

University of Pretoria
Faculty of Health Sciences
School of School of Medicine

Title of the Research Project

**Effect of a ward-based outreach team and adherence game interventions on retention in care
and virological suppression of HIV-infected patients newly initiated on antiretroviral
treatment in Tshwane**

For the degree PhD in Family Medicine

Author Ngcobo Sanele

Student number: 28723041

Contact details:

Address: Ntuzuma G315 kukhanya road

Tel: 012 356 3324

Fax: 012 354 1317

Cell: 083 797 1463

E-mail: Sanele.Ngcobo@up.ac.za / sanosanele@gmail.com

Supervisor: Prof Theresa Rossouw

Date: 02/02/2022

Declaration

I, Sanele Ngcobo, student number 28723041, hereby declare that this work was not copied or repeated from other studies and that I contributed suitably towards research findings and publications presented in this thesis. Research procedures were approved and carried out in accordance with the ethical rules as prescribed by the Faculty of Health Sciences Research Ethics Committee, University of Pretoria.

Signature of student.....Date.....

Name of Supervisor: Prof Theresa Rossouw



Signature of Supervisor Date...2 February 2022...

Dedication

I dedicate this work to my spiritual father his Holiness INkosi INcoyincoyi Shembe.

Acknowledgments

I would like to thank my supervisor Prof Theresa Rossouw for her untiring support and guidance. I would also like to acknowledge Tshwane district ward based primary health care outreach team (WBPHCOT) under the leadership of Sister Sophie Lerumo for their support throughout my PhD project. I acknowledge the contribution of WBPHCOT members including operational team leaders and CHWs. To more than 1200 people living with HIV who contributed in this project, I thank you. To the head of our department Prof Jannie Hugo, thank you for motivating me and believing in my ideas. I would also like to thank Ronald Mosweu, Dr Nontuthuko Maningi, Dr Nothando Mbatha, Clive Nkgadima, Lethabo Phefadu and Ofentse Mathibe for helping with logistical arrangements, administrative support and for motivating me throughout my journey.

I would like to thank my wife Nontobeko Ngcobo for her support and giving me time to work on this project. To my daughter Snazo Ngcobo and my son Limengawe Ngcobo thank you for being part of my PhD journey. To my mother, Ntombiyenkosi Ngcobo, none of this would have been possible without your lifelong contribution to my life. My siblings, Khayelihle, Lethiwe, Phiwayinkosi, Andile, Thandolwenkosi and Akhona Ngcobo I thank you all for your support. To my late father, Khaya Ngcobo and my late step-mother Thobile Ngcobo I thank you for your contribution in my career.

The community of Amanazareth has nurtured me from a very young age and it is close to impossible to imagine who I'd be without their stern but nurturing arm steering toward the right path. The process of conducting research and writing a detailed report is a painstaking one that requires one to pour their heart and soul into every stroke of ink put on this paper. Sometimes your cup alone is not enough and I do not for a second imagine that I could have completed this without friends, family, colleagues and a whole community of people pouring into my cup and making sure that I am able to keep going even in moments where giving up made more sense.

Lastly I would like to thank Makhadzi, Khuzani Mpungose and many other South African artists, their music gave me energy throughout the difficult PhD journey.

Executive Summary

This PhD research project was conducted in Tshwane district of Gauteng province, South Africa. This project was subdivided into four different papers.

First abstract

The aim of this study was to understand potential benefits and barriers to delivering HIV care at the community level in Tshwane district and develop recommendations for improvement. Seven focus group discussions were conducted with 58 participants. While home-based human immunodeficiency virus (HIV) care was seen as a support strategy which could motivate patients to take their medication, the unpredictability of patients' responses to HIV test results, incorrect addresses (driven by the need for identity documents), fear of stigma through association with ward-based primary health care outreach teams (WBPHCOTs), especially those in uniform, little or no preparation of patients for home-based care, and lack of confidentiality and trust were raised as potential barriers.

Second abstract

The aim of this study was to assess the acceptability of community-based HIV services offered by community health workers (CHWs). A survey was conducted in 10 clinics across Tshwane district, Gauteng, South Africa. CHWs conducted interviewer-administered standardised questionnaires with 674 adult participants. Overall, 95.5% of participants thought that home-based HIV care is a good initiative and rated screening for illnesses and referral to health facilities highly. Although the vast majority (>94%) were willing to disclose their status to health professionals in clinics, women were more willing to do so. However, only 53.6% of participants were willing to disclose their HIV status to a CHW from the same neighbourhood and 28.8% would find it problematic if CHWs visited them at home with branded cars.

Third abstract

This 2 x 2 factorial cohort study assessed the effect of two interventions - WBPHCOTs and an adherence game - on 12-month retention in care and virological suppression in participants newly initiated on ART. Clinics were randomized into four comparator arms: WBPHCOT; Game; WBPHCOT-Game in combination; and Control (standard of care). A total of 467 participants were included in the analysis: WBPHCOT (n=72); Games (n=126); WBPHCOT-Games (n=85); and Control (n=184). After 12 months, 340 participants (86.2%) remained in care. The Games group had the highest retention compared to the Control group (96.8% vs

77.8%; relative risk [RR] 1.25; 95% CI 1.13–1.38; $p=0.01$). While retention was better in the WBPHCOT-containing interventions than in the Control group, the differences were not statistically significant. Younger participants (<35 years) were significantly less likely to remain in care (71% vs 89%; RR 0.80; 95% CI 0.69 – 0.93; $p<0.001$). The overall virological suppression rate was 75.3% and was similar across the four arms.

Fourth abstract

Following the reporting requirements of the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines, an aggregative narrative synthesis approach was used to summarize the results of qualitative studies published between 1 January 2000 and 6 November 2020. In total, 17 studies met the selection criteria and were included in the analysis. They reported on a range of roles played by CHWs in HIV care, including 1) Education: home visits; health education and promotion; 2) HIV-specific care: HIV testing services; screening for opportunistic infections and acute illness; medication delivery; tracing persons who had defaulted from care; and 3) Support: treatment support; referral; home-based care; and psychosocial support. Many different barriers to community-based HIV care were reported and centred on the following themes: 1) Stigma and non-disclosure: stigma; non-disclosure of HIV status; concerns about confidentiality; 2) Inadequate support: lack of resources, inadequate training, lack of support, poor communication, inadequate funding, and inadequate monitoring; and 3) Health care system challenges: patient preference for more frequent visits, and poor integration. Most articles also provided a set of recommendations to mitigate these barriers, most notably: Professionalizing CHW programmes; intensifying health campaigns; strengthening CHW supervision, providing CHWs with the necessary equipment, and improving CHW attitudes.

Conclusion

The 2 x 2 factorial cohort study was the first to demonstrate that a physical adherence game improved the retention of people living with HIV (PLWHIV) newly initiated on ART and hence has the potential to improve treatment outcomes. In addition, home-based HIV care was largely accepted as an important and positive intervention. To successfully implement effective home-based HIV care in South Africa, it is important to address perceived barriers to such care and involve all stakeholders, from decision makers to CHWs and PLWHIV.

Keywords

Community health workers; adherence games; home-based HIV care; acceptability; disclosure; barriers; facilitators; antiretroviral; HIV stigma; retention in care

Table of Contents

Declaration	ii
Dedication	iii
Acknowledgments	iv
Executive Summary	v
List of Tables	xii
List of Figures	xii
List of Acronyms.....	xiii
1 Chapter 1.....	1
1.1 Introduction and literature review	1
1.1.1 HIV in South Africa	1
1.1.2 Antiretroviral treatment in South Africa	1
1.1.3 Benefits of antiretroviral medication.....	2
1.1.4 United Nations Programme on HIV/AIDS Goals: 90 90 90	3
1.1.5 Adherence to antiretroviral treatment	3
1.1.6 Loss to follow-up.....	4
1.1.7 Determinants of poor adherence to treatment	5
1.1.8 Community Oriented Primary Care.....	7
1.1.9 Community health workers	8
1.1.10 Role of community health workers in HIV care.....	8
1.1.11 Tier.net.....	9
1.1.12 Games.....	10
1.2 Aim(s) and objectives	13
1.2.1 Primary objectives:	13
1.2.2 Secondary objectives:.....	13
1.3 Outline of the next five chapters.....	13
2 Chapter 2.....	15
2.1 Introduction	17
2.2 Methods	18
2.2.1 Overview.....	18
2.2.2 Participants and procedures	19
2.2.3 Data analysis	20
2.3 Results	20
2.3.1 Experience of performing, receiving or observing home-based HIV care	21

2.3.2	Barriers to conducting home visits	22
2.3.3	The perceived value of WBPHCOTs and home-based HIV care.....	28
2.3.4	Recommendations by participants.....	29
2.4	Discussion.....	31
2.5	Conclusion	34
2.6	Acknowledgments	35
2.7	Interview guide	36
3	Chapter 3.....	37
3.1	Introduction	39
3.2	Methods	40
3.2.1	Overview.....	40
3.2.2	Inclusion and exclusion criteria	41
3.2.3	Participant recruitment.....	41
3.2.4	Interview procedure	41
3.2.5	Data analysis	42
3.2.6	Ethical considerations.....	42
3.3	Results	42
3.3.1	Description of participants	42
3.3.2	HIV status disclosure	43
3.3.3	Home visits	45
3.3.4	Home-based HIV services	48
3.4	Discussion.....	49
3.4.1	Disclosure	49
3.4.2	Home visits	50
3.5	Conclusion	51
3.6	Acknowledgments	52
3.7	Author Disclosure Statement.....	52
3.8	Funding Information	52
4	Chapter 4 (submitted article).....	53
4.1	Introduction	55
4.2	Methods	56
4.2.1	Overview.....	56
4.2.2	Clinic selection.....	56
4.2.3	Participant inclusion and exclusion criteria	57
4.2.4	Ethical considerations.....	57

4.2.5	Interventions	57
4.2.6	Outcome	58
4.2.7	Data analysis	58
4.3	Results	59
4.3.1	Characteristics of participants.....	60
4.3.2	Outcome at 12 months	61
4.3.3	Virological suppression.....	64
4.4	Discussion.....	65
4.5	Limitations.....	67
4.6	Conclusions.....	67
4.7	Competing interests	68
4.8	Authors' contributions.....	68
4.9	Acknowledgements	68
4.10	Funding.....	68
5	Chapter 5.....	69
5.1	Abstract.....	71
5.2	Introduction	71
5.3	Methods	72
5.3.1	Definition.....	72
5.3.2	Search strategy and study selection.....	73
5.3.3	Data extraction and analysis.....	73
5.3.4	Inclusion and exclusion criteria.....	74
5.3.5	Ethics approval and consent to participate	74
5.4	Results and Discussion.....	74
5.4.1	Roles of Community Health Workers.....	81
5.4.2	Barriers.....	83
5.4.3	Inadequate support.....	84
5.4.4	Health care system challenges.....	86
5.4.5	Recommendations.....	86
5.5	Conclusion	91
5.6	Authors' contributions.....	91
5.7	Acknowledgements	91
5.8	Funding	92
5.9	Disclaimer	92
5.10	Competing interests	92

6	Chapter 6: Conclusions and Recommendations.....	94
6.1	Introduction	94
6.2	Recommendations	96
6.2.1	Community-based HIV prevention and HIV counselling and testing services	96
6.2.2	HIV testing services	97
6.2.3	Role of CHWs and other stakeholders	99
6.2.4	Care coordination pathway	99
6.2.5	Home-based HIV care	100
6.2.6	Patient preferences	100
6.2.7	Stigma, disclosure and confidentiality.....	100
6.2.8	Resources and training.....	101
6.2.9	Preventing loss to follow-up.....	103
6.2.10	Safety of CHWs.....	103
6.2.11	Games.....	104
6.2.12	Recommendations for future research	104
6.3	Conclusion	105
7	References	106
8	Appendices.....	116

List of Tables

<i>Table 2-1. Description of participants involved in the focus group discussions.....</i>	<i>21</i>
<i>Table 3-1. Description of participants involved per region in Tshwane.....</i>	<i>43</i>
<i>Table 3-2. Perceptions regarding home visit by a community health worker</i>	<i>46</i>
<i>Table 3-3. Home-based HIV services offered by community health workers</i>	<i>49</i>
<i>Table 4-1. Characteristics of participants</i>	<i>60</i>
<i>Table 4-2. Participant outcomes at 12 months.....</i>	<i>62</i>
<i>Table 4-3. Retention in care</i>	<i>63</i>
<i>Table 4-4. Virological suppression</i>	<i>65</i>
<i>Table 4-5. Multivariable analysis of pregnancy, age, and interventions.....</i>	<i>65</i>
<i>Table 5-1. Summary of included studies and narrative synthesis.....</i>	<i>76</i>
<i>Table 5-2. Roles of community health workers in community-based HIV care</i>	<i>82</i>
<i>Table 5-3. Recommendations to improve HIV service delivery by CHWs in the community ...</i>	<i>88</i>

List of Figures

<i>Figure 1-1. ART and adherence game (a description of the ART adherence game, extracted from the Bridges of Hopes training guide).....</i>	<i>12</i>
<i>Figure 2-1. Location of clinics involved in focus group discussions in the Tshwane district, South Africa.....</i>	<i>19</i>
<i>Figure 2-3. Number of patients with no home address or cell phone number recorded for five clinics on tier.net.....</i>	<i>27</i>
<i>Figure 3-1. Location of the participating clinics in the Tshwane district of South Africa</i>	<i>40</i>
<i>Figure 3-2. Percentage of participants willing to disclose their HIV status to different types of health workers</i>	<i>44</i>
<i>Figure 4-1. Schematic representation of participants</i>	<i>59</i>
<i>Figure 4-2. Participants lost to follow up in the different groups.....</i>	<i>64</i>
<i>Figure 5-1. Flow chart of study selection</i>	<i>74</i>
<i>Figure 6-1. The relationship between incidence and prevalence.....</i>	<i>96</i>
<i>Figure 6-2. Community-based HIV testing services</i>	<i>98</i>
<i>Figure 6-3. Home-based HIV care for PLWHIV.....</i>	<i>102</i>

List of Acronyms

AIDS	Acquired Immunodeficiency Syndrome
AOD	Alcohol and Other Drugs
ART	Antiretroviral Therapy
ARV	Antiretroviral
CD4	Cluster of Differentiation 4
CHWs	Community Health Workers
CI	Confidence Interval
COPC	Community Oriented Primary Care
DDG	Deputy Director General
DOH	Department of Health
EMR	Electronic Medical Record
FGD	Focus Group Discussion
FS	Free State
GP	Gauteng Province
HAART	Highly Active Antiretroviral Therapy
HAST	HIV/AIDS, Sexually-transmitted infections and TB
HBC	Home-Based care
HCT	HIV Counselling and Testing
HH	Household
HIV	Human Immunodeficiency Virus
HPT	Hypertension
HTS	HIV Testing Services
IDI	In-Depth Interviews
KZN	KwaZulu Natal
LMIC	Low- and Middle-Income Countries
LO	Linkage Officer
LTFU	Lost to Follow Up
mHealth	Mobile Health
NGO	Non-Governmental Organization
NIDS	National Indicator Data Set
OR	Odds Ratio
OTL	Operational Team Leader

PLWHIV	People Living with HIV
PMTCT	Prevention of Mother-To-Child Transmission
PRISMA	Preferred Reporting Items for Systematic reviews and Meta-Analyses
RC	Research Coordinator
RCT	Randomized Control Trial
RR	Relative Risk
SA	South Africa
SSA	Sub-Saharan Africa
SD	Standard Deviation
TB	Tuberculosis
UNAIDS	United Nations Programme on HIV/AIDS
UP	University of Pretoria
VL	Viral Load
WBPHCOTs	Ward Based Primary Health Care Outreach Teams
WHO	World Health Organization

1 Chapter 1

1.1 Introduction and literature review

1.1.1 HIV in South Africa

In 2020, about 37.7 million (95% confidence interval [CI] 30.2 – 45.1 million) people (mostly in low- and middle-income countries) were living with the human immunodeficiency virus (HIV), the virus that causes the acquired immune deficiency syndrome (AIDS). In 2020, another ~1.5 million people became infected.(1) An estimated 660,000 people died of AIDS-related illnesses in 2020. Sub-Saharan Africa is the epicenter of the pandemic with more than 25 million people living with HIV (PLWHIV) and 46% of global new HIV infections occurring in this area.(2)

HIV/AIDS remains one of the most serious public health problems globally and in South Africa (SA), which has the largest HIV epidemic in the world, with an estimated 7.8 million (5.2 – 10 million) PLWHIV in 2020.(2) It is estimated that 230,000 people became infected with HIV in SA in 2020.(3) More than 2.8 million South Africans died of AIDS-related deaths between 1997 and 2010.(4) SA currently has the largest ART programme globally, with more than 4.1 million people on ART(5) and spends about \$2.5 billion annually to run its HIV/AIDS programmes. (6) It is important to note that significant progress has been made in dealing with the HIV pandemic: While 681,434 people died of AIDS-related causes in 2006, this number had decreased to 83,000 in 2021 with the expansion of the antiretroviral treatment (ART) programme.(3) In 2010 the life expectancy among males and females was 56.5 and 61.2 years, respectively; by 2015 this had increased to 61.9 and 67.7 years, respectively;(3) a change mostly ascribed to the country's successful HIV treatment programme.

In 2021 the national HIV prevalence in SA was 13.7%.(7) The three hardest hit provinces were KwaZulu Natal, Mpumalanga and Gauteng where the prevalence rates were 18%, 15.2% and 13.1% respectively.(8) Ekurhuleni had the highest HIV prevalence in Gauteng (14.3%), followed by the City of Tshwane (11.7%; 95% CI 8.1–16.6).(8)

1.1.2 Antiretroviral treatment in South Africa

Despite the overwhelming evidence of the effectiveness of ART, SA's HIV treatment programme had a slow start in the public sector. The delay was mostly due to AIDS denialism by politicians in top positions. Since 2008, there has been a positive change in the number of people on ART. South Africa now has the largest number of patients on ART in the world.(2) When the rollout of ART started, it was targeting patients with CD4 counts below 200

cells/mm³. In 2010, new guidelines were introduced to start patients on ART with CD4 counts below 350 cells/mm³; this was due to many studies, including a clinical trial in Haiti (9) that showed that starting ART at a CD4 count threshold of 350 cells/mm³ reduces deaths compared to a threshold of 200 cells/mm³.(9-11) In January 2015, SA introduced new guidelines with HIV-infected patients starting treatment at a CD4 count of less than 500 cells/mm³ as per the World Health Organization (WHO) recommendations. This also came in the wake of many studies showing that a threshold of 500 cells/mm³ reduces deaths compared to a threshold of 350 cells/mm³.(12, 13) On the 1st of September 2016, SA introduced a universal test and treat policy, with all HIV-infected patients now eligible to start on ART immediately after testing HIV positive, in line with international guidelines and based on convincing data from the START and TEMPRANO studies that demonstrated the mortality and morbidity benefit of immediate ART initiation. (14, 15)

1.1.3 Benefits of antiretroviral medication

ART has many benefits. It reduces the amount of HIV in the blood, potentially to undetectable levels.(16, 17) It also decreases the damage to the immune system brought about by persistent viral replication, thereby improving immune function and preventing the development of AIDS.(17) It reduces the risk of opportunistic infections; hence reducing morbidity and mortality and improving the quality of life of PLWHIV. There is increasing evidence that ART also reduces the risk of HIV transmission with recent studies showing that patients with undetectable HIV viral loads in plasma do not transmit the virus to their partners.(18, 19)

It is important to monitor the immunologic and virologic responses of patients who are on ART. This is done by means of two commonly-used laboratory tests, namely HIV RNA viral load (VL) and CD4+ T-cell (CD4) count, measured in plasma and blood respectively. VL is the term used to define the amount of the virus in the blood, reported as copies/millilitre blood, and gives an indication of the severity of the infection. CD4+ T-cells are white blood cells (lymphocytes) that display the cluster of differentiation 4 (CD4) receptor on their surface and act as helper cells that orchestrate the function of the immune system. These cells are preferentially infected and depleted by HIV and therefore give an indication of the general status of the immune system.

For ART to be defined as effective in a particular patient, the VL must be undetectable (below detectable levels of available assays, usually <50 copies/mL) and remain undetectable.(20) Continuous high adherence to ART is needed in order to maintain the VL at this level.(20) In SA, repeat VL testing is done once a year for patients with an undetectable VL; while 6-monthly

testing is done for patients with a VL of 50-1,000 copies/mL. If the VL is above 1,000 copies/mL, the VL is repeated after 8 weeks of intensive adherence counselling. The CD4 count is tested annually and informs the timing of discontinuation of prophylactic therapy.

1.1.4 United Nations Programme on HIV/AIDS Goals: 90 90 90

In December 2013, the United Nations Programme on HIV/AIDS (UNAIDS) launched the 90 90 90 goals, which ambitiously aimed that by 2020, 90% of all PLWHIV should know their HIV status; 90% of all people with diagnosed HIV infection should receive sustained ART; and 90% of all people receiving ART should have viral suppression.(3)

In 2019, the first target for SA was met with 92% (85% - 98%) of PLWHIV knowing their status. For the second 90, the SA target was not met since only 70% of those PLWHIV who knew their status were on treatment.(3) There was a 710 000 person gap in the third goal: only 64% of adults on ART were virologically suppressed.(1, 3) There is also a gender-based gap in meeting this target. A study published in November 2017, conducted in KwaZulu Natal, shows that for the 90 90 90 goals, performance in males was 52%, 69%, and 85% while in women it was 65%, 70%, and 90%.(21) The results of this study showed that for men, the bigger problem was with the 1st 90. There was a 13% gap between males and females in the 1st 90 and only 1% and 5% in the second and third 90, respectively.(21) In 2014, UNAIDS announced the 95 95 95 strategy which is aimed at ending the AIDS epidemic by 2030. This strategy is similar to the 90 90 90 one, except that the goals have ambitiously been increased from 90% to 95%.(22)

1.1.5 Adherence to antiretroviral treatment

With the increasing number of patients on ART because of the shift in international and national policy, including the universal test and treat strategy and the 95 95 95 target, the question of adherence has become even more important. Strict adherence to ART is essential in order to achieve viral suppression, to reduce the risk of drug resistance, improve overall health and quality of life, and reduce HIV transmission. Studies have shown that poor adherence to treatment remains the major cause of therapeutic failure. It also increases the risk of opportunistic infections and death.(23) Among the many factors affecting ART adherence, stigma, non-disclosure, unemployment, lack of transport, insufficient access to food, disability grants, and alternative forms of therapy were identified as major barriers to adherence, whereas inadequate follow-up and lack of patient confidentiality were also contributing factors.(24) Different studies in sub-Saharan Africa have shown that fewer than two-thirds of patients

initiated on ART remained on treatment 2 years after ART initiation.(25) Other studies have shown that only 70% of patients remained on treatment 24 months after treatment initiation, while only 65% remained after 36 months.(26) In a systematic review by Rosen and colleagues in sub-Saharan Africa between 2000 and 2007 (33 patient cohorts, 74,192 patients, and 13 countries), patient retention in ART programmes was estimated at 79.1%, 75.0%, and 61.6% at 6, 12, and 24 months respectively.(25)

1.1.6 Loss to follow-up

Many studies have employed different definitions of “loss to follow-up” (LTFU) to define patients who disengage from care. For most of these studies, LTFU is defined as a patient who had been followed up at a particular health institution, but hadn’t had contact with the facility for between 30 and 180 days. The SA guidelines for HIV management, divide LTFU into three different categories. The first is the early missed appointment; this is when the patient has failed to come to the clinic for follow-up at least 14 days after the scheduled appointment. The second is a late missed appointment; this is when the patient has not been to the clinic for at least 60 days after a scheduled appointment. The third category is that of defaulters, in which case patients have been without medication for at least 90 days.(27) In the SA public service clinics, a data capturer at each facility is responsible for generating a LTFU report from the national electronic recordkeeping system, Tier.net. Early LTFU is recorded every Friday and late LTFU and defaulters on the 1st Friday of every month.(28) To confirm LTFU, the data capturer generates a LTFU report from Tier.net and checks the files of the patients on the report to verify that they are really LTFU.(28)

Patients can also become LTFU after they have been diagnosed with HIV but before they initiate ART. This is referred to as pre-treatment LTFU.(29) A study conducted between January 2007 and February 2008 by Larson and colleagues in Johannesburg, SA, assessed LTFU during pre-ART care.(30) They reported that, of 356 patients who were not yet eligible for ART according to the guidelines in operation at that time (i.e. CD4 count <250 cells/mm³), 36% had a CD4 count between 251 – 350 cells/mm³ and were hence due to return for follow-up after three months.(30) Of this 36%, only 6% returned in 16 weeks, 35% returned within 17-52 weeks, while 59% had not returned by 52 weeks.(30) Among those with a CD4 count of more than 351 cells/mm³ (64%), only 15% returned at 36 weeks as per the guidelines, 11% returned at 37-52 weeks, and 74% were LTFU at 52 weeks.(30)

A systematic review by Brinkhof and colleagues of 6,420 patients who had become LTFU in ART programmes from 2000 to 2009 across 17 different studies (16 in sub-Saharan Africa and

one in India) looked at the mortality of these patients.(31) The definition of LTFU varied from missing appointments for more than 1 month to more than 3 months. The vital status of 4,021 patients could be obtained and 1,602 of them (40%) had died.(31) Out of the 17 studies, seven provided information on unsuccessful patient tracing: 83% of patients who could not be found were because of incorrect, incomplete or missing telephone numbers or addresses in the patients' files. Sixteen percent of these patients were reported to have moved to an unknown location. Reasons for not returning to the clinic varied, with the most common reasons being: transfer to another clinic, financial problems, improved or deteriorating health, stigma, and social problems.(31)

1.1.7 Determinants of poor adherence to treatment

A systematic review by Mills and colleagues obtained a pooled estimate of adequate adherence in sub-Saharan African patients of 77% (95% confidence interval (CI) 68–85%) based on a total of 12,116 patients.(32) Many factors contribute to poor adherence and LTFU. A systematic review by Mills and colleagues of 125 studies carried out across 38 different countries (16 of these in Africa), has shown that forgetting was the most frequently reported barrier to ART adherence, reported in 63.1% of studies.(33) Other barriers included being away from home (40.7%), stigma (40.1%), pill burden (37%), and distance to the clinic (35.0%).(33) Less frequently reported barriers included alcohol/substance misuse, falling asleep before taking medication, feeling good, palatability, being too busy, running out of pills, feeling sick, fear of drug toxicity, lack of good food, and medication stock-outs.(33)

Some interventions that have been implemented in response to the above-mentioned barriers and found to improve adherence include short message service and reminder devices, pillbox organizers, decentralization of services, and reduced frequency of clinic visits.(33) A meta-analysis by Langebeek and colleagues, including 207 studies and 103,836 patients, showed that the following predictors were significantly associated with adherence: adherence self-efficacy belief, concern about adverse events of ART, current substance use, trust or certification with the HIV care provider, depression symptoms, HIV stigma, and social support. It was concluded that adherence is strongly associated with adherence-related beliefs.(34)

In a systematic review by Heestermans and colleagues in sub-Saharan Africa, looking at the determinants of adherence to ART among PLWHIV, 146 articles were reviewed with a total of 162,922 participants.(35) It was reported by 20 studies that age was a detriment of adherence, with better treatment adherence reported among older patients (>35 years) when compared to younger patients.(35) In 11 studies, women were reported to have better

adherence, while six other studies reported the opposite.(35) Among patients with a higher level of education, higher levels of adherence were reported. The risk of non-adherence was increased by alcohol use, with some studies reporting that patients forgot to take their medication after drinking alcohol. Denialism also increased with alcohol use.(35) Financial challenges and food insecurity were also reported to increase the risk of non-adherence.(35) Interestingly, religion was reported to be both a barrier and a promoter of adherence.(35) As a promoter, there was a belief that ART was provided by God to save people; while as a barrier, some believed in a religious cure for HIV.

