptable services to prevent people from seeking care outside the system and their communities is required.

Policy recommendations

- Adopt a multisectoral approach on policies aimed at universal health coverage
- Strengthen and increase capacity of the mobile health clinic programme to meet the needs of communities that do not have primary health clinics.
- Increase investment in the public health system by employing enough skilled health workers to improve quality of service and reduce the amount of time spent at facilities.
- Invest in HIV medications that require less frequent clinic visits.
- Use evidence to develop and implement policy to ensure that it considers context and target populations.

References

1. Chimbindi, N. et al., 2015. Time and Money: The True Costs of Health Care Utilization for Patients Receiving "Free" HIV/Tuberculosis Care and Treatment in Rural KwaZulu-Natal. *Acquired Immune Deficiency Syndromme,* 70(2), pp. 52-60.
2. Cleary, S. M., Birch, S., Moshabela, M. & Schneider, H., 2012. Unequal access to ART: exploratory results from rural and urban case studies of ART use. *Sexually Transmitted Infections,* Volume 88, pp. 141-146.
3. Govender, K. et al., 2021. Primary healthcare seeking behaviour of low-income patients across the public and private health sectors in South Africa. *BMC Public Health,* Volume 21.
4. Mudzengi, D. et al., 2017. The patient costs of care for those with TB and HIV: a cross-sectional study from South Africa. *Health Policy and Planning,* Volume 32.
5. National Collaborating Centre for Infectious Diseases, 2016. *More than just numbers: Exploring the concept of "burden of disease",* Winnipeg: NCCID.
6. Negin, J. et al., 2017. Health expenditure and catastrophic spending among older adults living with HIV. *Global Public Health,* 12(10), pp. 1282-1296.
7. Pillai, N. et al., 2019. Patient costs incurred by people living with HIV/AIDS prior to ART initiation in primary healthcare facilities in Gauteng, South Africa. *PLoS ONE,* 14(2).

PART E: APPENDICES

Appendix 1: STROBE Statement

STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No.	Recommendation	Page No.	Relevant text from manuscript
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract		
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found		
Introduction				
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported		
Objectives	3	State specific objectives, including any prespecified hypotheses		
Methods				
Study design	4	Present key elements of study design early in the paper		
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection		
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants		

		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9	Describe any efforts to address potential sources of bias
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding
		(b) Describe any methods used to examine subgroups and interactions
		(c) Explain how missing data were addressed
		(d) Cohort study—If applicable, explain how loss to follow-up was addressed Case-control study—If applicable, explain how matching of cases and controls was addressed Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy
		(e) Describe any sensitivity analyses

Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time
		Case-control study—Report numbers in each exposure category, or summary measures of exposure
		Cross-sectional study—Report numbers of outcome events or summary measures
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included
		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses

Discussion		
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Appendix 2: BMC Public Health Services Research – Manuscript Guideline

This manuscript guideline was extracted from the BMC Public Health Services Research website.

Preparing your manuscript

The information below details the section headings that you should include in your manuscript and what information should be within each section.

Please note that your manuscript must include a 'Declarations' section including all of the subheadings (please see below for more information).

Title page

The title page should:

- present a title that includes, if appropriate, the study design e.g.:
    - "A versus B in the treatment of C: a randomized controlled trial", "X is a risk factor for Y: a case control study", "What is the impact of factor X on subject Y: A systematic review"
    - or for non-clinical or non-research studies a description of what the article reports
- list the full names and institutional addresses for all authors
    - if a collaboration group should be listed as an author, please list the Group name as an author. If you would like the names of the individual members of the Group to be searchable through their individual PubMed records, please include this information in the "Acknowledgements" section in accordance with the instructions below
- indicate the corresponding author

Abstract

The Abstract should not exceed 350 words. Please minimize the use of abbreviations and do not cite references in the abstract. Reports of randomized controlled trials should follow the CONSORT extension for abstracts. The abstract must include the following separate sections:

- **Background:** the context and purpose of the study
- **Methods:** how the study was performed and statistical tests used
- **Results:** the main findings
- **Conclusions:** brief summary and potential implications
- **Trial registration:** If your article reports the results of a health care intervention on human participants, it must be registered in an appropriate registry and the registration number and date of registration should be in stated in this section. If it was not registered prospectively

(before enrollment of the first participant), you should include the words 'retrospectively registered'. See our editorial policies for more information on trial registration

Keywords

Three to ten keywords representing the main content of the article.