Among treatment and health facility barriers, side effects negatively influenced adherence. The relationship with health care workers also had a significant effect: a confidential and good relationship resulted in better adherence, while unpleasant experiences with clinic staff were associated with non-adherence.(35) Non-adherence was also associated with a crowded pharmacy, long waiting times, no privacy at the facility, and lost files. Non-disclosure of HIV status, discrimination, stigma, depression, not feeling sick, and poor HIV knowledge were also associated with non-adherence.(35)

A study by Ochieng and colleagues has shown that males were more likely to become LTFU compared to females; they suggested that interventions should have a gendered differentiation.(36) Other factors, such as younger age, long travel time to the clinic, high CD4 counts, rural clinic location, and advanced stage of HIV were also among the factors contributing to LTFU in this study.(36)

In addition to quantitative data, qualitative studies add to the understanding of subjective patient experiences. A qualitative study conducted in Namibia (n=12), showed that the main reasons for poor adherence to treatment were spiritual and cultural beliefs, stigma, and discrimination.(37) Some participants in this study reported that when they asked for advice from friends, they were advised to have faith in God instead of the health care system.(38) Other reasons were poor understanding of the treatment regimen, forgetfulness, alcohol intake, lack of commitment, travelling, and being illiterate.(37)

In a study performed in Botswana (n=104) the factors associated with defaulting ART were the inaccessibility of clinics (22.4%), improved health (about 21.4% of respondents reported that they were feeling better), running out of pills (11.2%), depression (8.2%), lack of support (8.2%), misunderstanding instructions (7.7%), side effects (6.1%), and alcohol abuse (3.1%).(39)

In a qualitative study carried out in Limpopo and Gauteng in SA, with a random sample of patients (n=528), only 3.2% (n=17) had defaulted their treatment.(40) Of the 14 patients

interviewed, the common reasons for defaulting treatment were transport costs, time needed for accessing treatment, and logistical challenges.(40) In another study (a retrospective observational cohort study) at the Medunsa National Pharmacovigilance Centre (n=529), 139 patients were LTFU.(41) The common reasons cited in this study for LTFU were not having a committed partner and a history of an adverse event prior to becoming LTFU.(41) This study also found that the risk of LTFU increased with the duration of treatment: retention rates decreased from 82% at 2 years after treatment initiation to 55% after 5 years.(41)

1.1.8 Community Oriented Primary Care

In 1944, the South African National Health Services Commission recommended the establishment of health centres.(42) Pholela, a community with about 30,000 people, was among the few areas identified for the pilot project. Drs Sidney and Emily Kark joined the health centre and observed that there was a need for a new approach in dealing with the burden of diseases they encountered. They developed a new strategy where, with the support of the community health workers (CHWs), they started mapping areas and developed an understanding of the culture, beliefs and habits, socio-economic status, as well as the prevalent health conditions of the community. The health workers conducted home visits and provided health education to the community members. When the apartheid government took over, Drs Kark left SA for Israel, where they continued working around the Pholela concept, which was later internationally recognised as community orientated primary care (COPC).

In 2010, the SA government launched a plan to ‘revitalise’ primary health care through ‘re-engineering’ health care in the country. It comprises three streams: a school health team, ward-based primary health care outreach teams (WBPHCOTs), and district clinical specialist teams. To support this initiative, the Gauteng Province entered into an agreement with the University of Pretoria (UP) to implement a COPC approach.(43, 44) COPC is primary care where professionals from different disciplines work together with organizations and people in defined communities to identify and respond systematically to health and health-related needs in order to improve health.(45) COPC is guided by five principles, namely: local health and institutional analysis, comprehensive care, equity, practice with science, and service integration around users.(45) Translating these principles into practice involves several practical steps, namely: defining the community and identifying households, creating teams and allocating CHWs to households, identifying and networking with local organisations and institutions, registering households and assessing family and individual health, using data to plan, implement, monitor and review service, as well as learning and management activities.

1.1.9 Community health workers

CHWs are community members who serve as frontline health care professionals. They generally work with the underserved and are indigenous - ethnically, linguistically, socioeconomically, and experientially - to the community in which they work.(46) In low-resource settings, CHWs are frontline providers who shoulder much of the health service delivery burden. While the exact number of CHWs in SA is unknown, an article published in 2011 estimated that there were 72,839 CHWs in the country.(46)

CHWs create a bridge between vulnerable communities and health services. CHWs operate in communities, which are mostly vulnerable, giving talks about health promotion and disease prevention. They take some health services to the people in an attempt to relieve the overburdened health facilities. They register households and household members, with the aim of using the data to benefit the members of the households, e.g. part of registration includes triage questions about tuberculosis (TB) and, if there is a member of the household with TB symptoms, they will be assisted.

Increasingly, mobile technologies are developed, tested, and deployed and CHWs facilitate these tasks in order to improve outcomes.(47) CHWs have used mobile technology tools to advance a broad range of health aims throughout the globe, particularly maternal and child health, HIV/AIDS, and sexual and reproductive health. Most commonly, CHWs use mobile technology to collect field-based health data, receive alerts and reminders, facilitate health education sessions, and conduct person-to-person communication.(47)

1.1.10 Role of community health workers in HIV care

Mwai and colleagues conducted a systematic review of the role of CHWs in HIV care in sub-Saharan Africa.(48) In the 21 studies (five qualitative, seven cohorts, six mixed methods and three randomized control trials) reviewed, it was reported that CHWs were educating families, caregivers, and communities about HIV/AIDS and its symptoms. CHWs were also teaching HIV-infected patients about the side effects of ART and assessing their readiness for ART. The impact of these functions was, however, not measured. (48)

1.1.10.1 Disclosure

In a cohort study done in SA (n=457), there was a statistically significant difference between patients exposed to community-based adherence support and those not exposed to this intervention: 57% versus 25% disclosed their status ($p=0.005$).(48) Those exposed to adherence support were also more likely to disclose to more than two people compared to those not exposed (77.6% versus 22.7%). These findings were supported by a study (n= 307)

conducted in the Free State province of SA, that found that the support of CHWs created a safe environment for PLWHIV to disclose their status. (48)

1.1.10.2 Adherence and loss to follow-up

In a cluster RCT performed in Kenya, it was shown that adherence among those receiving care from CHWs was 95% compared to 80% in the control group.(49) In another retrospective cohort study (n=500) conducted in Zambia, it was reported that LTFU decreased from 15% to 0%(50), and that the proportion of people receiving adherence support increased from 0% to 55.2%.(50) Increased motivation to adhere to ART was also reported in a cohort of 268 patients in the Free State province .(51)

1.1.10.3 Disease screening

An increase in early TB diagnosis was reported in a study where there was an intervention involving CHWs in Malawi. In this study, CHWs screened 806 HIV-infected patients for TB; 161 were diagnosed with TB. (52)

1.1.10.4 Viral suppression

In a cohort study done in SA, better viral suppression at 6 months was reported among patients receiving adherence support from CHWs.(53)

1.1.10.5 Mortality

Two cohort studies of PLWHIV on ART in Malawi reported a reduced risk of death (relative risk [RR] 0.22; 95% CI 0.15-0.33) among patients receiving care from CHWs, compared to those not receiving care from CHWs.(54) In a cohort study of 3 563 children living with HIV and on treatment in South Africa, the mortality rate after three years of ART was 3.7% (95% CI: 1.9% to 7.4%) vs. 8.0% (95% CI: 6.5% to 9.8%) amongst children with and without CHWs, respectively (p=0.060).(55)

1.1.11 Tier.net

With the increasing number of people on ART on SA, the Department of Health encountered a challenge in coping with a paper-based system. There was therefore a need to introduce an electronic medical record (EMR) system). Tier.net is made up of three tiers: (1) a paper-based system; (2) an electronic version of a paper register; and (3) fully electronic medical software. Depending on the context and resources available at the facility, the appropriate tier is selected. The clinics that were part of this study utilized the second tier: an electronic version of a paper-based register. In this tier, there are individual patient folders with standardised clinical records. This tier is divided into 4 parts: the first part contains the patient details, such as folder number, name and surname, date of birth and gender. The second section includes data on ART,

including ART start date and TB treatment started (yes/no). The next section assesses the outcome: died, transferred, LTFU and in care. The last section gives information about the treatment visits; this section is updated every time that patients come to collect their medication. Information in this section includes pregnancy status, TB status, VL and CD4 count.

1.1.12 Games

There is a growing interest in games that improve patient care, health literacy, and treatment adherence since traditional ways of patient instruction have met with limited success.(56) Most of these games are designed to help train health workers, educate patients, and improve physical fitness.(56) Education is especially important since studies have shown that low health literacy is associated with poor health outcomes.(57)

A scoping review of health game research by Kharrazi and colleagues reported an increase in research in this area over the last decade.(58) The average sample size of the studies reviewed was 109.5 users per study. There was, however, a very large standard deviation of 381 and, more than 82.6% of the studies had fewer than 100 participants. Results were skewed by 3 studies that had more than 1,000 participants.(58) Recommendations were made that future research should increase the number of participants in control groups, lengthen the intervention period and user-game interaction duration, and expand the application of games in new clinical contexts.(58)

Bridges of Hope training is an innovative, global package of practical interactive training activities and behaviour change techniques addressing a spectrum of health and wellness issues. They have won several awards including the Global Business Coalition Workplace and Community Investment Awards with Standard Bank Group, and the AfriComNet Award for Excellence in HIV and AIDS Communication in Africa (Best community/interpersonal strategy, campaign or tool). In 2016, they presented their game at the 21st International AIDS Conference and in 2018 at the International Social and Behaviour Change Communication (SBCC) Conference. Bridges of Hope Training activities involve participants in a way that goes far beyond just discussing and understanding the issues related to HIV/AIDS, ART adherence, disclosure, and others. They create multi-sensory learning experiences, which are easy to understand and apply. The range of activities and games can be used for both literate and non-literate participants.

1.1.12.1 Example of an HIV-related game / activity

One Bridges of Hope Training activity designed specifically to explain HIV and ART, and motivate treatment adherence is designed around the process of getting five participants to interact with one another as five masked characters (representing white blood cells, HIV, two opportunistic infections, and ART). This activity has the following objectives: to clarify the difference between HIV and AIDS; to demonstrate what happens to a person's body when they are infected with HIV and how this can progress to AIDS; to demonstrate in simple terms what the antiretroviral (ARV) medications do and their effectiveness; and to clarify why adherence to treatment is so important.

There are five different stages covered by this activity. The first one focuses on the immune system of those not yet infected with HIV, with their immune system, i.e. WBCs, able to expel any infections that enter the body. The second stage focuses on being infected with HIV and living with no symptoms. In this phase, the game demonstrates how WBCs push HIV into the corner and remain strong and able to fight infections. The third stage demonstrates what happens to people living with AIDS: HIV weakens the WBCs allowing different types of infections to take over the body. The fourth stage demonstrates how ARVs work in the body and how WBCs recover to be able to fight infections. The final stage looks into adherence to treatment; it shows what happens to the body when someone defaults on ART.

Some of the key messages from these games include that, when you are infected with HIV, it does not mean that you are living with AIDS. It also encourages patients to adhere to treatment as instructed.

These games have been well received by the community and health professionals alike. There is, however, no scientific evidence or articles published about the effectiveness of the Bridges of Hope Training activity.

Stage 4: Antiretroviral Treatment

As soon as someone tests HIV-positive, it is recommended to start life-long anti-retroviral treatment, or ART. This is a pill taken at the same time each day, containing a combination of Anti-retroviral drugs which suppress HIV. But they cannot get rid of HIV completely. They allow the white blood cells to build up again, so that they can once more fight off infections. The persons CD4 white blood cell count increases, the viral load drops and they return to a state where they are living with HIV, but no longer have AIDS.

Provided anti-retroviral treatment is not left too late, there are very good prospects for getting healthy again. The sooner they start the treatment, the more likely it is to work effectively.

ARV enters the body and attacks HIV, freeing the **White Blood Cell** from HIV's grip. ARV pushes HIV back into a corner and holds HIV there. **White Blood Cells** recovers its strength and once again fights the two **Infections** and pushes them out of the body.



Stage 5: Adherence to taking ARVs

This body is strong again and the person thinks: "I am well again. Why should I carry on taking these anti-retroviral drugs?" So they stop for a while.

ARV leaves the body.

Without the ARVs to constrain it, HIV is able to develop and mutate – it can change its form slightly, in a way which may then be resistant to the combination of ARV drugs being used.

Take the **HIV** mask off the person wearing it, turn it round and put it on again, showing the opposite side with a different "mutated" image of HIV.

HIV regains strength, and attacks and weakens the body's immune system again, allowing other infections to freely infect the body.

HIV attacks and holds **White Blood Cells** again. Both **Infections** enter and dance around the body again.

The person starts taking ARVs again. However, HIV is now resistant to that combination of ARVs and they no longer work. HIV continues to suppress the immune system, allowing more infections to move freely around the body.

ARV enters the body again, but this time HIV ignores or pushes ARV away. HIV continues to hold **White Blood Cells**. Both **Infections** continue to dance around the body.

A different combination of ARVs may be considered, called second line therapy. This may be less available and more expensive; it may have other side effects and it may not work.



Figure 1-1. ART and adherence game (a description of the ART adherence game, extracted from the Bridges of Hopes training guide)

1.2 Aim(s) and objectives

The aim of this study was to assess the effects of WBPHCOTs and the Bridges of Hope ART adherence game on retention in care and virologic suppression after 12 months among patients newly initiated on ART.

1.2.1 Primary objectives:

1. To assess the impact of a WBPHCOTs intervention on retention in care.
2. To assess the impact of the ART adherence game on retention in care.

1.2.2 Secondary objectives:

1. To assess the impact of WBPHCOTs intervention on virologic suppression.
2. To assess the impact of the ART adherence game on virologic suppression.
3. To assess the perceived role, barriers and benefits of implementing HIV care at the community level.

1.3 Outline of the next five chapters

The next four chapters of this thesis are presented as research articles. Chapter two deals with the perceived barriers and benefits of implementing HIV care at the community level in the Tshwane district in SA. Qualitative findings of this study were published in the Plos One journal (<https://doi.org/10.1371/journal.pone.0240740>). The candidate's role in this study included designing the study, conducting focus group discussions, data cleaning, and thematic analysis with the assistance of the PhD supervisor.

Chapter three focuses on the acceptability of home-based HIV care offered by CHWs in Tshwane district. This article has been accepted for publication in the AIDS Patient Care and STDs journal. The candidate's contribution in this paper involved the study design, developing a questionnaire, training data collectors, analyzing data, and writing the first and final version of the manuscript with input from the PhD supervisor.

In Chapter four, an article titled “Effect of a ward-based outreach team and adherence game intervention on retention in care and virological suppression of HIV-infected patients newly initiated on antiretroviral treatment in Tshwane, South Africa” is presented. This article has been submitted for publication and is currently undergoing peer review in an accredited international journal. In consultation with the PhD supervisor, the candidate conceptualized and designed this study, implemented the study procedures and data collection process. Data analysis was conducted with the assistance of two biostatisticians. The candidate further wrote

the first draft of the article draft, coordinated the revisions, and prepared and submitted the final manuscript for review.

In Chapter five, the final article titled “Roles, barriers and recommendations for community health workers providing community-based HIV care in sub-Saharan Africa: A systematic, aggregated, narrative review” is presented. This article has also been submitted for publication in an accredited international journal. It is currently undergoing peer review. In consultation with the PhD supervisor, the candidate conceptualized and designed this study. Together with two librarians, the candidate screened and conducted quality assessment of the articles. The candidate further analyzed, aggregated, and narrated the evidence obtained from the 17 studies included in this review paper. Finally, the candidate wrote the first article draft, worked on revisions, and prepared and submitted the final manuscript for review.

In the final chapter, Chapter six, the candidate provides conclusions and recommendations based on the evidence and knowledge gained during this PhD project.

2 Chapter 2

PLOS ONE

RESEARCH ARTICLE

"They come and knock at the gate until the neighbours see". Perceived barriers and benefits of implementing HIV care at the community level in Tshwane district: A qualitative study

Sanele Ngcobo¹*, Theresa Rossouw²

1 Department of Family Medicine, University of Pretoria, Pretoria, South Africa, **2** Department of Immunology, University of Pretoria, Pretoria, South Africa

* These authors contributed equally to this work.

* Sanele.Ngcobo@up.ac.za



OPEN ACCESS

Citation: Ngcobo S, Rossouw T (2020) *"They come and knock at the gate until the neighbours see". Perceived barriers and benefits of implementing HIV care at the community level in Tshwane district: A qualitative study.* PLoS ONE 15(10): e0240740. <https://doi.org/10.1371/journal.pone.0240740>

Editor: Ricardo Q. Gurgel, Federal University of Sergipe, BRAZIL

Received: February 14, 2020

Accepted: October 1, 2020

Published: October 15, 2020

Copyright: © 2020 Ngcobo, Rossouw. This is an open access article distributed under the terms of the [Creative Commons Attribution License](https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Data Availability Statement: Data cannot be shared publicly due to ethical restrictions. Data are available from the University of Pretoria, dept of family medicine, HWS building 7-13 Institutional Data Access / Ethics Committee (Tel: 012 356 3084 or 012 356 3085) for researchers who meet the criteria for access to confidential data.

Funding: The author(s) received no specific funding for this work.

Abstract

Little is known about the barriers and benefits of home-based HIV services offered by community health workers. These are especially important as the South African government embarks on scaling up community-based health services, which include HIV care. This study set out to understand potential benefits and barriers of these services in Tshwane district and develop recommendations for improvement. From June to August 2019, seven focus group discussions were conducted with 58 participants: four with 36 ward-based outreach team (WBOT) members and three with 22 people living with HIV (PLWHIV). Three aspects of care were explored: 1. Experience of performing, receiving or observing home-based HIV care; 2. Barriers to conducting home visits; and 3. The perceived value of WBOTs and home-based HIV care. While home-based HIV care was seen as a support strategy which could motivate patients to take their medication, the unpredictability of patients' responses to HIV test results, incorrect addresses (driven by the need for identity documents), fear of stigma through association with WBOTs, especially those in uniform, little or no preparation of patients for home-based care, and lack of confidentiality and trust were raised as potential barriers. To successfully implement effective home-based HIV care in South Africa, perceived barriers should be addressed and recommendations offered by people providing and receiving these services should be seriously considered. Pertinent recommendations include integrating WBOTs into clinics and existing support structures, improving training on confidentiality and HIV testing, and rethinking the recruitment, scope of work and safety of WBOTs. In addition, research should be conducted into the impact of the requirements for identity documents and community health worker uniforms.

***“They come and knock at the gate until the neighbours see”*. Perceived barriers and benefits of implementing HIV care at the community level in Tshwane district: A qualitative study**

Sanele Ngcobo¹, Theresa Rossouw²

¹Department of Family Medicine, University of Pretoria, South Africa.

²Department of Immunology, University of Pretoria, South Africa

*** Corresponding author: Sanele Ngcobo**

Sanele.Ngcobo@up.ac.za

2.1 Introduction

South Africa has the largest HIV epidemic in the world, with an estimated 7.7 million people living with HIV (PLWHIV) in 2018.(2) South Africa also has the largest antiretroviral treatment (ART) programme globally, with an estimated 4.8 million people on ART.(59) Optimal adherence to ART in persons with HIV improves health outcomes and prevents drug resistance.(60) A systematic review by Mills and colleagues obtained a pooled estimate of adequate adherence in sub-Saharan African patients of 77% (95% confidence interval 68–85%) based on a total of 12,116 patients.(32) Traditionally, sub-optimal adherence is defined as <95%, although it appears that current ART regimens require 70–90% adherence in order to be effective.(61) In addition to sub-optimal adherence, large treatment programmes are plagued by high numbers of patients who become lost to care.

Barriers to HIV care at the facility level are well documented in the literature. Amongst the leading barriers are personal, social, financial, geographic/transportation, and health system barriers .(62) New models of health care delivery are needed to improve treatment adherence and patient retention. Community-Oriented Primary Care, which makes use of community health workers, has been successful in countries such as Brazil and Spain and is currently piloted in Tshwane district. Community health workers have been reported to improve adherence to ART, enhance the reach, uptake and quality of HIV services, as well as the dignity, quality of life and retention in care of PLWHIV.(63) Their role in the South African HIV response is, however, understudied.

Community health workers are community members who serve as frontline health care workers. They are indigenous - ethnically, linguistically, socioeconomically, and experientially - to the community in which they work.(46) Supervised by a professional nurse or enrolled nurse, they work with the underserved and offer integrated and comprehensive health care services, which include health promotion, disease prevention and early detection, ante- and post-natal care as well as psychosocial support, at community, household and individual level.(64) Community health workers are organised into ward-based outreach teams (WBPHCOTs), which are supervised by an operational team leader, usually a nurse. These health workers are collectively known as WBPHCOT members. They visit patients who are receiving chronic medication at least once a month. In South Africa, community health workers receive a 10-day theory course, followed by practical and in-service training(64, 65) which focuses on communication skills, disease prevention, health promotion, screening for different

conditions, palliative care and treatment support for chronic conditions.(66) The South African government is currently phasing in a matric requirement for all community health workers. While the scope of work of community health workers is comprehensive, their focus in the South African setting has been on supportive HIV care. Naidoo (67) summarized the potential contribution of community health workers in this domain according to four themes: prevention of HIV transmission through health education; identification and testing of those at risk; adherence support; and early identification of individuals with deteriorating health while on ART. All these activities should happen at a household level in the community. While this model appears to overcome some of the limitations of facility-based care, little is known about the benefits and barriers of home-based HIV care services offered by community health workers. As the South African government has embarked on scaling up community-based health services, which include HIV care, it is essential to develop a more in-depth understanding of this care modality and explore options to address perceived barriers.

2.2 Methods

2.2.1 Overview

This is a qualitative study that was conducted in eleven clinics across Tshwane district, Gauteng, South Africa, between June and August 2019. Tshwane district covers 6 298 km², has an estimated population of 3,275,152 and has a total of eight community health centres and 68 Clinics. We conducted seven focus group discussions in order to obtain a detailed group perspective about home-based HIV care, perceptions of the benefits and barriers of delivering HIV care in the community by WBPHCOTs and the experience of receiving HIV care by PLWHIV. A focus group discussion methodology was specifically selected since it allows people to discuss everyday situations in a non-threatening environment which encourages disclosure of real attitudes and beliefs around sensitive issues.(68)

Ethics approval was granted by the University of Pretoria, Faculty of Health Science's Research Ethics Committee (reference number: 580/2018). Permission to collect data was obtained from Tshwane health district and all facilities involved. Each participant gave informed consent before participating in the study. No personal identifying information was captured.

2.2.2 Participants and procedures

Three groups of PLWHIV (PLWHIV_1 to 3) and four groups of WBPHCOT members (WBPHCOT 1 to 4) were purposively selected based on their respective experience of living with HIV (PLWHIV) and with home-based HIV care (WBPHCOTs and PLWHIV). This number was deemed adequate to achieve code saturation.(69)

PLWHIV_1 was made up of patients who were already receiving home-based HIV care. PLWHIV_2 and PLWHIV_3 were receiving HIV care at a clinic and, while they had not received HIV care in the community, they had observed community health workers in their communities. PLWHIV were invited by health care workers to join the study, either during their home (PLWHIV_1) or clinic (PLWHIV_2 and 3) visit.

WBPHCOT_1 to WBPHCOT_4 were made up of operational team leaders and community health workers who were delivering HIV care at the community level across Tshwane (Figure 2-1).

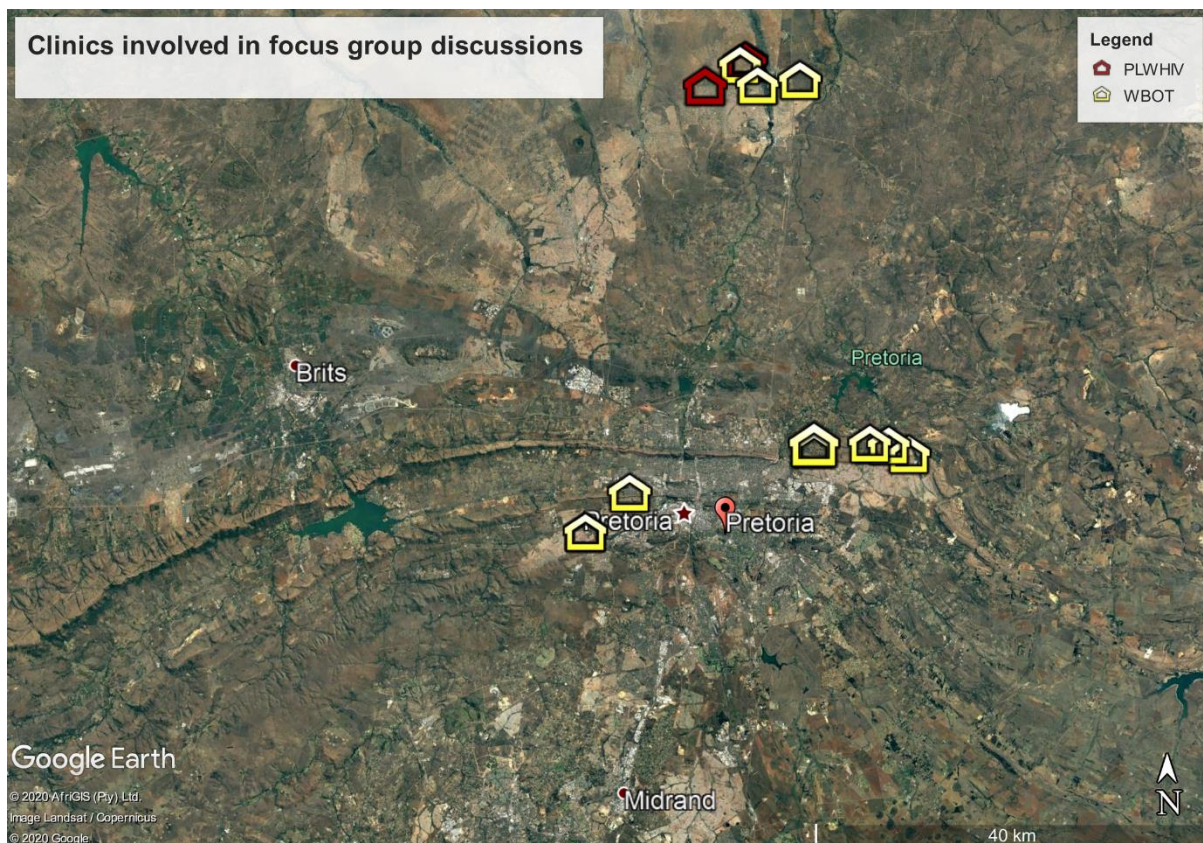


Figure 2-1. Location of clinics involved in focus group discussions in the Tshwane district, South Africa

In order to capture a diversity of views, WBPHCOTs working in different locations within Tshwane were recruited. WBPHCOTM_2 and 3 covered one clinic each, while WBPHCOT_1 and WBPHCOT_4 covered three and four clinics respectively.

WBPHCOTs who had performed home-based HIV care for at least one year were invited to participate. A focus group discussion guide (Supplementary Table 2.1) was developed by the principal author based on the literature reviewed. The guide was pilot tested in Kekanastad clinic with a group of five community health workers and small changes were made to improve understanding.

With participants' permission, focus group discussions were audio-recorded and transcribed by a research assistant. Questions centred around three aspects of care 1) Experience of CHWs offering home-based HIV care or experience of PLWHIV receiving home-based HIV care; 2) Barriers to conducting home visits; and 3) Perceived value of WBPHCOTs and home-based HIV care. At the end of the interviews, participants were questioned about a fourth aspect, namely recommendations to improve HIV care in the community.

2.2.3 Data analysis

Data analysis was conducted qualitatively by means of thematic analysis.(70) Castleberry's thematic approach was used with five different steps: compiling data; disassembling data to different codes; reassembling data to themes; interpretation of themes; and conclusion.(70) The transcripts were read by the principal author multiple times to become familiar with the data, emerging themes and codes. The principal author also discussed his understanding of different themes emerging from the interviews with the transcriber. ATLAS.ti 8 windows was used to arrange, resemble and manage qualitative data, and to facilitate text searching and coding. Codes, concepts and ideas that had some connection with each other were grouped together to form different themes. The quality and boundaries of themes were assessed, followed by analysis of the thickness and thinness of different themes.(70) Diversity and coherence of data were also assessed. Participants' biographic information was analysed by performing descriptive statistics in SPSS version 26 (IBM Corp., 2019).

2.3 Results

A total of 58 participants were interviewed, as outlined in Table 2-1. Results of the focus group discussions are presented according to the following four areas of enquiry: 1. Experience of performing, receiving or observing home-based HIV care; 2. Barriers to conducting home

visits; 3. The perceived value of WBPHCOTs and home-based HIV care; and 4. Recommendations by participants.

Table 2-1. Description of participants involved in the focus group discussions

Group	N	Females n (%)	Community health worker (Operational team leader) N (n)	Number of clinics covered	Age (years) Mean (SD)
PLWHIV_1	4	3 (75%)		1	43.5 (16.4)
PLWHIV_2	9	6 (66%)		1*	40.0 (9.5)
PLWHIV_3	9	8 (89%)		1*	44.8 (10.1)
WBPHCOT_1	10	8 (80%)	7 (3)	3	36.0 (1.2)
WBPHCOT_2	7	5 (71%)	6 (1)	1	43.1 (11.4)
WBPHCOT_3	7	7 (100%)	6 (1)	1	32.8 (4.0)
WBPHCOT_4	12	10 (83%)	6 (6)	4	36.1 (6.6)
Total	58	47 (81%)	25 (11)	11	
*PLWHIV 2 and 3 were from the same clinic					

PLWHIV = people living with HIV; n = number; SD = standard deviation; WBPHCOT = ward-based outreach team

2.3.1 Experience of performing, receiving or observing home-based HIV care

The majority of PLWHIV who have received home-based HIV care were generally satisfied with and those who had observed WBPHCOTs in the community were supportive of the service. Men were especially enthusiastic about the WBPHCOT services and believed that male patients should be prioritised for this service.

“You see door to door [WBPHCOT services] is good because some of us are afraid to come to the clinic as most man [men], they don’t like coming to the clinic.” PLWHIV_2

Participants providing care, however, reported that it was difficult for them to do HIV counselling and testing at the household level, due to the unpredictability of individuals’ responses.

“I requested a small table and then sterilised [disinfected] it, then explained the process and then allowed the client to sign the consent form, then started with pre-testing counselling. I then tested the patient. When I showed him the results, he jumped from where he was sitting straight to the next room. By this time, I was confused and scared to what is happening to the person in the room but then, after some time, he came out and we continued with post counselling.”

WBPHCOT_4

Other members of the WBPHCOTs believed that performing HIV counselling and testing in the household compromises their safety.

“It might happen that the person might vent on you after the results. It is not a safe place to test; the best place for testing is in the facility.” WBPHCOT_4

WBPHCOTs have to trace patients who have defaulted from tuberculosis (TB) and HIV treatment and this raises the concern that they are at high risk of being infected with these pathogens.

“At times during tracing, you find that you don’t have a mask and the patient is very sick and you cannot turn back without assisting that client. And sometimes you find that they didn’t even open the window, so you need to go inside and assist such a client. We even have a community health worker who passed away from TB which she contracted while tracing a TB client.” WBPHCOT_2

2.3.2 Barriers to conducting home visits

Despite the perceived value of WBPHCOTs and home-based HIV care, all participants reported perceived barriers to the successful implementation of HIV care at the household level. These barriers were divided into three themes: stigma-related; disclosure and trust; and facility- and health system-related.

2.3.2.1 Stigma-related barriers

Several stigma-related barriers were raised by both WBPHCOTs and PLWHIV. The most common barriers were around drawing unwelcome attention and the perception that WBPHCOTs only visit people who are ill.

HIV care at the community level involves regular visits to households of PLWHIV. This practice was viewed by some PLWHIV as drawing unwelcome attention.

“I wouldn’t want them to come and visit me. After knowing that you are HIV positive, they then visit you every day, and they come and knock at the gate until the neighbours see.” PLWHIV_2

PLWHIV felt that the official uniforms of community health workers and Department of Health branding added to the problem.

“When they first came with their uniform, everyone was looking. They also had branded cars; it attracted unnecessary attention.” PLWHIV_1

“Everyone can see who they are, what they are doing. I requested them to stop wearing uniform when they are coming to see me.” PLWHIV_1

However, wearing a uniform was seen as potentially important by the WBPHCOTs since this facilitated access to some households.

“A certain woman told us that when we enter a house [without a uniform] they think we are from a religious community, so they lock themselves in their houses and watch us through the windows.” WBPHCOT_2

PLWHIV felt that WBPHCOTs are seen as people who only visit people who are ill, thereby potentially adding to stigma.

“Some people know in the community that those people are only visiting sick patients.” PLWHIV_1

In addition, some PLWHIV indicated that when WBPHCOTs spend more time at a particular household, it raises suspicion among other community members.

“When they come and spend too much time at your house, people start thinking that someone is sick.” PLWHIV_3

2.3.2.2 Disclosure and trust

Both WBPHCOTs and community health workers voiced reasons why PLWHIV are reluctant to disclose their status to WBPHCOTs. Community health workers can only know the HIV status of individuals once they disclose to them or if they are provided with a list of those who are HIV-infected by the clinic.

Many PLWHIV were not comfortable disclosing their status to community health workers.

“The first time they came to me I hide [hid] my identity from them.” PLWHIV_2

“When they come to us, they are harsh towards us, so they must try to being [be] nice and I can disclose to [them], though I don’t think my status will be safe with them. It is better if I come to the clinic” PLWHIV_2

One of the reasons given for not disclosing to CHWs was the fear of gossip.

“They should not come to me because if there is one who is my neighbour, [they] will go around speaking about my health status so and I don’t like that because you end up being stigmatised and be stressed about such gossip.” PLWHIV_2

Such fears appeared to be grounded in experience. WBPHCOTs reported that there had been a complaint about a CHW who had disclosed individuals’ status to family members without their consent.

“We once had patients who complained that their status was disclosed to their family without their approval.” WBPHCOT_4

There was also a concern that there might be no benefit of disclosing their status to CHWs.

“Let’s say I disclose with such a community health worker having little knowledge; what will happen?” PLWHIV_2

While some participants indicated that they would disclose their status to WBPHCOTs, concerns were raised about WBPHCOTs coming from the local area.

“I can trust them, and even disclose my status to them, as long as they aren’t staying closer to where I am staying.” PLWHIV_2

Having community health workers as neighbours was seen as a barrier which could erode confidentiality and trust.

“Neighbour never loved their neighbour. When they see you, they greet you well; but when they get to their home, you become a topic.” PLWHIV_2

There was a feeling that community health workers recruited from other areas are only there to do their work and not to judge. Asked if they would trust those coming from other areas, most PLWHIV indicated that they could disclose to them.

“Yes, because they don’t know anything about me and they come there to do their jobs. Then that’s fine; I can disclose to such a person unlike the person from the same area.” PLWHIV_2

“Yes I will disclose, and will also be open to them (WBPHCOTM from other areas).” PLWHIV_3

This sentiment was further supported by the operational team leaders:

“They don’t trust community health workers that they know, that are staying in their community, because they think they will disclose their status to everybody in their community; as a result, they will either not tell you the truth or not welcome you at all to their household.” WBPHCOT_4

There was also a perception among WBPHCOTs that PLWHIV are more likely to disclose to more senior WBPHCOTs.

“On more than one occasion, I was called whereby they could see that the patient didn’t want to disclose to them. So when I went, that person was a different person, he could relate more to me as an OTL [operational team leader].” WBPHCOT_2

WBPHCOTs perceived shared confidentiality among the multi-disciplinary team as a potential threat to confidentiality and accountability since the HIV status of PLWHIV is known to so many people in the facility: at least by a lay councillor, a nurse, a doctor, and the data entry clerk involved in the care of these patients.

“The confidentiality becomes a challenge because now the patient will have disclosed to too many people and, when the information comes out, you never know who broke such confidentiality.” WBPHCOT_1

The structure of the household also has the potential for compromising confidentiality.

“If we go into the house and you find that there is a two-room house we try looking for an alternative place; like you look for a place that will be at least far from everyone but inside the yard and then go there to talk to the person.” WBPHCOT_1

WBPHCOTs were further concerned that HIV-related counselling and testing in the household could compromise confidentiality through the observation of non-verbal clues. They cited concerns about inadvertent disclosure by the persons being tested.

“The reaction of the person gives the other family members a particular outcome because they already know what the person is doing; so, if the test comes positive and the person’s reaction is not good, then they conclude that the person is positive.” WBPHCOT_4

2.3.2.3 Facility- and health system-related barriers

There are many different role players involved in the provision of HIV services. While the HIV/AIDS, sexually-transmitted infections and TB (HAST) programme involves WBPHCOTs in meetings about PLWHIV, their involvement is limited to performing HIV testing and tracing people who have defaulted from HIV care.

Some PLWHIV supported the idea that WBPHCOTs should only be involved in tracing patients who have defaulted treatment.

“I think they must come, but not to those who are attending clinic regularly; but they must follow up those who don’t come (to the clinic).” PLWHIV_3

However, some WBPHCOTs didn’t like the idea of only being involved once patients have become lost to follow up.

“They don’t involve us, we never hear of HIV patients who are compliant on treatment.” WBPHCOT_4

In addition, WBPHCOTs believe that facility staff do not prepare patients well enough for WBPHCOT services.

“They are not made to understand what WBPHCOT is and what WBPHCOT does and how are they going to assist them.” WBPHCOT_3

Community health workers refer people to the clinic on a regular basis, but there was a concern that some of these people are not well received at the clinics.

“Two days back we referred a client, but they come back to us saying that the staff refused to take the referral.” WBPHCOT_2

Community health workers sometimes come across patients who do not have treatment, but are unable to assist them because of facility policies. An example given by one community health worker was of a patient who had relocated from another province without a referral letter.

“So in the clinic they are only giving her weekly medication, so she still needs to get the letter so that she can be transferred to Gauteng. She is struggling to get the letter or proof of her medication, because KZN (KwaZulu Natal) is far from here and we haven’t gone back to her.” WBPHCOT_3

Neither PLWHIV nor WBPHCOTs thought that HIV post-test counselling was done adequately in facilities. This placed a great burden on community health workers, as they have to re-do the counselling.

“They aren’t doing it (post-test counselling)... They just told me everything will be well, you will be ok; they never sat down with me and do proper post-test counselling. They just asked me, are you here to test? I said yes, they pricked me, I never received counselling at all at the facility.” PLWHIV_1

“They are busy, she (lay counsellor) just said, after telling you what I am about to tell you, please don’t panic. Do you know about HIV? I responded and said, I have heard people talking about it. She said, you are HIV positive but don’t lose hope. They (lay counsellor) never sat down with me and counsel[led] me. I started getting information from [my] brother and sister (community health workers).” PLWHIV_1

WBPHCOTs thought that an association existed between poor counselling and the testing targets that lay councillors have to reach.

“When they (lay councillors) are testing people, they are thinking of targets. While you are busy taking long with counselling, others (lay counsellor) are busy testing more patients. They have to be fast.” WBPHCOT_1

“If someone tested positive and they want to rush the process, that results in more frustration which patients have and what we come across in the community as community health workers, because those clients were rushed through the process. Rather than concentrating on the patients, the counsellors are concentrating on the targets.” WBPHCOT_1

“They are busy with the numbers because they have allocated targets so that [they] can’t give more and appropriate counselling because they need to reach their target of counselled clients.” WBPHCOT_4

Community health workers reported that patients providing incorrect home addresses was one of the biggest barriers to HIV care in the community. Wrong or incomplete addresses significantly impaired community health workers’ ability to trace patients.

“I have a list here which I received today: there are twenty people who we have to trace: fifteen of those are incomplete and only five have proper address, of which of those five addresses, we don’t know whether we will find the person or not.” WBPHCOT_3

The accuracy of this information was assessed in five randomly selected clinics, using tier.net, an electronic patient management system with modules to capture patient-level data on HIV-related counselling and testing, pre-ART and ART services, as the data source. There was great variability between the five clinics with the proportion of entries with no home address or no cell phone number recorded ranging from 2.9% – 55.6% and 0% – 37% respectively (Figure 2-2). These numbers do not include those with incorrect or incomplete addresses.

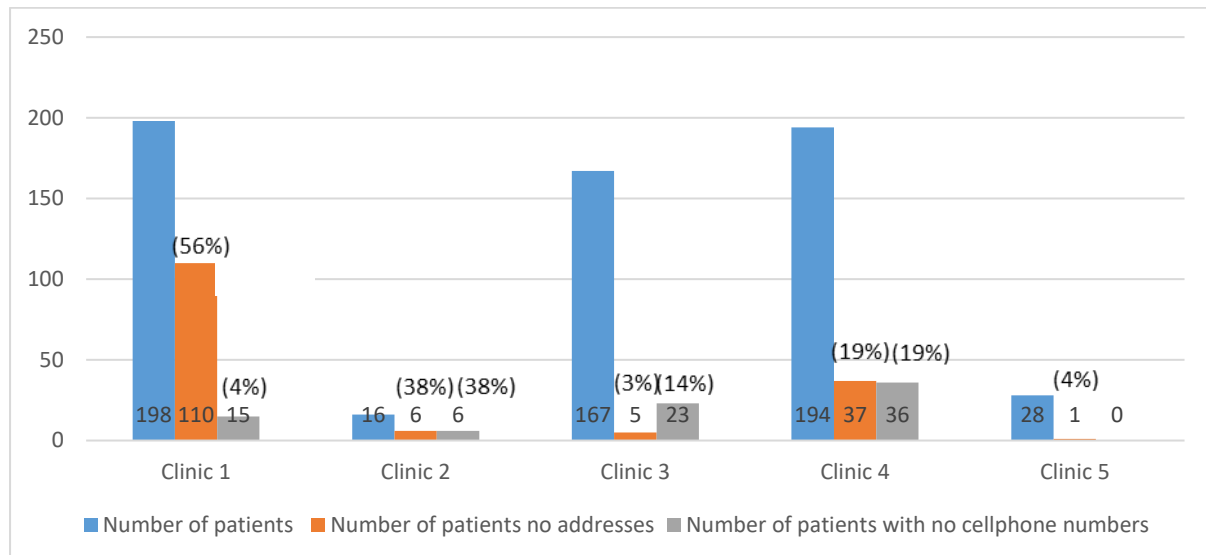


Figure 2-2. Number of patients with no home address or cell phone number recorded for five clinics on tier.net

Protests from community health workers that they cannot trace patients without addresses seemingly fall on deaf ears.

“I told him (linkage officer) there is no need for such a list with wrong and incomplete address as the results won’t have any effects on the list, but he insisted that we need to

check these people. But we cannot let community health workers go around the inner township checking on these people because it will be just a waste of time.”

WBPHCOT_3

Since community health workers' time in the community is closely monitored by a team leader, they felt it is essential that time is not wasted by looking for incorrect addresses.

“The issue of wrong address make us to spend a lot of time in one area and then we finally get the place and you find that, when we enter, it is the wrong address: there is no person whom we are looking for, ...so we end up spending a lot of time in one area rather than covering more people.” WBPHCOT_3

Various reasons were offered for people providing the clinic with incorrect addresses. The predominant reason offered by WBPHCOTs was that people do not want to go to their nearest clinics and fear being turned away at other clinics if they are not from that area.

“According to me, these people are choosy because people from area A come to clinic B* because the nurses in clinic A*, they are strict; and so they come to B* and they give wrong addresses so to receive services because, if not, they will be asked why don't you go to your local clinic.”* WBPHCOT_3 (*area and clinic name anonymised to protect confidentiality)

Particular clinics are perceived to be lenient with regards to the requirement of patient identity documents. WBPHCOTs reported that these clinics end up being dominated by foreign nationals who give incorrect addresses.

“When you can go to the clinic, 90% of the attendees you will find are foreign nationals. These foreign nationals, they don't have identity documents or asylum. When they go to clinic X, they don't offer them services, so when they come to [clinic] Y* they are attended to, so they end up giving wrong addresses and left the community health worker group in [clinic] Y* having clients to be traced, but they don't reside in Y*.”* WBPHCOT_3 (*area and clinic name anonymised to protect confidentiality)

2.3.3 The perceived value of WBPHCOTs and home-based HIV care

While it was not the intention of this study to question the effectiveness of the WBPHCOT intervention, valuable information was offered by PLWHIV on the importance of this intervention.

“This thing (WBPHCOT intervention) motivates us. When they come to visit us, it gives us that support, they care, so we are motivated not to give up. It (home-based HIV care is) a good initiative.” PLWHIV_1

“They made me to be alright. First month I wasn’t ok; they taught me a lot.” PLWHIV_1

PLWHIV currently receiving care from WBPHCOTs reported that they only started understanding their illness when they were visited by WBPHCOTs.

“They came at the right time; I was asking myself what I was living for. When they came, they guided me. I wish God could give us more people like them. They know how to counsel people, they don’t harass you. When they came, I was very confused; when I see them coming in, I become very happy.” PLWHIV_1

2.3.4 Recommendations by participants

Participants had several recommendations for dealing with perceived barriers to home-based HIV care.