Background

The Background section should explain the background to the study, its aims, a summary of the existing literature and why this study was necessary or its contribution to the field.

Methods

The methods section should include:

- the aim, design and setting of the study
- the characteristics of participants or description of materials
- a clear description of all processes, interventions and comparisons. Generic drug names should generally be used. When proprietary brands are used in research, include the brand names in parentheses
- the type of statistical analysis used, including a power calculation if appropriate

Results

This should include the findings of the study including, if appropriate, results of statistical analysis which must be included either in the text or as tables and figures.

Discussion

This section should discuss the implications of the findings in context of existing research and highlight limitations of the study.

Conclusions

This should state clearly the main conclusions and provide an explanation of the importance and relevance of the study reported.

List of abbreviations

If abbreviations are used in the text they should be defined in the text at first use, and a list of abbreviations should be provided.

Declarations

All manuscripts must contain the following sections under the heading 'Declarations':

- Ethics approval and consent to participate
- Consent for publication
- Availability of data and materials

- Competing interests
- Funding
- Authors' contributions
- Acknowledgements
- Authors' information (optional)

Please see below for details on the information to be included in these sections.

If any of the sections are not relevant to your manuscript, please include the heading and write 'Not applicable' for that section.

Ethics approval and consent to participate

Manuscripts reporting studies involving human participants, human data or human tissue must:

- include a statement on ethics approval and consent (even where the need for approval was waived)
- include the name of the ethics committee that approved the study and the committee's reference number if appropriate

Studies involving animals must include a statement on ethics approval and for experimental studies involving client-owned animals, authors must also include a statement on informed consent from the client or owner.

See our editorial policies for more information.

If your manuscript does not report on or involve the use of any animal or human data or tissue, please state "Not applicable" in this section.

Consent for publication

If your manuscript contains any individual person's data in any form (including any individual details, images or videos), consent for publication must be obtained from that person, or in the case of children, their parent or legal guardian. All presentations of case reports must have consent for publication.

You can use your institutional consent form or our consent form if you prefer. You should not send the form to us on submission, but we may request to see a copy at any stage (including after publication).

See our editorial policies for more information on consent for publication.

If your manuscript does not contain data from any individual person, please state "Not applicable" in this section.

Availability of data and materials

All manuscripts must include an 'Availability of data and materials' statement. Data availability statements should include information on where data supporting the results reported in the article

can be found including, where applicable, hyperlinks to publicly archived datasets analysed or generated during the study. By data we mean the minimal dataset that would be necessary to interpret, replicate and build upon the findings reported in the article. We recognise it is not always possible to share research data publicly, for instance when individual privacy could be compromised, and in such instances data availability should still be stated in the manuscript along with any conditions for access.

Authors are also encouraged to preserve search strings on searchRxiv https://searchrxiv.org/, an archive to support researchers to report, store and share their searches consistently and to enable them to review and re-use existing searches. searchRxiv enables researchers to obtain a digital object identifier (DOI) for their search, allowing it to be cited.

Data availability statements can take one of the following forms (or a combination of more than one if required for multiple datasets):

- The datasets generated and/or analysed during the current study are available in the [NAME] repository, [PERSISTENT WEB LINK TO DATASETS]
- The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.
- All data generated or analysed during this study are included in this published article [and its supplementary information files].
- The datasets generated and/or analysed during the current study are not publicly available due [REASON WHY DATA ARE NOT PUBLIC] but are available from the corresponding author on reasonable request.
- Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.
- The data that support the findings of this study are available from [third party name] but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data are however available from the authors upon reasonable request and with permission of [third party name].
- Not applicable. If your manuscript does not contain any data, please state 'Not applicable' in this section.