2.3.4.1 WBPHCOT office

WBPHCOTs recommended that every clinic should have a WBPHCOT office and that all newly-diagnosed persons should pass through this office on the day of treatment initiation. WBPHCOTs believed that PLWHIV were most likely to trust them if they had met them at the facility level before.

“I think they must really promote us, they must make people aware of the WBPHCOT services especially during the testing and counselling, and even the community at large, because people are not aware of us and they don’t easily welcome us, but I believe that, if they were aware of WBPHCOT, they would show a different attitude towards WBPHCOT service providers.” WBPHCOT_2

2.3.4.2 Health talks

In one of the clinics, WBPHCOTs reported doing health talks in the clinic, including talks about the roles and functions of WBPHCOTs. In this way, most patients came to know them and it became easier for them to conduct household visits.

“Before they were not opening for us, but since we started doing health talks at the clinic and introducing the role of WBPHCOTs, they now welcome us to their households.” WBPHCOT_4

“They used to say, oh it is those ones for HIV. Now they understand that we aren’t just dealing with HIV.” WBPHCOT_4

There was a belief that WBPHCOTs who were themselves HIV-infected, could perform home-based HIV care better as they would have a richer understanding of the situation of PLWHIV compared with those who were uninfected.

“If they are also HIV positive, rather than (community health workers who are HIV-negative) just people who know nothing about what we have been through; someone going through the same experience won’t come to a household with an attitude.”

PLWHIV_2

2.3.4.3 Training

Some WBPHCOTs also indicated that they needed extra training on HIV-related counselling and testing.

“We need training about HIV testing and counselling, because you find that you are at the household and a client wants to test and we can’t do that as we are not trained on that.” WBPHCOT_2

It was also recommended that PLWHIV should be trained as community health workers in order to take on roles of offering home-based HIV care.

“They (Department of Health) should take us to go offer the services, whether we volunteer or be employed, because, even us here at the club, we are able to counsel and advise each other because of the experience we are having.” PLWHIV_3

2.3.4.4 Comprehensive approach

There was also a recommendation that HIV services should not focus on the individual, but rather have a comprehensive approach involving the whole family.

“(To improve treatment adherence and support by family members), there should be family (HIV) counselling. It will be good to focus on the family rather than a patient. So, the HIV care services should have a family focus rather than a patient focus.”

WBPHCOT_2

Some PLWHIV suggested that WBPHCOTs should focus mostly on men, as they are the ones who are least likely to attend the clinic.

“Men are scared of the clinic, they don’t like coming to the clinic. These services should be directed to [at] them.” PLWHIV_2

Linking home-based HIV care to existing structures, like adherence clubs, was recommended and this was seen to have the potential to improve the relationship between WBPHCOTs and PLWHIV.

“Before they (nurses) initiate any new clients they should first come to WBPHCOT, as we are the ones who will continue with care in the community, currently it not like that they take them straight to the adherence club.” WBPHCOT_4

2.4 Discussion

This study which assessed the experience and value of, as well as the barriers to community health workers offering home-based HIV care and related services in Tshwane district yielded imported findings that are relevant to the current focus on Community-Oriented Primary Care. While home-based HIV care was seen as a support strategy which could motivate patients to continue taking their medication, the unpredictability of patients’ responses to HIV test results, incorrect addresses, fear of stigma through association with WBPHCOTs, little or no preparation of patients for home-based HIV care, and lack of confidentiality and trust were raised as potential barriers.

In addition, fears were expressed about the occupational health and safety of community health workers. While there are many guidelines that address this at facility level, there are limited resources addressing the safety of community health workers in the community. South Africa has the highest prevalence of TB/HIV coinfection in the world. (71) Part of offering home-based HIV care includes meeting people who have defaulted from treatment as well as those newly diagnosed with TB/HIV but who are not yet on treatment. This could place community health workers at risk since these individuals are potentially infectious, possibly also with drug-resistant organisms. The fact that some community health workers report having no masks to protect themselves from TB is therefore very concerning. Similar concerns were raised in a study (72) in which 39.1% (n=270) of community health workers complained about inadequate protection from contracting TB. These fears are not unfounded: In a South African decade-long cohort study, health workers were reported to have a TB incidence of 1,496.32 per 100,000 compared to an incidence rate of 719.37 per 100,000 in the general population. (73) There is a concerted effort in South Africa to achieve the UNAIDS 90 90 90 targets. (21) Concerns were, however, expressed that the quality of HIV counselling was compromised by the pursuit of large numbers of HIV-infected patients tested and enrolled in treatment programmes, as required by donors. With lay counsellors seeing up to 25 patients a day on a busy day and also having many other duties apart from HIV counselling (74), the quality of counselling is easily compromised. While HIV post-test counselling is known to improve treatment adherence and virological suppression (75), WBPHCOTs reported that many patients had not received adequate counselling in the facility. Even though this necessitated

time and energy spent on re-counselling at the household level, the findings of this study suggest that this counselling does assist patients to better understand their illness. Formalizing a model of extending HIV post-test counselling through the involvement of WBPHCOTs could be effective and serve as a support structure which could motivate patients to continue taking their medication.(76)

WBPHCOTs expressed the sentiment that their role should not be limited to only tracing defaulters, but should be expanded to support patients from the day they are diagnosed. This is supported by a systematic review (48) which reported on the positive outcomes achieved secondary to the expanded role of WBPHCOTs in the management of HIV in terms of patient support (counselling, home-based care, education, adherence support and livelihood support) and health services support (screening, referral and health service organization and surveillance) in sub-Saharan countries. These activities would fit nicely with the family focused home-based HIV care suggested by WBPHCOTs in this study.

Many perceived barriers, which could undermine the important role of WBPHCOTs, were raised. According to Katz *et al* (77), internal and external stigma are important barriers to treatment initiation. Similarly, results from our study suggest that fear of stigmatization is also a major barrier to home-based HIV care. Fear of the association that exists between WBPHCOTs who do repeated household visits and serious illness was raised and such visits were reported to be attracting unwelcome attention. Just as in some studies where infrastructural challenges were reported to create unintended stigma, since specific buildings were exclusively used as ART clinics, it was reported in this study that WBPHCOTs were seen as those offering just HIV care. (78) This fear of being associated with WBPHCOTs was exacerbated by the symbols used by such teams, such as cars branded with signs of the clinic and the Department of Health and the wearing of standard medical uniforms. The discomfort of PLWHIV with WBPHCOTs visiting them in uniforms was contrary to the belief expressed by some WBPHCOTs in this study that uniforms assisted them in gaining access to a household. It is also contrary to the facility-based care perception that uniforms symbolise confidence, intelligence, trust, and safety.(79) In the community, wearing a uniform was seen as a symbol of someone who offers home-based HIV care. Further research into this aspect of care is critical.

Results of this study show that there is a degree of mistrust towards WBPHCOTs since PLWHIV were uncertain whether they would keep their HIV status confidential. In fact, some cases of a breach of confidentiality were reported. Similar to the findings of Grant *et al* (80) who reported that inadequate levels of confidentiality and trust were key barriers to the

acceptability of community health workers delivering maternal and child health services, mistrust between PLWHIV and community health workers seemingly attenuate the acceptance of home-based HIV services offered by WBPHCOTs. To improve confidentiality and trust, Grant *et al* (80) suggested that community health workers' training on confidentiality and navigating complex relationships should be strengthened in conjunction with the provision of adequate supervision and support. Similarly, Hai *et al* (81) reported that training is an essential factor in practicing confidentiality.

The recruitment strategy for community health workers should also be reconsidered. While there are many logistical advantages of recruiting community health workers to work in their hometown, the results from this study suggest that this approach could be problematic for home-based HIV care. Other studies (80, 82) reported the same challenges regarding the complexity of relationships and familiarity between community health workers and household members staying in the same community. It was suggested that community health worker training and support should focus more on how to navigate these complex relationships.(80) Furthermore, since health care professionals' perceptions of community health workers' competence and trustworthiness is fundamental to their credibility in the community, efforts to engender trust between personnel at health care facilities, community health workers and community members should be encouraged.(30)

According to Chellaiyan *et al*, the quality of the infrastructure of facility-based HIV-associated counselling and testing is regarded as an essential component of the quality of counselling offered, with a separate and private counselling room regarded as essential.(83) This poses a significant challenge to home-based HIV care as each household's infrastructure is unique, with no guarantee of confidentiality. From the results of this study, patients' responses after receiving HIV results are unpredictable, with one community health worker reporting fearing for her physical safety after delivering the bad news. According to Naik (84), an impersonal setting, lack of compassion, and the unavailability of support staff may lead to violent reactions towards bad news. This insecurity can affect the performance of community health workers.(85) There is an urgent need for more research to be conducted on how to improve the physical safety of community health workers as they continue offering home-based HIV care. Immigration policies and discrimination in health facilities have previously been reported as barriers to offering care to foreign nationals in South Africa (86); home-based HIV care is no exception. A large number of patients reportedly didn't have identity documents and therefore did not go to their nearest clinic but rather went to clinics where they could receive help without providing formal documentation. This however meant that they had to provide incorrect

addresses so that they could be accepted in these clinics, thereby frustrating WBPHCOT services. The need for an identity document as a prerequisite to access care should be revisited. WBPHCOTs recommended that every clinic should have a WBPHCOT office in line with the “Ideal Clinic” recommendations.(87) It was also recommended that WBPHCOTs should receive more training on HIV, that PLWHIV should be trained as community health workers, and that home-based HIV care should be linked to existing support structures. It is, however, important to note that the South African Department of Health is moving away from disease-specific community-based services towards a more comprehensive approach. (88) While employing people based on their disease status might seem to be at odds with this approach, a person living with HIV could add a valuable perspective as part of a WBPHCOT.

This study has some strengths and limitations. One of the strengths is that the WBPHCOTs who participated in the study were highly experienced with deep knowledge about home-based HIV care. While the sample size was small, participants were recruited from eleven clinics across Tshwane. One of the limitations of this study is that it was restricted to a relatively small area with a small number of participants and focus groups, which could have prevented the study from obtaining meaning saturation, especially for complex or subtle issues. Participants came mostly from an urban community and were dominated by female participants (81%) as can be expected from the gender proportions of PLWHIV in care as well as community health workers in the country.(89) This may have prevented identification of nuances influenced by demographic characteristics such as gender and geographic location.(69)

2.5 Conclusion

To successfully implement effective home-based HIV care in South Africa, it is important to address perceived barriers to such care and involve all stakeholders, from decisionmakers to community health workers to PLWHIV. In addition, recommendations offered by people providing and receiving these services should be seriously considered. The most pertinent issues in need of attention are integrating WBPHCOTs into clinics and existing support structures, improving training on confidentiality and HIV-related counselling and testing for community health workers, and rethinking the recruitment, scope of work and safety of WBPHCOTs. Finally, the impact of the requirement for identity documents, and the acceptability and value of community health worker uniforms should be explored.

2.6 Acknowledgments

We would like to thank all participants who were part of the focus group interviews. We would also like to thank Errol Baloyi for transcribing.

2.7 Interview guide

This interview interrogates three aspects of care:

- 1) Experience of community health workers offering home-based HIV care or experience of people living with HIV with home-based HIV care;
- 2) The perceived value of ward-based outreach teams (WBPHCOT) and home-based HIV care; and
- 3) Barriers to conducting home visits. At the end of the interviews, a fourth area is explored where participants are given an opportunity to suggest recommendations to improve HIV care in the community.

Supplementary Table 2.1. Focus group discussion guide for community health workers

WBPHCOT member	PLWHIV
1. Experience of CHWs offering HBHIVC or experience of PLWHIV with HBHIVC;	
Please share your experience in working with PLWHIV	Have you ever been visited by WBPHCOT members?
For how long have you been working with PLWHIV	Please share your experience in receiving care from WBPHCOTM (door to door people)
Any other comment on experience.	Any other comment on experience
2) Barriers to conducting home visits.	
What challenges have you faced in offering HBHIVC?	What challenges do you face or could you potentially face when visited by WBPHCOTM?
Any other comments?	Any other comments?
3) The perceived value of WBPHCOTS and HBHIVC	
From your experience what is the value of offering HBHIVC?	What value do you think WBPHCOT members bring or could bring to PLWHIV?
Any other comment?	Any other comment?

CHW – Community health worker. HBHIVC – Home base HIV care. PLWHIV – People living with HIV. WBPHCOT – ward based outreach team. WBPHCOTM – Ward Based Primary Health Care Outreach Teams member.

3 Chapter 3

AIDS PATIENT CARE and STDs
Volume 36, Number 2, 2022
Mary Ann Liebert, Inc.
DOI: 10.1089/apc.2021.0216

CLINICAL AND EPIDEMIOLOGIC RESEARCH

Open camera or QR reader and
scan code to access this article
and other resources online.



Acceptability of Home-Based HIV Care Offered by Community Health Workers in Tshwane District, South Africa: A Survey

Sanele Ngcobo, MPH,^{1,i} and Theresa Rossouw, PhD²

Acceptability of home-based HIV care offered by community health workers in Tshwane
district: A survey

Sanele Ngcobo¹, Theresa Rossouw²

¹Department of Family Medicine, University of Pretoria, South Africa.

²Department of Immunology, University of Pretoria, South Africa

* Corresponding author: Sanele Ngcobo

Sanele.Ngcobo@up.ac.za

Key words: Community health workers; home-based HIV care; acceptability; disclosure

3.1 Introduction

South Africa (SA) currently faces a quadruple burden of diseases: maternal, new-born and child-related illness; human immunodeficiency virus (HIV) and tuberculosis (TB); non-communicable diseases; and violence and injury. Of these, HIV is arguably still the biggest public health challenge facing the country. In 2020, Statistics SA estimated that the HIV prevalence was approximately 13% in the general population, 19.1% (95% confidence interval [CI] 12.1% - 24.7%) in adults aged 15–49 years, with the total number of people living with HIV (PLWHIV) estimated to be ±7,8 million. In addition, 79 625 AIDS-related deaths were recorded in 2020.(7) Enrolling and keeping PLWHIV on antiretroviral treatment (ART) is a key factor in reducing HIV-related mortality and HIV transmission.(19) In SA, only 72% (95% CI 48% - 93%) of PLWHIV were on ART in 2020(1), and this proportion was even lower in Gauteng province and Tshwane district: 56% and 55.4%, respectively.(90) To effectively respond to this quadruple burden of diseases in general, and HIV in particular, SA had to move away from a passive, vertical, disease-specific and individually-oriented health system to an integrated, preventative and population-oriented health system.(91) Accordingly, the SA government started a process of reengineering the primary health care sector with the ultimate aim of increasing access to quality health care for all.(91) Ward-based primary healthcare outreach teams (WBPHCOTs) are one of the key components of this reengineered sector. These teams consist of community health workers (CHWs), led by a nurse who is linked to a primary health care facility.(92)

The SA Department of Health recently introduced a scope of work for CHWs. In terms of HIV-related care, CHWs are tasked with various prevention activities, such as distributing condoms, promoting voluntary medical male circumcision, and providing information about pre-exposure prophylaxis. In the treatment realm, CHWs are expected to promote the disclosure of HIV status, trace patients who have become lost to follow-up, and provide adherence support. For these activities to be successful, there is a need to understand if they will be accepted by PLWHIV and, if so, what preferences they have for receiving these services at a household level. This study is an extension of a qualitative study that looked at perceived barriers and benefits (by WBPHCOTs and PLWHIV) of implementing HIV care at the community level in Tshwane district.(93) The aim of the current study was to assess the acceptability of community-based HIV services offered by CHWs to PLWHIV.

3.2 Methods

3.2.1 Overview

We conducted a survey in 10 clinics in the seven Tshwane regions (Figure 3-1) in Gauteng, South Africa, between November 2020 and May 2021.

CITY OF TSHWANE METROPOLITAN MUNICIPALITY

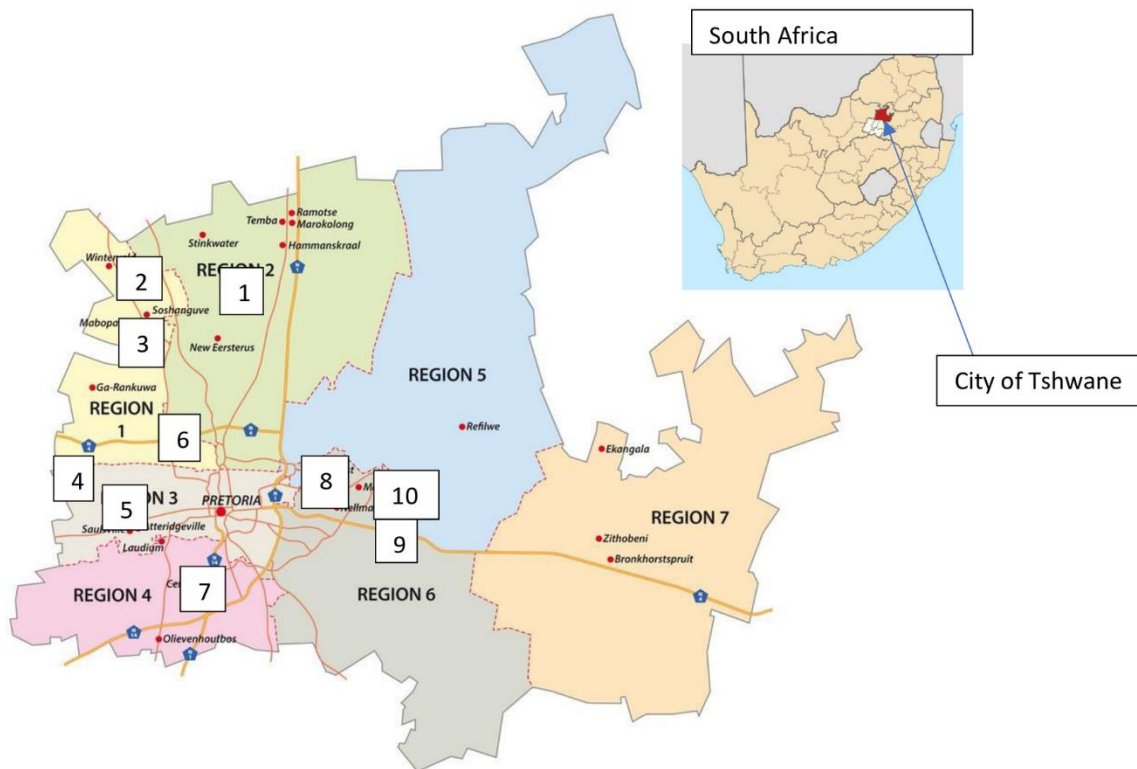


Figure 3-1. Location of the participating clinics in the Tshwane district of South Africa

Region seven was excluded from the analysis due to non-response. Since patient satisfaction can be influenced by patient volume (94), clinics were purposefully selected based on the number of PLWHIV seen on a monthly basis. A combination of high ($\geq 3\,500$ PLWHIV on ART, $n=5$) and low volume ($< 3\,500$ PLWHIV on ART, $n=5$) clinics were selected. Trained CHWs completed 674 structured, interviewer-administered questionnaires, with participants answering questions related to home-based HIV care. Questionnaires were in English, but the CHWs, who are conversant with the local languages in the area, ensured that all participants clearly understood the questions asked. Questionnaires were completed with smartphones using the Qualtrics online survey platform. The principal investigator and research assistant conducted a four-hour practical training session with CHWs. This training included an

overview of the Qualtrics online survey platform; research ethics, such as the importance of confidentiality and informed consent; and the questionnaire itself. The questionnaire was designed based on the themes that had emerged from the focus group discussions during the prior study.⁽⁹³⁾ The questionnaire covered sociodemographic information, the role of CHWs, CHW services, HIV status disclosure, and CHW home visits. The questionnaire was piloted in one of the sites among 20 PLWHIV and minor changes were made to improve the comprehension of some questions. Completed questions were imported to the Qualtrics online survey platform (University of Pretoria).

3.2.2 Inclusion and exclusion criteria

Only adult (≥ 18 years) PLWHIV currently on ART at one of the 10 clinics were included in this study. Participants who were unable to provide informed consent (i.e. too ill) were excluded from the study.

3.2.3 Participant recruitment

From 1 November 2020 to 10 May 2021, 64 trained CHWs recruited participants among PLWHIV attending one of the 10 clinics for routine HIV care. All potential participants were invited to participate in the survey and were selected according to the inclusion and exclusion criteria. Informed consent was obtained electronically from each individual participant.

3.2.4 Interview procedure

CHWs informed PLWHIV about the study, explained the entire process, and assured them about the voluntary nature of participation and confidentiality. All participants were provided with a standard definition of CHWs to ensure a shared understanding. This definition was:

“A community health worker is a member of a community who is linked to a local clinic and provides basic health and medical care services within their community under the supervision of a nurse. They work in the community to help people live a healthy lifestyle, check and assist those with illnesses to take their medication, educate them about their illnesses and link them to clinics if needed. They work together in ward-based outreach teams”.⁽⁹⁵⁾

Once participants understood what a CHW was, they continued with the interview.

3.2.5 Data analysis

Data were cleaned and exported from the Qualtrics online survey platform (University of Pretoria) to SPSS version 26 (IBM Corp., 2019) for analysis.⁽⁹⁶⁾ Using “identify duplicate cases wizard” on SPSS, we identified two duplicates using participants’ file numbers and these duplicates were excluded from the analysis. Data analysis was conducted quantitatively: frequencies, proportions, means, and standard deviations (SD) were calculated and compared according to region, patient volume, age, gender, duration on treatment, and information provided about CHWs and their role. Studies from Zambia, Kenya and Tanzania, found that levels of internalised stigma decreased 2 years after treatment initiation⁽⁹⁷⁻⁹⁹⁾ and we therefore categorised treatment duration into <2 or ≥ 2 years in our analysis. We also assessed the association between disclosure to CHWs in the community and gender, duration on treatment, and age using logistic regression and the Kruskal-Wallis H test.

3.2.6 Ethical considerations

The Research Ethics Committee of the Faculty of Health Sciences of the University of Pretoria granted ethics approval for the study (reference number: 580/2018). Permission to collect data was obtained from Tshwane health district and all facilities involved. Each participant gave informed consent before participating in the study. No personal identifying information was captured.

3.3 Results

Results of this survey are presented according to the following four areas: description of participants, HIV status disclosure, home visits, and home-based HIV services. There were no differences observed between high volume and low volume clinics, so this analysis is not included in the results.

3.3.1 Description of participants

A total of 674 participants, with a mean age of 38.2 years (SD ± 11.1), were interviewed in 10 clinics (Table 3-1). These clinics were spread across six regions: two in region 1; one in region 2; four in regions 3 and 4; and three in regions 5 and 6. A total of 500 participants (76.5%) were female while male participants made up less than a quarter ($n=154$; 23.5%) of the participants. While more than half of the participants in all the regions were women, this was especially notable in region 1 where women accounted for 95.2% ($n=119$) of the participants.

The majority of participants (n=406; 63.1%) had been on ART for ≥ 2 years . Notably, region 5 and 6 were the only regions dominated by participants who had been on treatment for <2 years.

Table 3-1. Description of participants involved per region in Tshwane

		Total	Region 1 (N=126) n (%)	Region 2 (N=228) n (%)	Region 3&4* (N=337) n (%)	Region 5&6* (N=83) n (%)
Age mean (SD)		38.2 (11.1)	32.6 (6.9)	40.4 (11.3)	39.2 (10.8)	38.2 (13.6)
Gender**	Female	500 (76.5%)	120 (95.2%)	162 (72.0%)	163 (74.1%)	55 (66.3%)
	Male	154 (23.5%)	6 (4.8%)	62 (28.0%)	57 (25.9%)	28 (33.7%)
Duration of ART (years)	<2	237 (36.9%)	38 (30.4%)	60 (26.8%)	77 (36.3%)	62 (75.5%)
	≥ 2	406 (63.1%)	87 (69.6%)	164 (73.2%)	135 (63.7%)	20 (24.4%)
SD = standard deviation; ART = antiretroviral treatment; n = number *These regions are very close to one another, they are usually combined when reporting and they had very low numbers when separated. **20 participants didn't have gender indicated.						

3.3.2 HIV status disclosure

Asked if they were willing to disclose their status to health professionals working in clinics, 94.0%, 95.6% and 97.0% participants indicated that they were willing to disclose their status to nurses, CHWs and doctors respectively (Figure 3-2).

Fewer participants were willing to disclose their status to nurses, CHWs and doctors in the community: 80.5%, 80.4% and 82.7%, respectively (Table 3-2). There was no difference in the mean age of participants willing to disclose their status to nurses, doctors, and CHWs in the community: 38.3 years (SD ± 10.9), 38.2 years (SD ± 11.0) and 38.3 years (SD ± 11.0) respectively.

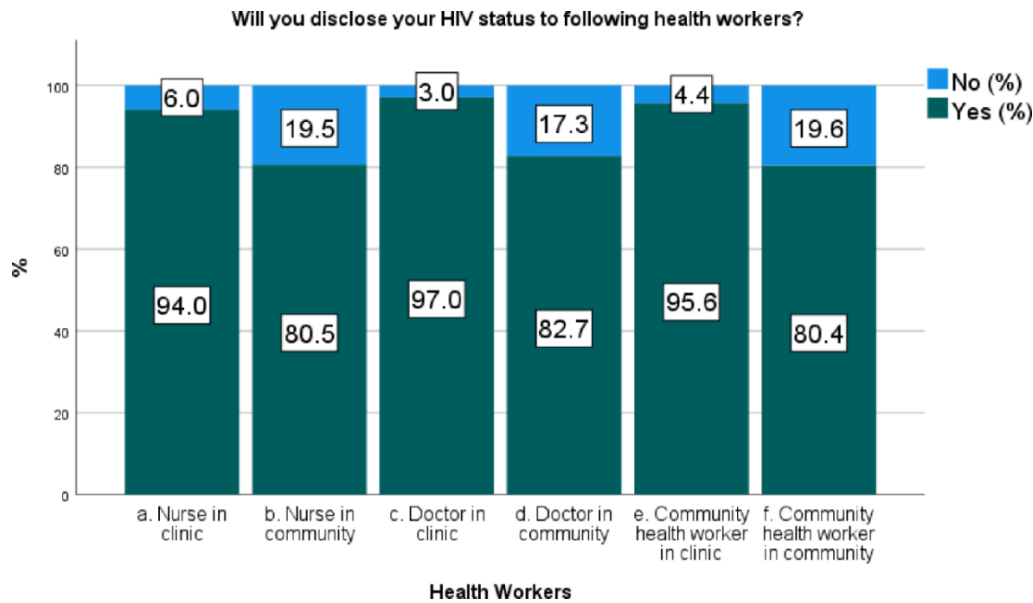


Figure 3-2. Percentage of participants willing to disclose their HIV status to different types of health workers

Women were significantly more willing to disclose their HIV status to nurses and CHWs at the clinic than men: 95.9% vs 90.1% ($P < 0.01$) and 96.6% vs 92.0% ($P=0.035$), respectively (Table 3-2). Participants who had been on treatment for <2 years were significantly less likely to disclose their HIV status to nurses (71.6% vs 86.3%) ($P < 0.01$), doctors (72.6% vs 88.1%) ($P < 0.01$) and CHWs (71.4% vs 85.5%) ($P < 0.01$) at a community level, but not at clinic level, when compared to those who had been on treatment for ≥ 2 years. Participants who had been informed about CHWs and their role when they started treatment were significantly more likely to disclose their status to nurses (85.4% vs 72.4%) ($P < 0.01$), doctors (88.7% vs 73.8%) ($P < 0.01$) and CHWs (86.8% vs 71.1%) ($P < 0.01$) at a community level. Willingness to disclose differed significantly among regions. For instance, participants from region 1 (compared to region 4 and 5) were significantly more likely to disclose their HIV status to nurses (90.2% vs 55.7%) ($P < 0.01$), doctors (91.0% vs 53.7%) ($P < 0.01$) and CHWs (87.6% vs 53.4%) ($P < 0.01$) at a community level. Similar patterns were observed between region 2 (compared to region 4 and 5) (S1 Table). In multivariable logistic regression, only the association between disclosure to CHWs at the community level and region remained statistically significant with an odds ratio (OR) of 0.4 (95% CI 0.3 – 0.6, $P < 0.01$) (S6 Table).

Participants were much less willing to disclose their HIV status to a CHW who was from the same neighbourhood, with only 53.6% of participants overall agreeing to this option, compared to 81.5% who would disclose to someone from a different neighbourhood (Table 3-2). Participants who had been on treatment for <2 years were significantly less likely to be willing to disclose to a CHW from the same neighbourhood (45.9% vs 57.6% on treatment for ≥ 2

years; $P < 0.01$) as were participants who had not been informed about CHWs when diagnosed (41.0% vs 61.1% of those who had been informed; $P < 0.01$). The main reasons (from pre-specified responses) for unwillingness to disclose to CHWs who were from the same neighbourhood were: “I don’t trust my neighbours” (42.4%; $n=118$); “I don’t like to talk about my personal things with my neighbours” (31.3%; $n=87$); and “I am afraid that they will tell other people about my HIV status” (16.9%; $n=47$) (S4 Table).

3.3.3 Home visits

The majority of participants ($n=580$; 89.4%) would like to be visited by a CHW; however those who had been on treatment for ≥ 2 years were significantly more comfortable with this option: 91.4% vs 85.8% ($P < 0.01$) (Table 3-2). Participants who had been informed about CHWs were also more comfortable with home visits than their uninformed counterparts: 94.4% vs 81.7% ($P < 0.01$). Participants from region 1 were more comfortable with home visits than participants from regions 5 and 6: 94.4% vs 73.5% ($P < 0.01$). There was no significant difference regarding willingness to be visited by CHWs between males and females or between different age groups.

More than half of the participants ($n=383$; 57.5%) preferred monthly visits by CHWs to discuss HIV/AIDS-related issues. More participants who had been on treatment for < 2 years and more participants who had never been told about CHWs and their role, indicated that they never wanted to be visited by CHWs to discuss HIV/AIDS-related issues, compared to their counterparts: 14.0% vs 7.0% ($P < 0.01$) and 18.2% vs 4.2% ($P < 0.01$), respectively. Overall, 16.3% of participants would not want CHWs to wear an official uniform during home visits. This was especially true for participants who had not been informed about CHWs when they started treatment compared to those who had received CHW-specific information: 27.6% vs 9.6% ($P < 0.01$). Similarly, 28.8% of participants did not want CHWs doing home visits with branded cars. Interestingly, 81% of participants wanted to be traced by CHWs after missing a clinic appointment. This was also true for the majority (72.6%) of participants who had never been informed about CHWs’ roles. Overall, 95.5% of participants thought that home-based HIV care is a good initiative that will help them.

Table 3-2. Perceptions regarding home visit by a community health worker

		Total n (%)	Duration on treatment n (%)		Gender n (%)		Informed about CHWs and their role n (%)		
			<2 years (A)	≥2 years (B)	Female (A)	Male (B)	No (A)	Yes (B)	Not sure (C)
Would you like to be visited by a CHW where you stay?	No	69 (10.6)	32 (14.2)B	34 (8.6)	46 (9.5)	20 (13.6)	42 (18.3)B	22 (5.6)	4 (16.0)
	Yes	580 (89.4)	193 (85.8)	361 (91.4)A	436 (90.5)	127 (86.4)	187 (81.7)	371 (94.4)A	21 (84.0)
How often should a CHW visit you at home?	Weekly	144 (21.6)	43 (18.2)	86 (21.4)	101 (20.4)	28 (18.5)	30 (12.7)	110 (27.4)A	4 (15.4)
	Monthly	383 (57.5)	132 (55.9)	241 (60.0)	300 (60.6)	82 (54.3)	137 (58.1)	228 (56.7)	17 (65.4)
	6- monthly	65 (9.8)	26 (11.0)	38 (9.5)	46 (9.3)	18 (11.9)	23 (9.7)	40 (10.0)	2 (7.7)
	Yearly	11 (1.7)	2 (0.8)	9 (2.2)	8 (1.6)	3 (2.0)	3 (1.3)	7 (1.7)	01 (0.0)
	Never	63 (9.5)	33 (14.0)B	28 (7.0)	40 (8.1)	20 (13.2)	43 (18.2)B	17 (4.2)	3 (11.5)
Should CHWs wear a uniform?	No	101 (16.3)	34 (15.6)	64 (17.2)	74 (15.9)	24 (17.5)	59 (27.6)B	37 (9.6)	5 (23.8)
	Yes	519 (83.7)	184 (84.4)	309 (82.8)	390 (84.1)	113 (82.5)	155 (72.4)	347 (90.4)A	16 (76.2)
Should CHWs come to your house with branded cars?	No	410 (71.2)	134 (69.1)	253 (71.9)	310 (71.9)	88 (69.8)	120 (62.5)	279 (75.8)A	10 (66.7)
	Yes	166 (28.8)	60 (30.9)	99 (28.1)	121 (28.1)	38 (30.2)	72 (37.5)B	89 (24.2)	5 (33.3)
Should CHW to come to your house if you missed your clinic appointment?	No	113 (18.3)	37 (17.5)	71 (18.8)	78 (17.0)	31 (22.1)	59 (27.4)B	49(12.9)	5 (23.8)
	Yes	505 (81.7)	174 (82.5)	306 (81.2)	380 (83.0)	109 (77.9)	156 (72.6)	332 (87.1)A	16 (76.2)
General impression of home-based HIV care offered by ward-based outreach team members?	Not a good initiative	29 (4.5)	14 (6.3)	14 (3.6)	16 (3.3)	11 (7.4)A	21 (9.3)B	8 (2.0)	01 (0.0)
	Good initiative	617 (95.5)	210 (93.8)	378 (96.4)	462 (96.7)B	137 (92.6)	206 (90.7)	384 (98.0)A	251 (100.0)
CHW = community health worker; n = number Results are based on two-sided tests. For each significant pair, the key of the category with the smaller column proportion appears in the category with the larger column proportion. Significance level (A, B, C): <0.05"									

2. Tests are adjusted for all pairwise comparisons within a row of each innermost sub-table using the Bonferroni correction.

3.3.4 Home-based HIV services

On a scale of 0 to 10, where 0 is not at all and 10 is very much, participants were asked to rate different services which they thought CHWs should focus on. The most highly-rated home-based HIV service offered by CHWs was screening participants for illnesses related to HIV, such as TB, followed by referral to a health facility when needed (Table 3-3). Adherence support was also a highly-regarded service and participants rated CHWs' help in finding ways to remember to take medication every day third highest on the list (Table 3-3). HIV status disclosure was scored as the least important service. While home delivery of medication was the 3rd least important service, the standard deviation was the highest, indicating the highest heterogeneity among responses.

In univariate logistic regression analysis, no significant associations were evident regarding the rating of home-based HIV service offered by CHWs (S7 Table). The same was true for younger (<37 years) participants (71% vs 75%, OR 0.7, 95% CI 0.4 – 1.0, P = 0.05) (S8 Table). Participants who had been on treatment for ≥ 2 years rated home delivery of medication significantly higher than those who had been on treatment for <2 years (80% vs 65%, OR 2.4, 95% CI 1.3 – 4.5, P < 0.01) (S10 Table) while participants who had been informed about CHWs rated being referred to a health facility significantly higher than those who had not been informed (85% vs 73%, OR 2.1, 95% CI 1.0 – 4.4, P = 0.05) (S9 Table).

Table 3-3. Home-based HIV services offered by community health workers

How much should CHWs focus on each of the following aspects of HIV care, when visiting you? On a scale of 0 to 10, where 0 is not at all and 10 is very much.	Number of responses	Mean	Std. Deviation
Screen me for illnesses related to HIV such as TB	661	7,73	2.47
Refer me to a health facility when there is a need	579	7.67	2.59
Help me find ways to remember to take my medication every day	660	7.54	2.60
Educate me about side effects of HIV treatment	657	7.47	2.50
Teach me about my HIV medication	648	7.43	2.62
Help me with counselling after an HIV test	654	7.42	2.61
Educate and assist me with psychosocial well-being (cognitive, emotional, and spiritual strength combined with positive social relationships)	640	7.37	2.57
Deliver my medication at home	608	7.31	2.89
Educate me about the type of food I should eat to stay healthy	647	7.28	2.64
Assist me to be able to disclose my HIV status	656	7.25	2.66

3.4 Discussion

The aim of this study was to capture the voices of a representative group of PLWHIV regarding the acceptability of and their preferences for home-based HIV care offered by CHWs in Tshwane district. Emphasis was placed on participants' willingness to disclose their HIV status to different categories of health workers at both the household and clinic level, as well as perceptions about the various services offered.

3.4.1 Disclosure

In clinical practice, great emphasis has been placed on disclosure of PLWHIV's status to family members, partners or friends, but little attention has been paid to disclosure to health care workers in general and CHWs in particular.(100, 101) The few studies that have assessed disclosure to health care workers have done so in the context of health facilities, with little or no focus on disclosure outside this environment.(101) Results of this study demonstrate that participants were more comfortable disclosing their HIV status in a health facility compared to a community setting. Willingness to disclose did not differ significantly between profession type (doctor, nurse or CHW), but was rather determined by the environment (clinic versus the community).

Approximately 20% of PLWHIV in this study were not willing to disclose their HIV status to health care workers in the community and can, consequently, not benefit from home-based HIV services. Participants who had been informed about HIV services offered by CHWs in the community were more willing to disclose their status to these health care workers, suggesting that a targeted information campaign could help to allay fears and improve engagement with this cadre of workers. This is especially important for PLWHIV who had been on treatment for a shorter duration, i.e. <2 years. Regional differences, independent of duration of treatment, also emerged and it is important to explore the reason for these differences through further qualitative research. Attention should also be paid to recruitment strategies for CHWs. While there are clear advantages of recruiting CHWs from a local area where they are knowledgeable about the local languages, logistics, socioeconomic realities, and life experiences of the community members they serve, this also poses problems.(102, 103) In this study, one of the main reasons participants were not willing to disclose their HIV status was distrust of neighbours. Patient-health care provider trust has been defined as the expectation of the patient that the health care worker will act in their best interest. It is, however, unclear how patient-health care provider trust is modified in the context of pre-existing social relationships. While it is worrying that a large proportion of participants were unwilling to disclose their HIV status to CHWs from their neighbourhood, a large proportion would disclose their status to CHWs who come from other areas. There is therefore a need to reevaluate the composition of WBPHCOTs and their geographic diversity to accommodate patients' needs.

3.4.2 Home visits

One of the most important findings of our study is that more than 95% of participants thought that home-based HIV care is a good initiative that will help them. This demonstrates that there is significant support for this intervention, but that specific issues need to be addressed to make the intervention acceptable to all. While some PLWHIV view visits by CHWs as attracting unnecessary attention from community members(93), results of this study show that the vast majority (close to 90%) of participants want to be visited by CHWs. Importantly, however, $\pm 28\%$ of participants did not want CHWs to visit them with branded cars, while $\pm 16\%$ did not want CHWs to wear uniforms.

A systematic review on the frequency of clinic visit for PLWHIV showed that decreasing the number of clinics visits was effective in improving retention in care, but called for the introduction of community-based services to improve clinical outcomes.(104) In this study, there was great variability in how often participants wished to receive home visits: from weekly, to monthly, to 6-monthly. SA currently does not have enough CHWs to cover those in need of their services(105), so less frequent visits are the only realistic option. Quarterly visits could still be effective since these visits should not be seen as a replacement of facility-based services, but rather as supplemental visits. Screening for opportunistic infections such as TB topped the list of services that participants preferred. PLWHIV, especially in the early stages of treatment, have an increased risk of opportunistic infections. In SA, TB remains the leading natural cause of death (90). In 2017, $\pm 60\%$ of patients with TB in SA were HIV positive and 56 000 of them died as a result of their infection.(106) If PLWHIV are willing to be periodically screened by CHWs for TB, this could improve outcomes and reduce deaths.

The second ranked activity was being referred to a health facility when there is a need. Participants who had been informed about CHWs and their roles were more likely to value this service. This demonstrates the importance of the linkage between community-based services and facility-based services as well as provision of information about CHW roles to patients. While women have been reported to be 33% more likely to have optimal adherence to ART compared to men in a South African study(107), men from our study appeared not to value assistance with identifying ways to remember their medication as high as women. Interestingly, participants who had been on treatment for longer and participants who were older, rated delivery of medication higher than their counterparts. This information is valuable when considering ways in which to decongest clinics in a rational manner.

3.5 Conclusion

In this study, home-based HIV care was largely accepted as an important and positive intervention. Participants did, however, have different preferences with regards to the practicalities of these visits. Differences were mostly determined by region, how long participants had been on ART, and whether they had been informed about the role of CHWs. Small differences were also evident between older and younger participants, as well as between genders. More work is needed to understand individual preferences and the extent to which they can be accommodated. Trust and

disclosure of HIV status to CHWs remain central issues, which might require changes in recruitment and deployment of CHWs.

3.6 Acknowledgments

We would like to thank all participants who were part of the study. We would also like to thank Clive Nkgadima and Ofentse Mathibe for helping with logistical arrangements.

3.7 Author Disclosure Statement

No competing financial interests exist.

3.8 Funding Information

SN is supported by the South African Medical Research Council through the Bongani Mayosi National Health Scholars Programme.

4 Chapter 4 (submitted article)

PLOS ONE

Effect of a ward-based outreach team and adherence game intervention on retention in care and virological suppression of HIV-infected patients newly initiated on antiretroviral treatment in Tshwane, South Africa

--Manuscript Draft--

Manuscript Number:	PONE-D-22-05480
Article Type:	Research Article
Full Title:	Effect of a ward-based outreach team and adherence game intervention on retention in care and virological suppression of HIV-infected patients newly initiated on antiretroviral treatment in Tshwane, South Africa
Short Title:	Effect of a ward-based outreach team and adherence game intervention
Corresponding Author:	Sanele Ngcobo, MPH University of Pretoria School of Medicine Pretoria, SOUTH AFRICA
Keywords:	HIV; Community health workers; Games; retention to care; viral load Suppression; AIDS
Abstract:	South Africa remains the epicenter of the HIV pandemic. With only 66% of South African PLWHIV virologically suppressed, it is important to develop strategies to improve outcomes. This 2 x 2 factorial cohort study assessed the effect of interventions on 12-month retention in care and virological suppression in participants newly initiated on ART. Clinics were randomized into four comparator arms: WBPHCOT; Game; WBPHCOT-Game in combination; and Control (standard of care). A total of 558 participants from 26 clinics across Tshwane district were enrolled. After excluding ineligible participants, a total of 467 participants were included in the analysis: WBPHCOT (n=72); Games (n=126); WBPHCOT-Games (n=85); and Control (n=184). After 12 months, 340 participants (86.2%) remained in care. The Games group had the highest retention compared to the Control group (96.8% vs 77.8%; relative risk [RR] 1.25; 95% CI 1.13–1.38; p=0.01). While retention was better in the WBPHCOT-containing interventions than in the Control group, the differences were not statistically significant. Younger participants (<35 years) were significantly less likely to remain in care (71% vs 89%; RR 0.80; 95% CI 0.69 – 0.93; p=<0.001). The overall virological suppression rate was 75.3% and was similar across the four arms. This study demonstrated that an adherence game intervention could help keep PLWHIV in care. Several operational challenges emerged in the WBPHCOT-containing interventions, which deserve further study. More studies should be performed to assess the optimal way of including WBPHCOTs in home-based HIV care as well as how to combine different interventions in a meaningful way.
Order of Authors:	Sanele Ngcobo, MPH Steve Olorunju Tshifhiwa Nkwenika Theresa Rossouw

Effect of a ward-based outreach team and adherence game intervention on retention in care and virological suppression of HIV-infected patients newly initiated on antiretroviral treatment in Tshwane, South Africa

Sanele Ngcobo^{1§}, Steve Olorunju², Tshifhiwa Nkwenika,² Theresa Rossouw³

- 1 Department of Family Medicine, University of Pretoria, Pretoria, South Africa
- 2 Biostatistics unit, South African Medical Research Council, Pretoria, South Africa
- 3 Department of Immunology, University of Pretoria, Pretoria, South Africa

[§] Corresponding author: Sanele Ngcobo

Street Name: 31 Bophelo road, Gezina

Pretoria, 0001, South Africa

012 3563313

Email: Sanele.Ngcobo@up.ac.za

E-mail addresses of authors:

SN : Sanele.Ncobo@up.ac.za

TN: Tshifhiwa.Nkwenika@mrc.ac.za

SO: Steveolorunju@outlook.com

TR : Theresa.Rossouw@up.ac.za

Keywords: HIV, Community health workers, barriers, facilitators.

Word count:

Abstract: 350

Main text: 5000

4.1 Introduction

In 2019, an estimated 7 800 000 (95% confidence interval [CI] 5 200 000 - 10 000 000) adults and children were living with HIV in South Africa.(1) This equates to 20% of the global population of people living with HIV (PLWHIV). With regards to South Africa's progress towards the UNAIDS 2020 90-90-90 goals, 90% of PLWHIV knew their status, 62% of PLWHIV were on antiretroviral treatment (ART) and 66% of PLWHIV were virally suppressed in 2020.(1) A systematic review by LeMessurier *et al* found that there is negligible risk (0.00 transmissions/100 person-years, 95% CI 0.00-0.28) of sexual transmission of HIV among HIV-discordant couples when the partner with HIV adheres to ART and maintains a suppressed HIV viral load (VL), i.e. <200 HIV-1 RNA copies/mL plasma, measured routinely every 4 to 6 months.(108) The concept of "Undetectable = Untransmittable" emphasizes the public health importance of an undetectable VL and lends further weight and impetus to the UNAIDS' updated 2030 95-95-95 goals which aim to get more than 85% of PLWHIV virally suppressed.(19)

Poor adherence to ART remains the major cause of therapeutic failure. It also increases the risk of opportunistic infections and death.(23) Many factors impede adherence, such as stigma, non-disclosure, unemployment, lack of transport, insufficient access to food, alternative forms of therapy, inadequate follow-up, and lack of patient confidentiality.(24) In the face of these challenges, there is an urgent need to develop and implement strategies to increase adherence and, subsequently, the proportion of PLWHIV who attain and maintain an undetectable VL. One such strategy is assigning community health workers (CHWs) to care for PLWHIV at a household level as ward-based primary healthcare outreach teams (WBPHCOTs). A systematic review by Mwai and colleagues on the role of CHWs in HIV care in sub-Saharan Africa reported that CHW activities included educating families, caregivers, and communities about HIV/AIDS and its symptoms, as well as preparing PLWHIV for ART and the possible side effects they may experience.(63)

Since low health literacy has been associated with poor health outcomes,(57) there is growing interest in ways to improve patients' health literacy in order to improve retention in care and treatment adherence.(109, 110) Traditional ways of patient education have met with limited success (56, 111) and many health disciplines have started experimenting with gamification, where gaming techniques are used to engage audiences and make everyday tasks more fun and engaging. In the HIV field, Bridges of Hope training developed experiential learning games and activities to

enhance treatment adherence. The ART adherence games were designed based on educationally validated theories, such as using experimental metaphor, multisensory learning, social cognitive theory, logical and neurological behavioral frameworks,(112) and skilled task performance: association, dissociation, and mental models(113). The adherence games are specifically designed for use with groups of people who have recently tested HIV positive, to help them address a range of issues they may face around living positively, such as: stigma, support, disclosure, and treatment adherence. The program includes 12 sessions, each requiring about 1 hour. Each of the first 9 sessions includes two experiential learning activities.

Although both WBPHCOTs and various gaming strategies have shown promise in the health space (58, 63, 114), neither have been tested in South Africa. To fill this gap, this study assessed the independent and combined effect of a WBPHCOT and games intervention on retention in care and virological suppression of PLWHIV newly initiated on ART in Tshwane district, South Africa.

4.2 Methods

4.2.1 Overview

This 2 x 2 factorial cohort study consisted of four arms: WBPHCOTs; Bridges of Hope's adherence game (henceforth referred to as "Games"); WBPHCOTs and Games combined; and a Control group that received standard care. Recruitment started in February 2019 and ended in December 2019. All participants were recruited from primary healthcare clinics that provide ART. In line with the national program, newly-diagnosed patients were assessed for same-day ART initiation as part of the universal test and treat strategy, and visited the clinic monthly to collect treatment.(115) The sample size was calculated on the assumption that the intervention groups would achieve a 12% improvement in the primary outcome (retention in care) analyzed as a binary outcome. Accordingly, a sample size of 460 participants with complete follow-up would give the study an estimated power of 82%.

4.2.2 Clinic selection

Facilities in Tshwane were selected based on the expected number of newly-infected persons in their catchment area as calculated from the population size and the national HIV incidence of 1.2%.(7) Clinics with fewer than 60 potential participants in 6 months were excluded. Facilities

that met the inclusion criteria were randomized in Microsoft excel into the four study arms. Clinics that did not recruit participants within the first 6 months of the study were excluded.