More examples of template data availability statements, which include examples of openly available and restricted access datasets, are available here.

BioMed Central also requires that authors cite any publicly available data on which the conclusions of the paper rely in the manuscript. Data citations should include a persistent identifier (such as a DOI) and should ideally be included in the reference list. Citations of datasets, when they appear in the reference list, should include the minimum information recommended by DataCite and follow journal style. Dataset identifiers including DOIs should be expressed as full URLs. For example:

Hao Z, AghaKouchak A, Nakhjiri N, Farahmand A. Global integrated drought monitoring and prediction system (GIDMaPS) data sets. figshare. 2014. http://dx.doi.org/10.6084/m9.figshare.853801

With the corresponding text in the Availability of data and materials statement:

The datasets generated during and/or analysed during the current study are available in the [NAME] repository, [PERSISTENT WEB LINK TO DATASETS].[Reference number]

If you wish to co-submit a data note describing your data to be published in *BMC Research Notes*, you can do so by visiting our submission portal. Data notes support open data and help authors to comply with funder policies on data sharing. Co-published data notes will be linked to the research article the data support (example).

Competing interests

All financial and non-financial competing interests must be declared in this section.

See our editorial policies for a full explanation of competing interests. If you are unsure whether you or any of your co-authors have a competing interest please contact the editorial office.

Please use the authors initials to refer to each authors' competing interests in this section.

If you do not have any competing interests, please state "The authors declare that they have no competing interests" in this section.

Funding

All sources of funding for the research reported should be declared. The role of the funding body in the design of the study and collection, analysis, and interpretation of data and in writing the manuscript should be declared.

Authors' contributions

The individual contributions of authors to the manuscript should be specified in this section. Guidance and criteria for authorship can be found in our editorial policies.

Please use initials to refer to each author's contribution in this section, for example: "FC analyzed and interpreted the patient data regarding the hematological disease and the transplant. RH performed the histological examination of the kidney, and was a major contributor in writing the manuscript. All authors read and approved the final manuscript."

Acknowledgements

Please acknowledge anyone who contributed towards the article who does not meet the criteria for authorship including anyone who provided professional writing services or materials.

Authors should obtain permission to acknowledge from all those mentioned in the Acknowledgements section.

See our editorial policies for a full explanation of acknowledgements and authorship criteria.

If you do not have anyone to acknowledge, please write "Not applicable" in this section.

Group authorship (for manuscripts involving a collaboration group): if you would like the names of the individual members of a collaboration Group to be searchable through their individual PubMed records, please ensure that the title of the collaboration Group is included on the title page and in the

submission system and also include collaborating author names as the last paragraph of the "Acknowledgements" section. Please add authors in the format First Name, Middle initial(s) (optional), Last Name. You can add institution or country information for each author if you wish, but this should be consistent across all authors.

Please note that individual names may not be present in the PubMed record at the time a published article is initially included in PubMed as it takes PubMed additional time to code this information.

Authors' information

This section is optional.

You may choose to use this section to include any relevant information about the author(s) that may aid the reader's interpretation of the article, and understand the standpoint of the author(s). This may include details about the authors' qualifications, current positions they hold at institutions or societies, or any other relevant background information. Please refer to authors using their initials. Note this section should not be used to describe any competing interests.

Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

References

Examples of the Vancouver reference style are shown below.

See our editorial policies for author guidance on good citation practice

Web links and URLs: All web links and URLs, including links to the authors' own websites, should be given a reference number and included in the reference list rather than within the text of the manuscript. They should be provided in full, including both the title of the site and the URL, as well as the date the site was accessed, in the following format: The Mouse Tumor Biology Database. http://tumor.informatics.jax.org/mtbwi/index.do. Accessed 20 May 2013. If an author or group of authors can clearly be associated with a web link, such as for weblogs, then they should be included in the reference.