4.2.3 Participant inclusion and exclusion criteria

Patients were invited to participate in the study if they were 18 years or older, newly diagnosed with HIV, and initiated on ART within the last month. Patients who were too ill to provide informed consent were excluded.

4.2.4 Ethical considerations

The Research Ethics Committee of the Faculty of Health Sciences of the University of Pretoria granted ethics approval for the study (reference number: 580/2018). Permission to collect data was obtained from Tshwane health district and all facilities involved. Each participant gave informed consent before participating in the study. No personal identifying information was captured. Patients meeting the eligibility criteria were informed about the study by lay counsellors and gave written informed consent before being enrolled in the study. Participation was completely voluntary, no treatment was delayed, and confidentiality was always respected.

4.2.5 Interventions

4.2.5.1 *WBPHCOT intervention*

Participants from clinics with the WBPHCOT intervention were visited at home by a CHW within a week of treatment initiation. The purpose of the first home visit was to continue with HIV post-test counselling, making use of a patient-centered approach. This session was conducted in a private setting, unless the participant requested members of their family to be present. Counselling was performed by a trained CHW with relevant counselling experience. This session focused on the following: medical implications of the diagnosis, including prognosis and treatment; disclosure; psychological issues (coping, support, relationships); and social implications (stigma, employment, discrimination). At the end of the first visit, the CHW scheduled a follow-up visit. The second visit focused on treatment adherence support and addressed any arising medical and psychosocial issues. CHWs also performed a pill count; screened for opportunistic infections, such as tuberculosis (TB), and adverse effects of the medication; and assisted participants with disclosure. After the first two visits, depending on the response of the participant, a CHW did follow-up visits at least once a month, mostly before the date of the participant's appointment at

the clinic. These visits focused on treatment adherence support; checking for, educating about, and managing adverse effects; screening for opportunistic infections, including TB; providing nutritional advice, mental health care and other services.

4.2.5.2 Games intervention

At least one lay counsellor was trained per facility to offer the Games intervention. The training was conducted over three days by Bridges of Hope training in collaboration with the Department of Family Medicine of the University of Pretoria. Participants enrolled into this intervention arm had their clinic visits scheduled to coincide with the return dates of at least five other participants in the study. A minimum of six participants played the game at any given time and the game lasted approximately one hour. The first game (focusing on treatment adherence) was played approximately one month after initiation of ART and subsequent sessions were scheduled for at least once every month. Each participant was required to play at least the first game to be part of the study.

4.2.5.3 WBPHCOT and Games intervention

This arm consisted of a combination of the two interventions: WBPHCOT and Games. Scheduling occurred in the same way as described above.

4.2.5.4 Control group

Lay counsellors from clinics allocated to the Control group were trained on the recruitment of participants. Participants in this group received the usual HIV care offered by the clinics.

4.2.6 Outcome

The primary outcome of the study was retention in care at 12 months. Retention was measured monthly and possible outcomes included: retained in care; lost to follow-up (LTFU - missed three consecutive clinic visits); died; missed a visit; or transferred to another health facility. The secondary outcome was virological suppression at 12 months, coded as a binary variable: detectable VL (≥ 50 copies/mL) and undetectable VL (< 50 copies/mL). Clinics taking part in this study monitored VL load six and twelve months after treatment initiation, in line with the national HIV guidelines.(116)

4.2.7 Data analysis

Monthly retention in care data and VL at 12 months were extracted from Tier.net (an electronic patient management system with modules to capture patient-level data on HIV-related counselling

and testing, pre-ART and ART services)(28) and exported to Microsoft excel. The principal researcher cleaned the data with the assistance of a statistician. Participant characteristics and retention outcome status were analyzed using SPSS version 26 (IBM Corp., 2019).(96) Results were described according to the mean and standard deviation (SD), frequencies and proportions, as appropriate. Age was analyzed as both a continuous, binary (dichotomized according to the mean), and categorical (18 – 24, 25 – 34, 35 – 44, 45+) variable. For the outcomes of interest (retention in care and virological suppression) participants who missed visits, transferred to other facilities, died, or had no outcome at 12 months, were excluded from the analysis. The relative risk (RR) was calculated for retention in care and virological suppression at 12 months, and an odds ratio was calculated by means of multivariable regression analysis. All main outcome analyses and planned comparisons defined statistical significance as $p < 0.05$.

4.3 Results

Results are presented in four sections: characteristics of participants; overall outcome; retention in care; and VL suppression. Of the 558 participants enrolled in the study, 73 were excluded from the analysis as they started treatment before January 2019 and therefore did not meet the inclusion criteria (Figure 4-1). An additional 18 participants, who did not have retention in care data for at least 6 months at the end of the study, were excluded from the data analysis.

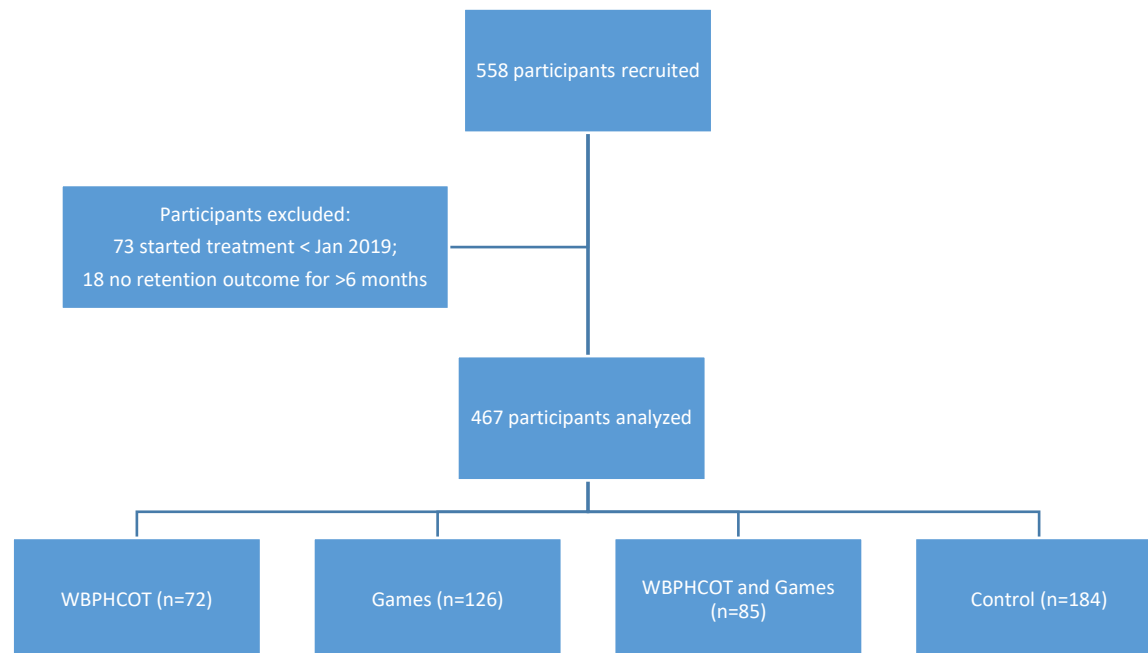


Figure 4-1. Schematic representation of participants

4.3.1 Characteristics of participants

Four hundred and sixty-seven participants from 26 clinics across Tshwane met the inclusion criteria for this study and were included in the analysis: 72, 126, 85, and 184 in the WBPHCOT, Games, WBPHCOT and Games, and Control group, respectively (Figure 4-1). Of these, 320/467 (68.5%) were female of whom 64 (20%) were pregnant. The WBPHCOT and Games group had the highest proportion of females 62/85 (72.9%) and the Games group had the highest proportion of pregnant women 25/62 (30.1%). The WBPHCOT group had the highest proportion of participants ≥ 35 years old (56.9%), while the Games group had the highest proportion of participants < 35 years old (57.1%) (Table 4-1). The mean pre-initiation CD4 count for all participants was 381 (SD ± 280.35) cells/mm³. No pre-initiation VL was available since this test is not conducted in the national HIV treatment program.

Table 4-1. Characteristics of participants

Characteristics	WBPHCOT	WBPHCOT + Games	Games	Control	Total
Number of participants [N (%)]	72 (15.4)	85 (18.2)	126 (27.0)	184 (39.4)	467 (100)
Number of Clinics per intervention [N (%)]	6 (23.1)	4 (15.4)	6 (23.1)	10 (38.5)	26 (100)
Age [Mean (SD)]	36.60 (10.78)	36.94 (10.99)	33.84 (10.93)	34.66 (10.95)	35.18 (11.00)
Categories [N (%)]					
<35 years	31 (43.1)	40 (47.1)	72 (57.1)	94 (51.1)	237 (50.7)
≥ 35 years	41 (56.9)	45 (52.9)	54 (42.9)	90 (48.9)	230 (49.3)
Gender categories					
Female N (%)	46 (63.9)	62 (72.9)	85 (67.5)	127 (69.0)	320 (68.5)
Male N (%)	26 (36.1)	23 (27.1)	41 (32.5)	57 (30.1)	147 (31.5)
Pregnant women out of all women [N (%)]	9 (19.6)	4 (6.5)	25 (30.1)	26 (21.7)	64 (20)
Pre-ART CD4 count in cells/mm ³ [Mean (SD)]	399.11 (270.23)	362.24 (257.27)	417.83 (311.36)	348.07 (282.54)	381 (280.35)

4.3.2 Outcome at 12 months

4.3.2.1 Overall outcome

At 12 months, 293 out of the 467 participants (64.4%) remained on treatment in the facility where they were initiated, while seven (1.8%) died, 23 (4.8%) had missed a clinic visit, 47 (9.4%) were confirmed LTFU, and 79 (15.9%) had been transferred to another facility (Table 4-2). There were no significant differences between the intervention and control groups in terms of the number of deaths or missed clinic visits. Only three participants (2.4%) were confirmed to be LTFU at 12 months in the Games group, compared to 28 (15.2%) in the Control group ($p<0.001$). A higher proportion of participants remained in care in both the Games (72.2%, $p<0.001$) and the WBPHCOT and Games group (68.2%, $p=0.02$), compared to the Control group (53.3%). There was, however, no significant difference in retention of participants in the WBPHCOT group (63.9%, $p=0.12$) when compared to the Control group. A higher proportion of participants were transferred to other facilities in the Control group (21.2%) compared to the WBPHCOT and Game group (10.6%, $p=0.03$).

There were no significant differences between males and females in any of the outcomes. However, the proportion of pregnant women who remained in care at 12 months was significantly lower than non-pregnant women: 46.9% vs 68.0% ($p<0.0001$). In addition, a higher proportion of pregnant women were transferred to other facilities when compared to non-pregnant women (25.0% vs 14.2%, $p=0.04$). The age group, 25-35 years, had the largest proportion of LTFU (16.4%). In contrast, the age group 45 years and above had the highest proportion of participants who remained in care (81%) and were the least likely to be transferred (8%).

Table 4-2. Participant outcomes at 12 months

	No data N (%)	P	Died N (%)	P	Missed visit N (%)	P	LTFU N (%)	P	Retained in care N (%)	P	Transfer N (%)	P
Total	18 (3.7)		7 (1.8)		23 (4.8)		47 (9.4)		293 (64.4)		79 (15.9)	
Intervention												
WBPHCOT	5 (6.9)	0.64	1 (1.4)	0.48	2 (2.8)	0.58	6 (8.3)	0.14	46 (63.9)	0.12	12 (16.7)	0.42
W+G	0 (0.0)	0.03	3 (3.5)	0.06	5 (5.9)	0.57	10 (11.8)	0.46	58 (68.2)	0.02	9 (10.6)	0.03
Games	3 (2.4)	0.19	2 (1.6)	0.35	8 (6.3)	0.43	3 (2.4)	<0.001	91 (72.2)	<0.001	19 (15.1)	0.18
Control	10 (5.4)	Ref	1 (0.5)	Ref	8 (4.3)	Ref	28 (15.2)	Ref	98 (53.3)	Ref	39 (21.2)	Ref
Gender												
Female	12 (3.8)	Ref	4 (1.3)	Ref	17 (5.3)	Ref	32 (10.0)	Ref	202 (63.1)	Ref	53 (16.6)	Ref
Male	6 (4.1)	0.88	3 (2.0)	0.57	6 (4.1)	0.58	15 (10.2)	0.95	91 (61.9)	0.80	26 (17.7)	0.77
Pregnant												
No	6 (2.4)	Ref	3 (1.2)	Ref	12 (4.9)	Ref	23 (9.3)	Ref	168 (68.0)	Ref	35 (14.2)	Ref
Yes	3 (4.7)	0.33	1 (1.6)	0.80	6 (9.4)	0.17	8 (12.5)	0.45	30 (46.9)	<0.001	16 (25.0)	0.04
Age group (years)												
18 - 24	3 (3.5)	0.45	1 (1.2)	0.90	6 (7.1)	0.20	7 (8.2)	0.38	47 (55.3)	<0.001	21 (24.7)	<0.001
25 - 34	6 (3.9)	0.40	0 (0.0)	0.22	11 (7.2)	0.15	25 (16.4)	0.01	89 (58.6)	<0.001	21 (13.8)	0.16
35 - 44	7 (5.4)	0.19	5 (3.8)	0.18	3 (2.3)	0.74	10 (7.7)	0.41	76 (58.5)	<0.001	29 (22.3)	<0.001
45+	2 (2.0)	Ref	1 (1.0)	Ref	3 (3.0)	Ref	5 (5.0)	Ref	81 (81.0)	Ref	8 (8.0)	Ref
P = p value; LTFU = Lost to follow-up; WBPHCOT = Ward Based Primary Healthcare Outreach Teams; Ref = Reference; W+G = WBPHCOT and Games												

4.3.2.2 Retention in care

When analysis was restricted to the binary outcome, retention in care, at 12 months, 340 participants were either retained in care (86.2%) or LTFU (13.8%) (Table 4-3). The Games group had the highest retention in care rate of 96.8% and RR 1.25 (95% CI 1.13 – 1.38; $p = 0.01$) when compared to the Control group (77.8%). Although proportionally more participants were retained in the other intervention groups, there was not a significant difference in retention rates between the WBPHCOT and Control group, or the WBPHCOT and Games and the Control group. Younger participants (<35 years) were significantly less likely to be retained in care when compared to older (≥ 35 years) participants (71.3% vs 89%, RR 0.80, 95% CI 0.69 – 0.93, $p = 0.002$).

Table 4-3. Retention in care

	Retention in care rate (%)	Relative risk	P Value
Intervention			
WBPHCOT (n = 52)	88.5%	1.14 (0.99 – 1.30)	0.10
Games (n = 94)	96.8%	1.25 (1.13 – 1.38)	0.01
WBPHCOT + Games (n = 68)	85.3%	1.10 (1.00 - 1.27)	0.21
Control (n = 114)	77.8%	Ref	Ref
Gender			
Female (n = 237)	80.6%	1.00 (0.78 - 1.26)	0.92
Male (n = 95)	80.0%	Ref	Ref
Pregnant			
Yes (n = 48)	66.7%	0.51 (0.89 – 1.75)	0.10
No (n = 185)	83.0%	Ref	Ref
Age group (years)			
<35 (n = 94)	71.3%	0.80 (0.69 – 0.93)	0.002
≥ 35 (n = 100)	89.0%	Ref	Ref
WBPHCOT = Ward Based Primary Healthcare Outreach Teams; Ref = Reference			

Monthly LTFU data (Figure 4-2) show that 6.3% of the Control group, 2.7% in the WBPHCOT and Games group, and none in the WBPHCOT group or the Games group were LTFU a month after participants were initiated on treatment. At 3 months, 10.1% of participants in the Control group were LTFU, compared to 4.3% and 3.6% in the WBPHCOT and Games group and the WBPHCOT group, respectively. No participants were LTFU in the Games group at this point. By 12 months, 22.2% in the Control group were lost to follow up compared with 14.7% and

11.5% in WBPHCOT group (with and without games, respectively) and 3.2% in the Games group.

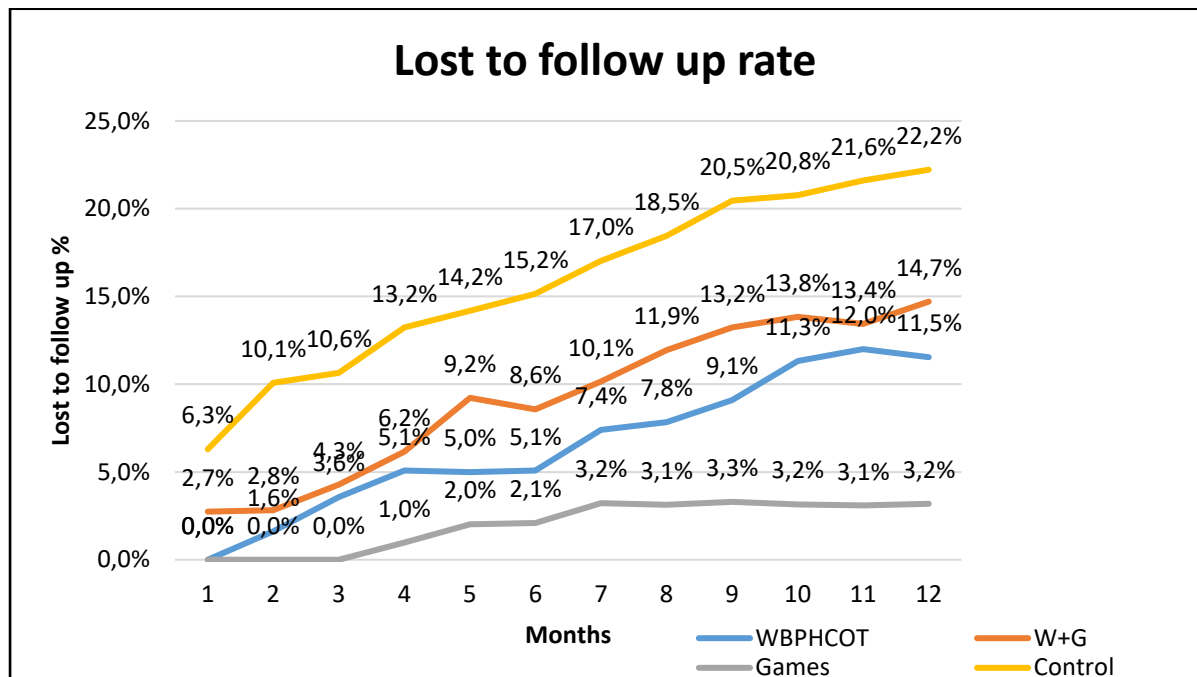


Figure 4-2. Participants lost to follow up in the different groups

4.3.3 Virological suppression

A similar proportion of participants achieved virological suppression in the three intervention arms when compared to the Control arm: WBPHCOTs - 82.7% (RR 1.23; 95% CI 0.67 – 2.27; $p = 0.49$); Games - 67.3% (RR 0.76; 95% CI 0.95 0.57 - 1.02; $p = 0.08$); WBPHCOT Game combination - 76.5% (RR 0.95; 95% CI 0.61 - 1.47); $p = 0.80$); Control - 78.1% (

Table 4-4). Women were more likely to achieve an undetectable VL when compared to men, but the difference was not statistically significant: 77.6% vs 69.5% (RR 1.14; 95% CI 0.95 - 1.36; $p = 0.12$). Pregnant women had a lower rate of virological suppression at 64.6%, with a RR of 0.52 (95% CI 0.32 – 0.87, $p = 0.01$) when compared to the suppression rate of 81.1% of non-pregnant women. There was no significant difference between participants <35 years and ≥ 35 years old.

Table 4-4. Virological suppression

	VL suppression rate (%)	Relative risk	P Value
Overall (n = 332)	75.3%		
Intervention			
WBPHCOT (n = 52)	82.7%	1.23.79 (0.67 - 2.27)	0.49
Games (n = 98)	67.3%	0.76 (0.57 – 1.02)	0.08
WBPHCOT + Games (n = 68)	76.5%	0.95 (0.61 - 1.47)	0.80
Control (n = 114)	78.1%	Ref	Ref
Gender			
Female (n = 237)	77.6%	1.14 (0.95 - 1.36)	0.12
Male (n = 95)	69.5%	Ref	Ref
Pregnant			
Yes (n = 48)	64.6%	0.52 (0.32 – 0.87)	0.01
No (n = 185)	81.1%	Ref	Ref
Age group (years)			
<35 years	74.4%	0.95 (7.6 – 1.21)	0.70
≥35 years	76.3%	Ref	Ref
VL = Viral load; WBPHCOT = Ward Based Primary Healthcare Outreach Teams; Ref = Reference			

In multivariable logistic regression, only the association between pregnancy and virological suppression remained statistically significant with an odds ratio (OR) of 2.37 (95% CI 1.15 – 4.9), $p = 0.019$) (Table 4-5).

Table 4-5. Multivariable analysis of pregnancy, age, and interventions

Variables in the Equation							95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower Upper
Step 1 ^a	Pregnant on ART Start	.862	.367	5.522	1	.019	2.367	1.154 4.856
	AgeBinary	.022	.336	.004	1	.949	1.022	.529 1.972
	Intervention	-.010	.150	.005	1	.946	.990	.738 1.328
	Constant	-1.437	.478	9.032	1	.003	.238	

a. Variable(s) entered on step 1: Pregnant on ART Start, AgeBinary, Intervention.

4.4 Discussion

In this study, we found that an adherence game intervention significantly improved retention of participants who had been newly initiated on ART. Our study is the first to objectively demonstrate the effectiveness of the Bridges of Hope adherence game in improving HIV treatment outcomes. While previous studies have evaluated digital games for HIV prevention and care (109, 110, 117, 118), there is little information on the effectiveness of physical games

that aim to improve patients' adherence to treatment. Physical games could be of special importance in settings where access and knowledge of digital technology are limited.

The overall LTFU rate was 9.4% after 12 months of treatment. When excluding participants who had died, missed visit, were transferred to other facilities, and those without an outcome at 12 months, the LTFU rate was 13.8%. A meta-analysis (2008–2013), published in 2016, reported a 23% LTFU rate at 12 months in 22 studies from South Africa.(119) This is comparable to the rate in the Control group (22.2%), but almost double that of the WBPHCOT intervention groups and ten times more than the Games group in our study.

In a study of 1041 patients who were receiving home-based HIV care from CHWs in Rwanda, 92.3% were retained in care, compared to 88.5% from our study.(120) Even though the groups exposed to the WBPHCOT intervention outperformed the Control group, the difference in retention in care was not significantly different. This was contrary to our expectation. The researchers therefore conducted a qualitative evaluation of perceived barriers to offering home-based HIV care among WBPHCOT members and PLWHIV in a different study population.(93) These included: patients giving incorrect addresses; fear of stigma through association with WBPHCOTs, especially those in uniform; little or no preparation of patients for home-based care; and lack of confidentiality and trust. Future interventions should take these perceived barriers into account in order to optimize the benefit that might be obtained by utilizing WBPHCOTs.

We expected the combination of the WBPHCOT and Games intervention to have the best results in terms of retention in care and viral suppression. While this group did indeed have better retention compared to the Control group, it was worse than in the Games group. It appears that logistical challenges had made it difficult for CHWs to work with lay counsellors who were offering the Games intervention; this could have negatively affected the outcome in this intervention. Some participants would have preferred one intervention, instead of both. For example, some participants preferred the Games intervention, but refused CHW visits to their households. Some of these challenges were previously noted in community-based HIV prevention trials in KwaZulu Natal, with some participants refusing to take part in some components of the intervention because of perceived stigma.(121) This is an important consideration for future intervention studies.

At time of our study, most participants were on tenofovir, emtricitabine and efavirenz which has higher pretreatment resistance when compared to the current first line option (tenofovir, lamivudine and dolutegravir). It is then expected that results of patients on tenofovir, lamivudine and dolutegravir may be different from that of this study.(122, 123) The overall

rate of VL suppression in our study was 75.3% and was similar among the groups. This is likely due to the fact that patients who remain in care are equally adherent.(124) Pre-treatment drug resistance in South Africa is currently at 23%, mostly driven by resistance to the non-nucleoside reverse transcriptase inhibitor (NNRTI) class.(125) Since participants in this study would have been initiated on an ART regimen including the NNRTI, efavirenz, it can be expected that a large proportion would fail to achieve virological suppression despite adequate adherence.(126)

It is interesting that the proportion of participants with virological suppression recorded in our study is lower than the national and Tshwane district suppression rate of 90.6% and 92.3% respectively at 12 months, reported in adult South Africans in 2018.(90) It is however important to note that this national and district suppression rate is based on national indicator data Set (NIDS) which defines suppressed VL as <400 copies/ml, while in our study we used a WHO definition of <50 copies/ml.(90) Pregnant women were significantly less likely to achieve a suppressed VL. Although not directly comparable, a study of 10 052 HIV-positive pregnant participants reported a 56.2% VL suppression rate, mostly due to late antenatal care booking.(127)The Games intervention had the highest proportion of pregnant participants; this could have contributed to the high proportion of participants with an unsuppressed VL in this group.