Example reference style:

Article within a journal

Smith JJ. The world of science. Am J Sci. 1999;36:234-5.

Article within a journal (no page numbers)

Rohrmann S, Overvad K, Bueno-de-Mesquita HB, Jakobsen MU, Egeberg R, Tjønneland A, et al. Meat consumption and mortality - results from the European Prospective Investigation into Cancer and Nutrition. BMC Medicine. 2013;11:63.

Article within a journal by DOI

Slifka MK, Whitton JL. Clinical implications of dysregulated cytokine production. Dig J Mol Med. 2000; doi:10.1007/s801090000086.

Article within a journal supplement

Frumin AM, Nussbaum J, Esposito M. Functional asplenia: demonstration of splenic activity by bone marrow scan. Blood 1979;59 Suppl 1:26-32.

Book chapter, or an article within a book

Wyllie AH, Kerr JFR, Currie AR. Cell death: the significance of apoptosis. In: Bourne GH, Danielli JF, Jeon KW, editors. International review of cytology. London: Academic; 1980. p. 251-306.

OnlineFirst chapter in a series (without a volume designation but with a DOI)

Saito Y, Hyuga H. Rate equation approaches to amplification of enantiomeric excess and chiral symmetry breaking. Top Curr Chem. 2007. doi:10.1007/128_2006_108.

Complete book, authored

Blenkinsopp A, Paxton P. Symptoms in the pharmacy: a guide to the management of common illness. 3rd ed. Oxford: Blackwell Science; 1998.

Online document

Doe J. Title of subordinate document. In: The dictionary of substances and their effects. Royal Society of Chemistry. 1999. http://www.rsc.org/dose/title of subordinate document. Accessed 15 Jan 1999.

Online database

Healthwise Knowledgebase. US Pharmacopeia, Rockville. 1998. http://www.healthwise.org. Accessed 21 Sept 1998.

Supplementary material/private homepage

Doe J. Title of supplementary material. 2000. http://www.privatehomepage.com. Accessed 22 Feb 2000.

University site

Doe, J: Title of preprint. http://www.uni-heidelberg.de/mydata.html (1999). Accessed 25 Dec 1999.

FTP site

Doe, J: Trivial HTTP, RFC2169. ftp://ftp.isi.edu/in-notes/rfc2169.txt (1999). Accessed 12 Nov 1999.

Organization site

ISSN International Centre: The ISSN register. http://www.issn.org (2006). Accessed 20 Feb 2007.

Dataset with persistent identifier

Zheng L-Y, Guo X-S, He B, Sun L-J, Peng Y, Dong S-S, et al. Genome data from sweet and grain sorghum (Sorghum bicolor). GigaScience Database. 2011. http://dx.doi.org/10.5524/100012.

Appendix 3: Ethics Approval Letter

From: PHFM DRC Ethics
To: Vuyi Mqoqi
Cc: Jill Olivier; Hlombekazi Majokweni; Edina Sinanovic
Subject: DRC Review MJKHLO001
Date: Wednesday, 22 June 2022 12:17:25
Attachments: FHS013_Student Research Proposal Application_Hlombekazi Majokweni (MJKHLO001)_MPH2022_LM.pdf

---

Dear Vuyi

I trust this email finds you well. Please find attached the protocol for the MPH student Hlombekazi Majokweni (MJKHLO001@myuct.ac.za), who submitted this to the SPHFM DRC for processing.

Please be advised that this protocol has been reviewed by Public Health and Family Medicine Departmental Research Committee - agreeing that the study does not require HREC review.

Title: "A systematic review of the impact of out-of-pocket payment removal policies on the economic burden caused by the cost of HIV service utilization in South Africa"