4.5 Limitations

The COVID-19 pandemic limited the availability of VL results since the number of clinic visits decreased as per national restrictions. Barriers to offering home-based HIV care by CHWs negatively affected this intervention arm; these barriers were clearly documented in our qualitative study.(93)

4.6 Conclusions

This 2 x 2 factorial cohort study is the first to demonstrate that a physical adherence game improves the retention of PLWHIV newly initiated on ART and hence has the potential to improve treatment outcomes. Despite the challenges encountered with the WBPHCOT-containing interventions, they still outperformed the Control arm, and the observed improvement might become significant once the potential barriers identified in the study have been addressed. More studies should be performed to assess the optimal way of including WBPHCOTs in home-based HIV care as well as how to combine different interventions in a meaningful way.

4.7 Competing interests

No competing interests exist

4.8 Authors' contributions

SN, TR, and SO conceptualized and designed the study. The study procedures and data collection were implemented by SN. Study analyses were completed by SO, SN and TN with input from TR and SN wrote the first manuscript draft. TR led review (with inputs from SO and TN) and substantive contributions to manuscript revisions, which all authors supported. All authors have read and approved the final manuscript.

4.9 Acknowledgements

We would like to thank all participants who were part of the study. We would also like to thank Clive Nkgadima, Lethabo Phefadu and Ofentse Mathibe for helping with logistical arrangements. We also acknowledge the support we received from Tshwane Health district management, including HAST (HIV and AIDS / STI / TB) and WBPHCOT leaders. We acknowledge the contribution of WBPHCOT members including operational team leaders and CHWs.

4.10 Funding

SN is supported by the South African Medical Research Council through the Bongani Mayosi National Health Scholars Programme.

Disclaimer: No disclaimer

5 Chapter 5

AIDS PATIENT CARE and STDs
Volume 36, Number 4, 2022
Mary Ann Liebert, Inc.
DOI: 10.1089/apc.2022.0020

Open camera or QR reader and
scan code to access this article
and other resources online.



Roles, Barriers, and Recommendations for Community Health Workers Providing Community-Based HIV Care in Sub-Saharan Africa: A Review

Sanele Ngcobo, MPH,¹ Susan Scheepers, BLIS,² Nothando Mbatha, MPH,³
Estelle Grobler, BLIS,² and Theresa Rossouw, PhD⁴

Abstract

Roles, barriers and recommendations for community health workers providing community-based HIV care in sub-Saharan Africa: A systematic, aggregated, narrative review.

Sanele Ngcobo^{1*§}, Susan Scheepers², Nothando Mbatha³, Estelle Grobler², Theresa Rossouw⁴

1. Department of Family Medicine, University of Pretoria, Pretoria, South Africa
2. Medical Library, University of Pretoria, Pretoria, South Africa
3. Department of Public Health, University of Pretoria, Pretoria, South Africa
4. Department of Immunology, University of Pretoria, Pretoria, South Africa

§ Corresponding author: Sanele Ngcobo

Street Name: 31 Bophelo road, Gezina

Pretoria, 0001, South Africa

012 3563313

E-mail addresses of authors:

SN: Sanele.Ngcobo@up.ac.za

TR: Theresa.Rossouw@up.ac.za

SS: Susan.Scheepers@up.ac.za

EG: Estelle.Grobler@up.ac.za

NM: mbathanothando@yahoo.com / u15414362@tuks.ac.za

Keywords: HIV, Community health workers, roles, barriers, Antiretroviral, stigma.

5.1 Abstract

While the impact of CHWs on home-based HIV care has been documented, barriers and recommendations have not been systematically reviewed. Following the reporting requirements of the PRISMA guidelines, we used an aggregative narrative synthesis approach to summarize the results of qualitative studies published between 1 January 2000 and 6 November 2020 in the following databases: PubMed, CINAHL, PsychINFO, Web of Science and Google Scholar. In total, 17 studies met the selection criteria and were included in the analysis. They reported on a range of roles played by CHWs in HIV care, including 1) Education and health promotion; 2) HIV-specific care: HIV testing services; screening for opportunistic infections and acute illness; medication delivery; tracing persons who had defaulted from care; and 3) Support: treatment support; referral; home-based care; and psychosocial support. Many different barriers to community-based HIV care were reported and centred on the following themes: Stigma and non-disclosure; 2) Inadequate support: lack of resources, inadequate training, inadequate funding, and inadequate monitoring; and 3) Health care system challenges: patients' preference for more frequent visits, and poor integration of CHWs in the wider health care system. Recommendations to mitigate these barriers included: addressing HIV-related stigma, introducing updated and relevant CHW training, strengthening the supervision of CHWs, coordinating care between the home and facilities, incorporating patient-centred mHealth approaches, and committing to the funding and resources needed for successful community-based care. Our review found that CHWs are providing treatment support together with HBC services. There is however a gap in training, resources, and supervision.

5.2 Introduction

An estimated 37.7 million (30.2–45.1 million) people were living with the human immunodeficiency virus (HIV) (PLWHIV) at the end of 2020.⁽¹⁾ About 5,000 new HIV infections are reported on a daily basis globally, 61% of which occur in sub-Saharan Africa (SSA).⁽¹²⁸⁾ Antiretroviral therapy (ART) increases life expectancy: a 2017 meta-analysis reported that starting ART at age 20 years increases life expectancy by an additional 22.9 years (95% CI 18.4–27.5 years) for men and 33.0 years (95% CI 30.4–35.6 years) for women living in low- and middle-income countries (LMIC). Despite this benefit, uptake has been suboptimal in LMIC.⁽¹²⁹⁾ Of the ± 20.6 million (95% CI 16.8–24.4 million) PLWHIV in Eastern and Southern Africa, only 78% were accessing ART in 2020.⁽¹⁾ Without innovative interventions, these regions will struggle to attain the United Nations Programme on HIV/AIDS (UNAIDS)

95 95 95 goals by 2030.(22) Specifically, the second goal of having all people diagnosed with HIV infection on sustained ART (130) remains an obstacle in SSA. A 2007 systematic review reported that fewer than two-thirds of PLWHIV in SSA remained on treatment 2 years after ART initiation.(25) This is supported by more recent studies that have shown that only 70%, 65% and 63% of people remained on treatment after 2, 3 and 6 years of ART, respectively.(26, 119, 131) Community Health Workers (CHWs) have emerged as a valuable health care cadre to manage and support the rising number of people who need to be initiated and maintained on ART.(132)

CHWs receive job-related training in the context of specific interventions, but have no “formal professional, certificated or degreed tertiary education”.(133) These individuals are selected on the basis of their in-depth understanding of a community’s culture and language, and their primary goal is to provide culturally-appropriate primary health care services to the community.(134) They generally work with the underserved and are mostly indigenous to the community in which they work, not only in terms of ethnicity and language, but also in terms of shared socioeconomical and structural experiences.(46) In low-resource settings, CHWs are frontline health care providers who shoulder much of the health service delivery burden. CHW programmes have been introduced in many SSA countries in an effort to expand HIV care to communities.(63, 135, 136) In addition, some have argued that more HIV care responsibilities should be shifted from doctors to nurses and CHWs.(137) While task shifting as well as the role and the impact of CHWs in HIV care in SSA have been documented and reviewed (63, 138, 139), the barriers to and recommendations for the delivery of such care in the community have not been systematically reviewed.

5.3 Methods

We performed a systematic, aggregated, narrative review using evidence from qualitative studies according to an established methodology (140) and followed the reporting requirements of the PRISMA guidelines.(141)

5.3.1 Definition

For the purposes of this review, a CHW was defined as “any health worker who performs functions related to health care delivery at a community level; has trained in some way in the context of the intervention; and has no formal professional or paraprofessional certificate or degree in tertiary education”.(142)

5.3.2 Search strategy and study selection

We searched the following databases for articles published in English between 1 January 2000 and 6 November 2020: PubMed, CINAHL, PsychINFO, and Web of Science. Google Scholar was used to identify papers that might have been missed in the other four databases. The initial search strategy was developed by the principal investigator in consultation with the librarian (SS). A second librarian (EG) reviewed and approved the search strategy before the screening process started. Initially, the following search words were used: barriers OR obstacles OR challenges OR difficulties OR issues OR problems AND Community Health Workers AND HIV care. Only 280 articles were found, and the search strategy was then broadened to also include the following MeSH words: “HIV AND Community Health Workers” in PubMed, CINAHL, PsychINFO, and Web of Science. Google Scholar was used to identify papers that might have been missed in the other four databases.

5.3.3 Data extraction and analysis

A total of 1669 articles were exported directly from different databases to EndNote X8. A total of 526 duplicates were identified and excluded. SN screened abstracts of 1143 using pre-defined screening criteria. Studies were included if they clearly documented the roles, barriers, or recommendations of CHWs providing community-based HIV care in SSA. After full text screening of 64 articles, SN and NM individually selected a total of 19 articles. Minor discrepancies around articles were identified and resolved through consensus (by SN and NM): two studies were further excluded; hence, 17 articles were included in the final analysis (Figure 5-1). The quality and relevance of all articles were reviewed by SN and NM, using the CASP tool (Supplementary Table 1).(143) A thematic analysis approach was used to produce rudimentary synthesis of findings across all 17 papers. Accordingly, all 17 articles were imported into ATLAS.ti 8 (Windows XP). Codes, ideas and concepts were identified, connections identified, and brought together to form different themes.

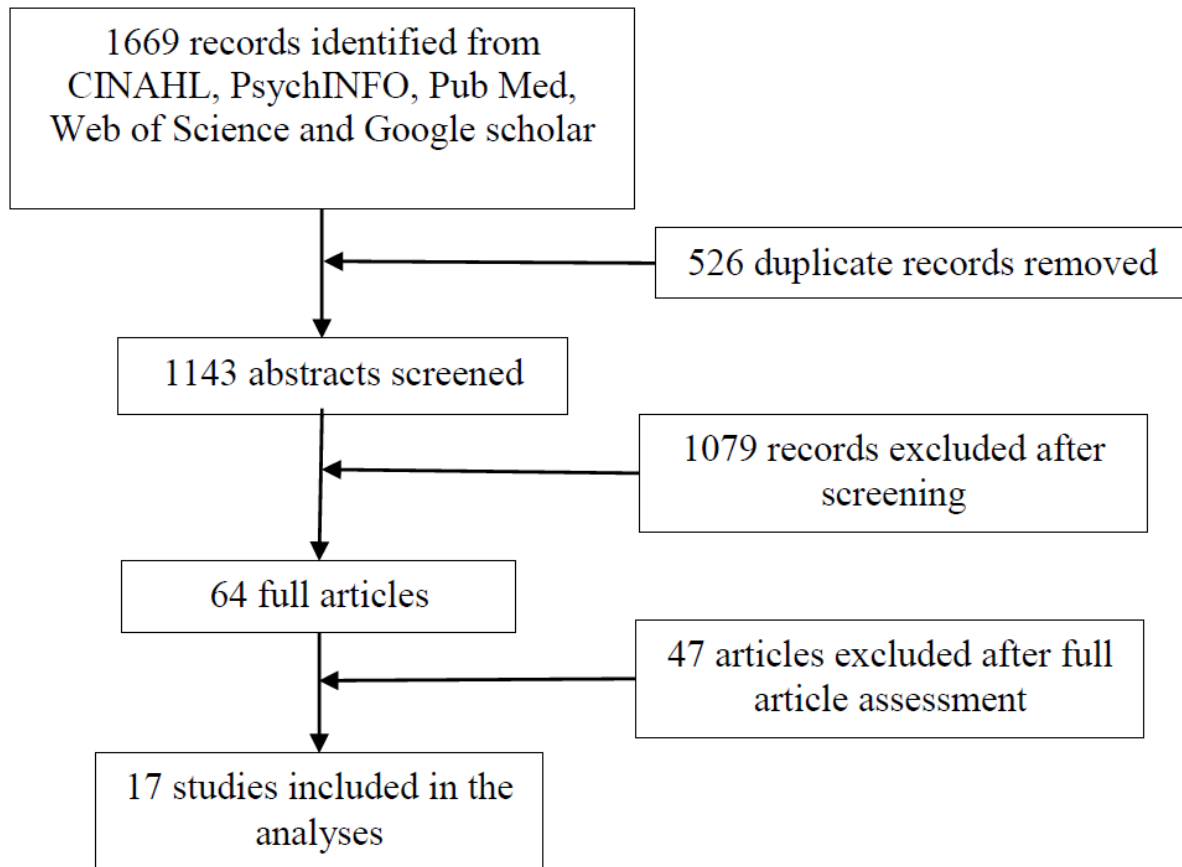


Figure 5-1. Flow chart of study selection

5.3.4 Inclusion and exclusion criteria

Qualitative studies from SSA which reported on the roles, barriers and/or recommendations for offering community-based HIV care by CHWs between 1 January 2000 and 6 November 2020 were included in this study. Papers without qualitative components were excluded.

5.3.5 Ethics approval and consent to participate

Since this is a review article, informed consent was not required. The study forms part of a larger study that was approved by the research ethics committee of the Faculty of Health Sciences, University of Pretoria (reference number: 580/2018).

5.4 Results and Discussion

The sample sizes of the 17 studies, which met the inclusion criteria, ranged from 19 to 393. Participants were from South Africa (10), Kenya (2), Uganda (2), Malawi (1), Zambia (1), Ethiopia (1), Lesotho (1), Mozambique (1), Zimbabwe (1) and eSwatini (1). One study was performed in four countries within the southern African region, namely Lesotho, Mozambique,

South Africa, and eSwatini.(144) A summary and narrative synthesis of the 17 included studies are provided in Table 5-1. The description includes the name of the country where the study was performed, the methodology, sample size, study participants, role of CHWs, barriers to providing community-based care, and recommendations to improve such care. This summary was extracted from each of the 17 articles by SN and reviewed by TR.

Table 5-1. Summary of included studies and narrative synthesis

#	Paper	Setting	Methodology	Sample size	Study participants	Role of CHWs	Barriers	Recommendations
1.	(145)	South Africa (KZN)	Mixed methods (survey and FGD)	135	CHWs - 120, Regional coordinators - 2 Doctors - 2 Nurses - 3 NGO staff - 4 RC - 3 DDG -1	Curtail HIV transmission through education and counselling	Lack of resources for CHW	Improve CHWs' accountability, monitoring, and availability of resources and support
2.	(146)	Western Kenya	Exploratory qualitative study (IDI and FGD)	288	PLWHIV - 110 TB patients - 39 HTN patients - 21 Caregivers - 24 Community leaders - 10 HCWs - 34	Promote primary health care and generate awareness about relevant health issues	Poor understanding of confidentiality; lack of CHW information on relevant health issues; non-intentional disclosure of HIV status; lack of formal training	Recruit well-respected members of the community as CHWs; offer comprehensive training; provide informative pamphlets to CHWs for distribution to households
3.	(147)	South Africa (Gauteng and Eastern Cape)	Comparative qualitative study (FGD, IDI and observations of CHWs)	74	CHWs, government representatives and policy makers*	Deliver medication; trace patients who have defaulted from ART; HIV-related health education	Lack of support; lack of trust by household members	Strengthen the links between sectors and departments at different levels of government
4.	(148)	South Africa	Qualitative exploratory study (IDI and FGD)	101	CHWs - 11 Nurses - 12 Community leaders - 21 Social workers - 10 Community members - 38 OTL - 9	Health education on HIV prevention; screening for HIV; adherence support and trace patients who defaulted; identify individuals with deteriorating health while on ART	Clients' denial of HIV status and fear of stigma; resource limitations and inadequate integration into the primary health care system and workflows	Integrate CHWs into the primary health care system; formalise ward-based outreach teams; increase CHW stipends

5.	(149)	South Africa (KZN)	Qualitative study (FGD)	21	CHWs - 21	Health education; counselling and treatment support; linkage to healthcare and social services	Insufficient patient education and social support; denialism; patient dissatisfaction with healthcare services; men prohibiting wives or children from taking ART	Equip CHWs with resources and knowledge to be able to provide HIV-related support to their patients; prioritize patient-centred care; collaborate with traditional healers and church leaders; deal with socioeconomic factors
6.	(93)	South Africa (Gauteng)	Qualitative study (FGD)	58	CHWs - 25 OTL - 11 PLWHIV - 22	HIV counselling and testing; trace patients who defaulted	Incorrect addresses; fear of stigma through association with CHWs (especially those in uniform); little or no preparation of patients for HBC; lack of confidentiality and trust	Integrate CHWs into clinics and existing support structures; improve training on confidentiality and HIV testing for CHWs; rethink the recruitment, scope of work and safety of CHWs as well as the requirement for patients' identification numbers
7.	(150)	South Africa	Qualitative study (FGD)	110	CHWs - 57 Lay councillors - 40 TB and HIV programme managers - 13	Treatment support	Perceived lack of confidentiality; lack of information, education, and communication materials provided in local languages	Improve HIV testing services; provide HTS-related training
8.	(151)	Kenya	Qualitative study (IDI and FGD)	70	PLWHIV - 40 HCWs - 30	Education and support for HIV and PMTCT; linking and referral to facilities	Potential breach of confidentiality by CHWs; inadvertent disclosure of HIV status; lack of private meeting places in clients' homes; potential stigmatization and social isolation of CHWs in the communities	Gain trust and provide information not always possible in a more formal provider-patient relationship.

9.	(152)	South Africa	Qualitative study (FGD and IDI)	37	Home-based HTC field staff -10 CHWs - 12 PLWHIV - 10 Health officials -5	Conduct home visits, give health education, conduct health assessment, and refer household members (to clinic) who need medical attention	Lack of communication and sharing of patient health information between clinics, between clinics and CHWs, and between clinics and patients; lack of trust between CHWs and facility staff	Introduce biometrics to improve patient identification
10.	(153)	Malawi	Qualitative study (FGD, IDI and participant observation)	94	CHWs - 60 PLWHIV - 9 Medical assistant - 5 Nurses - 2 Health surveillance assistants - 18	Adherence support; emotional support; income-generating activities	Stigma; unwillingness to disclose HIV status; change of residence	Bigger investment in community models of care, supported by strong networks of PLWHIV
11.	(154)	South Africa	Qualitative study (semi-structured qualitative interviews)	30	HIV and AOD treatment staff, and PLWHIV with moderate, problematic AOD*	Detect substance use problems among some PLWHIV	Little formal training in screening and interventions for problematic AOD use amongst PLWHIV; CHWs may perpetuate inaccurate messaging to patients about not mixing alcohol and ARVs	Additional training on problematic AOD use; accurate information about the risk of mixing AOD and ART
12.	(155)	South Africa	Qualitative study (FGD, questionnaire and IDI)	60	CHWs - 55 Leaders from AIDS organizations - 5	Identify patients with unknown HIV status and link them to HST services; treatment support, including adherence support; home delivery of ART; trace persons who have defaulted; help with facility-based duties,	Stigmatization of PLWHIV; fear of stigmatization; unsustainability of CHWs intervention	Direct supervision of CHWs by clinical staff members

						including screening for TB, measure vital signs, etc.		
13.	(156)	Zimbabwe	Qualitative study (longitudinal semi-structured interviews)	19	CHWs - 19	Deliver social support; adherence support	Lack of intensive supervision and mentoring; fear of stigmatization among PLWHIV when CHWs wear a uniform	CHWs should not wear uniforms when this is the preference of the PLWHIV they visit
14.	(157)	Uganda	Qualitative study (IDI and semi-structured interviews)	393	PLWHIV - 347 CHWs - 46	Basic counselling; medication adherence; TB and HIV treatment; referral for medication side effects; record keeping	Workload; poor performance by CHWs; lack of trust; bad attitude by CHWs; non-disclosure of HIV status to CHWs	Regularly assess performance and attitudes of CHWs; integrate CHW activities into the broader health system
15.	(158)	Uganda and Ethiopia	Qualitative study (semi-structured interviews)	118	Patients - 79 Peer counsellors - 17 Providers in ART facilities -22	Treatment adherence support, HIV awareness	Inadequate supervision; working too few hours a day; frustration and emotional agony when CHWs observed sick PLWHIV not initiated on ART due to lack of medicines; narrow geographic scope; fear of stigma by PLWHIV when traced by CHW after defaulting treatment; unwillingness of PLWHIV to provide correct addresses and phone numbers	Develop a support structure for CHWs; formal recognition and regulation of CHWs
16.	(159)	Zambia	Qualitative study (IDI and observations of CHWs)	104	Staff from 3 local HBC organisations - 17	Treatment adherence support; trace people who have defaulted; deliver medication; screen for	Lack of formal training and recognition; poor remuneration; non-disclosure of HIV status;	Professionalization of CHW programme; make the necessary specialised training available;

					ART clinic staff - 8 Home-based caregivers - 48 HBC clients - 31	opportunistic infections and ART side effects	some PLWHIV expect food and financial support from CHWs: if they are unable to provide these, their relationship with PLWHIV suffers	strengthen supervisory support
17.	(144)	Lesotho, Mozambique, South Africa, and eSwatini	A four-country qualitative study (semi-structured interviews)	60	Donors, government officials, and expert observers involved in CHW programmes*	Health education, HST, HBC and ART adherence support	Highly fragmented care and poorly integrated into national health systems; wide range of stakeholders; lack of long-term support; HIV-specific approach, neglecting other conditions; unbalanced demographic profile of CHWs	Officially recognize CHW programmes; standardize CHW training, incentives, and services; involve the community in decision-making; provide adequate and long-term resources for CHW programmes for HIV; move away from an HIV-specific approach towards comprehensive care
AOD = alcohol and other drugs; ART = antiretroviral therapy; ARVs = antiretroviral medication; CHW = Community Health Worker; DDG = Deputy Director General; FDG = focus group discussion; HBC = home-based care; HTN = hypertension; HTS = HIV testing services; IDI = in-depth interviews; KZN = KwaZulu Natal; PLWHIV = people living with HIV; PMTCT = prevention of mother-to-child transmission; NGO = non-governmental organization; OTL = operational team leader; RC = research coordinator; TB = tuberculosis. * Number of participants per sub-category not reported								

5.4.1 Roles of Community Health Workers

Table 5-2 provides a breakdown of the different roles that have been reported for CHWs while providing community-based HIV care. These roles can be categorised into three different themes: 1) Education and health promotion; 2) HIV-specific care: HIV testing services (HTS); screening for opportunistic infections and acute illness; medication delivery; tracing persons who had defaulted from care; and 3) Support: treatment support; referral; home-based care; and psychosocial support.(145-151, 154)

The first theme, education and health promotion, was a major focus of some articles and encompassed general health education as well as HIV-specific education, such as information about living with HIV, ART and its side effects, as well as HIV co-infections, such as tuberculosis (TB). In this educational role, CHWs built on their knowledge acquired during facility-based HIV/ART counselling and literacy classes.(149) Another major role fulfilled by CHWs was HIV-specific care across the HIV treatment cascade: from diagnosis to monitoring treatment adherence, screening for opportunistic infections and acute illness and tracing patients who have missed their clinic appointments and those who have become lost to follow-up.(146, 148, 151) Some CHWs were also doing home delivery of medication for individuals unable to travel to the clinic.(147, 156, 159) Treatment support ranged from screening for treatment-related side effects, to reminders to collect treatment and motivating patients to remain adherent to treatment.(151, 153, 154) CHWs were also responsible for referring all individuals who tested HIV positive, screened positive for opportunistic infections or acute illnesses, or ART side effects to health facilities.(157) In one study, CHWs were playing an important role in supporting women on PMTCT programmes.(151) Multiple studies reported that CHWs, supported by social workers, nurses and clinicians, were providing psychosocial support, including marital counselling and teaching coping strategies.(146-148, 151, 156, 157, 159) Some studies reported that CHWs even provided general home-based support, such as household cleaning for child-headed households affected by HIV (147) and activities such as cooking for and feeding patients (28, 37, 44), cleaning, and fetching water for sick individuals unable to perform these activities themselves.(148)

Table 5-2. Roles of community health workers in community-based HIV care

Themes	Sub themes	Activities
Education and health promotion		General health education (144, 146) HIV/AIDS-related education (147, 148) HIV prevention (144-146, 148, 151) Encourage males to undergo medical male circumcision (155) Nutrition education (151) Living with HIV (151, 157) HIV status disclosure (151, 158) HIV stigma (151) ART literacy (151, 157) HIV co-morbidities and co-infections (155, 157)
HIV-specific care	HTS	Identify clients who need HTS and provide HTS (144, 149, 157)
	Screening	Screen for opportunistic infections such as TB (145, 146, 150, 155, 157) Screen for acute illnesses (157)
	Medication delivery and monitoring	Deliver ART for patients who are unable to reach clinics (147, 153, 155) Perform pill count of ARVs (156)
	Trace ART defaulters	Trace patients who have been lost to follow-up or those who have missed their appointments (93, 147, 148, 157)
Support	Treatment support	Support patients on ART and other chronic medication (148-151, 157) Remind patients to collect medication (157) Motivate patients to take their medication (146, 150) Screen for treatment-related side effects (149, 155) Support women on PMTCT programmes (151)
	Referral	Refer individuals who test positive for HIV (149) Refer patients with ART side effects (157) Refer individuals who screened positive for opportunistic infections (148) Refer patients with acute illnesses (157)
	Home-based care and other activities	Cook for and feed patients (148, 155) Clean patients (147, 148, 159) Change soiled linen (155) Fetch water (148) Raise funds to feed PLWHIV (155)
	Psychosocial support	Provide psychosocial support (146-148, 151, 156, 157) Develop coping strategies (151) Linkage to social services (149) Marital counselling (151)
	ART = antiretroviral therapy; ARVs = antiretroviral medication; PMTCT = prevention of mother-to-child transmission; TB = tuberculosis; HTS = HIV testing services; PLWHIV = people living with HIV	

5.4.2 Barriers

Barriers faced by CHWs when delivering community-based HIV services were divided into three distinct themes: 1) Stigma and non-disclosure: stigma; non-disclosure of HIV status; concerns about confidentiality; 2) Inadequate support: lack of resources, inadequate training, lack of support from relevant stakeholders, poor communication, inadequate funding, and inadequate monitoring; and 3) Health care system challenges: patients' preference for more frequent visits and poor integration of HCWs into the healthcare system.

5.4.2.1 *Stigma and non-disclosure*

5.4.2.1.1 *Stigma*

Real or perceived stigma was almost universally documented as a barrier to CHWs delivering HIV-related care in communities. Stigma was identified at various levels: from the household to the community and up to the facility level, and involved a wide spectrum of people, namely family members, community members and health workers.(145, 147, 148, 152) In many studies, CHWs were involved in all these different levels and stigma therefore affected them in many ways. Stigma manifested as low acceptance of HTS (150), HIV status non-disclosure to CHWs (154), and patients attending facilities far from their communities and providing incorrect addresses in those clinics .(93, 148) Three studies documented that stigma was worse when a CHW came from the local community.(93, 151, 154) Conversely, some thought that CHWs from the community with the same ethnicity and language would have shared socioeconomical and structural experiences and therefore understand community members better.

5.4.2.1.2 *Non-disclosure of HIV status*

Many studies documented issues around disclosure. Patients feared unintentional disclosure of their HIV status since it is well known in the communities that HIV-infected persons are regularly visited by CHWs in their households.(93, 145, 146, 148-154, 157) Some patients therefore elected not to disclose their HIV status to CHWs, which regrettably also made it impossible for CHWs to support them.(93) Non-disclosure was also reported to be associated with the fear of stigmatization, in particular when CHWs came from the local community and thus shared the same social spaces as patients.(146, 157) Another reason PLWHIV feared unintentional disclosure was the lack of privacy in the household, which compromised confidentiality.(151) While such individuals were willing to disclose to CHWs, they did not want their family members to know their status (148) and some therefore elected not to be visited in their home but rather in a different location.(157) A negative attitude by CHWs towards PLWHIV was also reported to negatively influence disclosure.(157)

5.4.2.2 *Concerns about confidentiality*

Perceived lack of confidentiality was reported as a barrier and had a negative impact on disclosure and trust.(145, 146, 150, 151) According to Heunis *et al*, confidentiality was not a problem limited to CHWs; it also extended to the facility level where nurses and lay counsellors test and manage PLWHIV.(150) Confidentiality is even more important for CHWs staying in the same communities that they serve. Since they work with people they share social spaces with and constantly interact with their families and neighbours, confidentiality is an ethical and practical imperative.(146) In an Ugandan study, CHWs staying in the same village as the PLWHIV they served were rated significantly worse than those not staying in the same village.(157) The age of CHWs was also seen as an important factor, with some study participants fearing that younger people were not good at keeping private information secret.(146) Another factor that came into play was CHWs' own HIV status: some CHWs felt that it was more difficult to gain the trust of patients when they were themselves uninfected and they believed that this negatively affected disclosure.(93)

5.4.3 *Inadequate support*

5.4.3.1 *Lack of resources*

Lack of resources was frequently reported as a barrier to offering community-based HIV care by CHWs. These resources included educational material such as posters, flyers, pamphlets, and brochures that CHWs could distribute amongst community members, but also extended further to the equipment needed to perform their duties. In studies performed by Suri, Gan and Carpenter (145) and Naidoo *et al* (148), CHWs complained that they did not have personal protective equipment like aprons, masks, and gloves, which made it difficult to help some patients. Community members appreciated the availability of equipment, such as sphygmomanometers and haemoglucometers, and this improved the communities' acceptance of CHWs.(148) Unfortunately, most CHWs did not have such equipment. In addition, CHWs sometimes ended up using their own money to pay for work-related expenses such as stationary, travel, and airtime with which to communicate with patients.(148) Another resource that was frequently lacking was adequate space in health facilities, making it difficult for CHWs to conduct meetings and training sessions.(148) All these resource challenges hindered their ability to meet the communities' needs with the consequence that patients and households did not derive the optimum benefit from these potentially valuable services.(147)

5.4.3.2 Inadequate training

While Naidoo et al (148) reported that CHWs were happy with the initial training they had received, other studies found that CHWs requested more training, especially with regards to HIV.(93, 150, 157) Training should, however, not just be limited to HIV, since PLWHIV may present with many other physical and psychological health challenges. For instance, one study found that CHWs had not received adequate training to deal with PLWHIV using alcohol and other drugs.(154) Importantly, CHWs reported that their low level of training negatively affected their rating by patients.(157)

5.4.3.3 Lack of support from relevant stakeholders

For a community programme to be successful, there is a need for buy-in from stakeholders such as departments of health, non-governmental organisations (NGOs), facility staff, and facility managers.(148) Across SSA, it was reported that relevant stakeholders were not supporting CHWs adequately.(147, 148) When visiting households of PLWHIV, CHWs came across multifaceted challenges (social, clinical, financial etc.) requiring their intervention; without strong multidisciplinary and institutional support, they are unable to deal with these challenges.(147) The perceived lack of support extended to emotional and moral support, given the strain of dealing with HIV-infected and, sometimes, dying patients.(145)

5.4.3.4 Poor communication

Lack of communication was frequently reported as a barrier. Nurses at the facility level complained that the absence of structured platforms made it impossible for them to raise concerns about the work of CHWs.(145) The lack of communication in sharing accurate patient health information between clinics and CHWs, and between clinics and patients, was also reported as a barrier to care.(152) For instance, when CHWs were given inaccurate information about the physical whereabouts of patients, they were unable to fulfil the task of meeting with patients and deliver services as required.(152) This lack of communication was not only limited to clinics and CHWs, but extended to different stakeholders and structures (NGOs, clinic leadership, researchers, community leaders, etc) in CHW programmes, often with different priorities, .(93, 144) Poor communication not only disrupted workflows, but also resulted in mistrust between different stakeholders involved in patient care.(152)

5.4.3.5 Inadequate funding

Some CHW HIV programmes were donor funded and there was uncertainty about their sustainability in the long-term, as governments might not be able to take over these programmes when donor support ended.(144, 153) Concerns were specifically raised about CHWs creating expectations by giving patients donor-funded gifts, including financial help,

material support, and food.(159) When donors withdrew their funding, this loss of benefits could negatively affect the CHW-patient relationship.(146)

5.4.3.6 *Inadequate monitoring*

Non-performance of assigned duties was also reported: in one study, only 15% of CHWs allocated to this task traced patients who had been lost to follow-up.(157) Reasons given were the wide range of activities CHWs had to attend to and high patient volumes. Even more worrying is that there were no consequences for non-performance of allocated tasks. In a study by Suri, concerns about poor accountability and monitoring processes of CHW HIV programmes offered by NGOs were raised.(145)

5.4.4 Health care system challenges

5.4.4.1 *Patient preference for more frequent visits*

In contrast to the Alamo *et al* study (157) where many participants did not prefer home visits, a study by Van Heerden *et al* (152) reported that PLWHIV were more comfortable with home than clinic visits since the conversations at home were more confidential and less stigmatising. Patients preferred fewer short visits since more frequent visits interfered with their lives and daily routines.(157) More frequent visits to stable patients will, however, take time away from patients in greater need of CHW services and needs careful consideration.(157)

5.4.4.2 *Poor integration of HCWs into the healthcare system*

Several studies reported poor integration of community-based HIV services in clinic-based HIV treatment facilities.(93, 148) This ranged from poor integration of monthly reports on HTS performed at community and clinic level, to an ineffective referral system between facility staff and CHWs.(152) Issues of poor coordination of patient care between CHWs and facilities were raised, with limited platforms available for sharing patients' health information, resulting in poor and incomplete record keeping.(150, 152) On another level, there was also poor integration among CHWs, religious leaders, and traditional healers caring for PLWHIV.(146, 148, 149) Some CHWs felt that the influence of traditional healers negatively impacted their efforts to retain PLWHIV in care (149) but there seems to be no avenues for engagement with these role players.

5.4.5 Recommendations

While many different barriers were reported, most articles also provided a set of recommendations to mitigate those barriers. These recommendations are summarised in Table 5-3. To address stigma, recommendations were made for community-based campaigns to

improve health education and deal with stigma-related issues. In addition, a move away from disease-specific approaches in favour of generalised approaches was proposed together with programmes that aim to identify and address the stigma-related needs of patients.(145, 148, 149, 151) Professionalization of CHW programmes, intensifying health campaigns, strengthening CHW supervision, making the equipment needed by CHWs available, and improving CHW attitudes were amongst the recommendations to improve CHW HIV services.

CHWs are a very important cadre of health care workers since they have a privileged vantage point into the community. They have more time to interact with PLWHIV, are familiar with the environment and socioeconomic reality they live in and are more able to interact with family members when there is a need.(159) This systematic, aggregated, narrative review on the roles, barriers, and recommendations for CHWs with regards to community-based HIV care support this view but also found that barriers and challenges remain that have to be addressed in order for patients and households to derive the maximum benefit from such services.

Our findings on the roles of CHWs support those from another systematic review performed by Mwai et al.(16) Some important differences in our paper include CHWs offering HTS outside facility settings as well as CHWs providing psychosocial support. Additionally, we found that CHW activities in caring for PLWHIV also included non-traditional home-based care activities for severely ill patients such as cooking, feeding, cleaning, changing soiled linen, and fetching water.(147, 155, 159) While these activities might not be viewed to be part of CHWs' scope of practice, many PLWHIV, especially child-headed households, require them as some have suffered multiple crises and structural injustices, including chronic poverty, recurrent illnesses, weak social ties, deceased family members, and little or no ability to generate an income.(159) Due to their ground-level interaction with communities, well-functioning CHW programmes are better placed to address these needs of PLWHIV by liaising between community role players (including clinics, social services, government departments, NGOs, academic institution, etc.) and PLWHIV.(145)

Additional activities also included the delivery of medication, which has been shown to improve patient satisfaction with CHWs services (160) since it mitigates some of the reasons patients miss ART clinic visits, such as lack of time, transport costs, and long waiting times.(161, 162) This has proven to be critical during the coronavirus disease pandemic when traditional health services were severely disrupted and congestion at health facilities posed the risk of extensive spread of the disease.(163)

Table 5-3. Recommendations to improve HIV service delivery by CHWs in the community

Barrier	Recommendation
Stigma	Develop campaigns to improve health education and address stigma-related issues (148) Avoid services targeted at HIV only (93, 149) Identify and deal with factors leading to stigma (145) Address stigma-related needs of patients (151) Avoid wearing clothes that suggest provision of HIV services (93, 156)
Disclosure and confidentiality	Strengthen social support (149) Build strong patient-CHW relationships based on trust (151) Strengthen training of CHWs about confidentiality (93)
Resources	Equip CHWs with sufficient resources needed for HIV services (145, 149) Equip CHWs with pamphlets to distribute in households (146)
Training	Recruit well-respected members of the community to be trained as CHWs (93, 146) Strengthen and standardize formal and comprehensive training focusing on confidentiality, HIV and TB-related services, and non-communicable diseases, including mental health and substance use (93, 146, 150, 154, 159)
Supervision	Intensive supervision by clinical staff through individualized on-the-job mentoring (155, 156) Make use of mobile health (mHealth) tools to monitor and support CHWs (152)
Health system	Ensure that home-based HIV care builds on and integrates with existing structures (93) Integrate CHW activities into the broader health system (93, 157) Conduct campaigns aimed at improving knowledge about HIV and the role played by CHWs (148)
Communication and reporting	Introduce sustainable and safe mobile health (mHealth) platforms to improve the quality of data collected by CHWs, communication, and reporting.(152) Involve patients, in particular PLWHIV, in designing such platform (152) Strengthen the links between community- and facility-based health services (147) Integrate CHW programmes into the primary health care system and involve all other stakeholders caring for PLWHIV, including traditional healers and religious leaders (93, 157)
Funding	Create more sustainable ways of funding CHW programmes (153)
Performance	Introduce ongoing assessment of CHW performance and attitudes towards patients (157) Develop standard protocols to guide CHWs on activities, workflow, triaging of patients, accountability, and performance monitoring (145, 157)

Apart from such general assistance, results of this study suggest that the roles of CHWs are evolving towards more medicalised services, such as treatment support with the aim improving adherence to ART.(148) CHWs are therefore well positioned to help programmes achieve the UNAIDS 2030 goals and countries should be encouraged to actively incorporate them in their planning. Unfortunately, in most SSA countries, CHWs are not well equipped with sufficient and current HIV-related knowledge to offer accurate education about HIV and ART.(93, 148, 164) To adequately deliver these essential, and in many respects, medicalised services and meet the demands of PLWHIV and HIV programmes, CHWs require more training situated within a professionalized approach. We argue that CHWs should no longer be viewed as just a temporary intervention, but as allied health care professionals in their own right and, as such, undergo structured and well-coordinated certified training with specific core competencies that address the needs of the communities in which they work.(165)

Our findings reveal several, multilevel barriers related to community-based HIV services that should be considered in all SSA (and arguably in all) CHW programmes. One of the most important barriers was persistent and prevailing HIV-related stigma, which leads to non-disclosure of HIV status to CHWs, often secondary to a perceived lack of confidentiality. It is well known that stigma can affect access to health care, medication adherence, social interactions, and social support.(166) In this systematic review, it was clear that stigma and fear of stigmatization were some of the barriers that could hinder the delivery of health services by CHWs to PLWHIV. Both external and internalised stigma still play a significant role in the lives of PLWHIV, with some PLWHIV being excluded from social events, gossiped about, teased, and insulted. This affects their willingness to receive community-based HIV care.(93, 167) These findings are corroborated by previous studies that demonstrated that the fear of HIV-related stigma resulted in non-uptake of HIV services.(168, 169) To effectively deal with perceived and internalised stigma, it is important to understand the extent of this problem using tools such as validated HIV stigma indices. In a Stigma Index 2.0 study conducted in Cameroon, Senegal, and Uganda, HIV-related external stigma was experienced by more than one-third of respondents (170). Similarly, in a South African stigma index study of 10 473 PLWHIV, 35.5% of participants reported experiencing some external stigma.(167)

The introduction of CHW programmes in most SSA countries was closely linked to HIV services, resulting in CHW activities being associated with being HIV positive and potential social rejection and discrimination of the recipients of such programmes.(93, 169) This association is reinforced when PLWHIV who have physical manifestations of HIV and AIDS are regularly visited by CHWs, hence perpetuating the risk of social isolation and exclusion of

recipients.(157) To address this, there is a need to move away from programmes that focus on HIV-specific care only, towards programmes that deliver integrated health services; thereby addressing the needs of all household members and not just those of PLWHIV.(171) This could also have additional benefits, such as strengthening of community based non-communicable disease programmes, women's health including contraception, and improved child health programmes.

A review of the impact of physical environmental factors on patients in health facilities by Huisman *et al* highlights how the physical environment can impede privacy, confidentiality, the healing process, and the well-being of patients.(172) The average household size in SSA was 6.9 people per household in 2019, which was the largest average household size recorded worldwide.(173) With almost seven people per household, it is difficult to maintain the privacy and confidentiality that this review suggests is needed for disclosure of HIV status and acceptance of home-based HIV services.(151) This suggests that serious reconsideration of the household as the preferred site of CHW interactions is warranted. In order for CHWs to prioritize privacy and confidentiality for PLWHIV with this specific need, they should be empowered to make arrangements to meet with PLWHIV in areas where privacy and confidentiality can be maintained.

Other barriers related to the lack of support of CHWs in terms of resources, training, stakeholder assistance, communication channels, funding, and monitoring. Some of these resources, such as educational material, are already in existence and only need to be distributed effectively. It has been shown that educational pamphlets not only improve the health literacy of community members but also the evidence-based health knowledge of CHWs.(174) Appropriate and sufficient educational resources will therefore help ensure that CHWs offer better quality HIV services.

Poor communication and linkage between many stakeholders offering HIV services could be partially addressed through the introduction of mobile (mHealth) technology platforms. In recent years, there has been a shift towards technology-based approaches aimed at improving HIV service delivery, including improving patients' HIV literacy, improving linkage to care, retention in care, and treatment adherence.(175) A systematic review by Braun *et al* reported that mHealth improved the quality of services provided by CHWs.(47) These mHealth interventions could assist in improve reporting, communication, supervision, guide learning, improve linkage to care, and keep confidential information secured through user passwords.(47, 65)

Finally, from our review, it is clear that the sustainability of CHW programmes is still a challenge, with many CHW programmes relying on donor support.(146, 148) When funding comes to an end, this can severely disrupt patient care and affect CHW-patient relationships. There is evidence that outcomes improve when PLWHIV receive continuous care from CHWs.(63) Recently, the role of CHWs have successfully been expanded to the coronavirus disease pandemic, especially in poor countries, where CHWs were involved in contact tracing, coronavirus disease-related education, screening, and monitoring of patients.(176) Vertical, facility-based health care services are unable to deal with the growing burden of disease in the populations they serve.(163) In order to appropriately strengthen health care systems for this task, it seems opportune for governments to commit to supporting CHW programmes and invest the resources needed to successfully offer integrated healthcare services at a household level.

5.5 Conclusion

Given the large HIV burden in SSA, CHWs function as a critical link between the community and health facilities. Our review found that CHWs are providing treatment support together with HBC services. There is however a gap in training, resources, and supervision. To strengthen CHW programmes, substantial improvements are needed. The most urgent are addressing HIV-related stigma, introducing updated and relevant CHW training, strengthening the supervision of CHWs, coordinating care between the home and facilities, incorporating patient-centred mHealth approaches, and committing to avail funding and the resources needed for successful community-based care.

5.6 Authors' contributions

SN in consultation with TR conceptualized and designed the study. SN and NN contributed in screening and conducting quality assessment of articles. SN, SS and EG contributed to the literature search. Study analyses were completed by SN with input from TR and SN wrote the first manuscript draft. TR led review and substantive contributions to manuscript revisions, which all authors supported. All authors have read and approved the final manuscript.

5.7 Acknowledgements

We would like to thank all those who contributed in this study.

5.8 Funding

SN is supported by the South African Medical Research Council through the Bongani Mayosi National Health Scholars Programme.

5.9 Disclaimer

No disclaimer

5.10 Competing interests

No competing interests exist.

Supplementary Table 5.1. Quality of studies

References	(151)	(150)	(145)	(146)	(147)	(149)	(93)	(152)	(153)	(148)	(154)	(155)	(156)	(157)	(158)	(159)	(144)
Are the research questions clear? (1)	1	1	1	1	0.5	1	1	1	1	1	1	1	1	1	1	1	1
Are the research questions suited to qualitative inquiry (1)	1	1	0.5	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Are the following clearly described? (1) • Sampling • Data collection • analysis	1	1	1	1	1	1	1	1	1	1	1	1	0.5	1	1	1	1
Are the claims made supported by sufficient evidence (1)	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Are the data, interpretations and conclusions clearly integrated? (1)	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Does the paper make a useful contribution? (1)	1	1	1	1	1	1	1	1	1	1	0.5	1	1	1	1	1	1
How relevant is this study to this review (1)	4	4	4	4	2	3	4	3	2	4	3	4	4	4	4	4	4

6 Chapter 6: Conclusions and Recommendations

6.1 Introduction

In this PhD project, the candidate explored the perceived barriers, benefits, acceptability, and effectiveness of implementing home-based HIV care in Tshwane district. The project involved 1 255 people living with HIV (PLWHIV) in Tshwane and more than 50 health workers. These interactions varied with regards to the specific objectives of the study. For the primary and first two secondary objectives, community health workers (CHWs) and lay counsellors constantly interacted with PLWHIV during household visits and the adherence game session in a facility as part of the cohort study. For the qualitative study, designed to answer the third secondary objective about the perceived barriers and benefits of implementing HIV care at the community level, seven focus group discussions were conducted with 58 participants: four with 36 Ward-Based Primary Health Care Outreach Team (WBPHCOT) members and three with 22 PLWHIV. In addition, to obtain the views of more PLWHIV about the acceptability of home-based HIV care offered by CHWs, a further 674 PLWHIV were interviewed.

Based on these structured interactions, the candidate wrote four papers consisting of three empirical articles and a systematic review paper. The systematic, aggregated, narrative review considered the views expressed in papers emanating from sub-Saharan Africa that examined the roles, barriers and recommendations for CHWs providing community-based HIV care in this setting. This exploration played an essential role in the candidate's ultimate quest to make HIV care more inclusive, acceptable, sustainable, and effective for people living in underserved areas.

This chapter provides a summary of the conclusions and recommendations that emanate from the findings of this PhD project with the belief that these recommendations have several policy and practice implications for home-based HIV care in South Africa and, possibly, sub-Saharan Africa. The recommendations are presented in three different categories: 1. Community-based HIV prevention and HIV counselling and testing (HCT) services; 2. Community-based HIV care; and 3. Preventing loss to follow-up.

The aim of this PhD study was to assess the effects of WBPHCOTs and the Bridges of Hope ART adherence game on retention in care and virologic suppression after 12 months among patients newly initiated on ART. It was demonstrated by means of a 2 x 2 factorial cohort study that an adherence game intervention could indeed help keep PLWHIV in care. While retention was better in the WBPHCOT-containing interventions than in the Control group, the

differences were not statistically significant. When remaining in care, participants had similar rates of virological suppression after 12 months, regardless of the intervention. Other important findings were that younger participants were significantly less likely to remain in care and that pregnant women were less likely to achieve virological suppression.

Several operational challenges emerged in the WBPHCOT-containing interventions, which led to further investigation. Focus group discussions with PLWHIV and WBPHCOT members revealed that, to successfully implement effective home-based HIV care in South Africa, perceived barriers should be addressed and recommendations offered by people providing and receiving these services should be seriously considered. Pertinent recommendations included integrating WBPHCOTs into clinics and existing support structures, improving training on confidentiality and HIV testing, and rethinking the recruitment, scope of work and safety of WBPHCOTs.

A survey was also conducted with PLWHIV in Tshwane to assess the acceptability of community-based HIV services offered by CHWs. Overall, 95.5% of participants thought that home-based HIV care is a good initiative and rated screening for illnesses and referral to health facilities highly. The vast majority of participants were willing to disclose their status to health professionals in clinics, but men were less willing than women to do so, almost half were unwilling to disclose their HIV status to a CHW from the same neighbourhood, and more than a quarter would find it problematic if CHWs visited them at home with branded cars. Participants had different preferences, mostly determined by region, how long they had been on ART, and whether they had been informed about the CHWs' age and gender.

Finally, an aggregative narrative review of qualitative studies was conducted about the roles, barriers, and recommendations for CHWs performing HIV care in the community. A range of roles were reported, ranging from education, HIV-specific care, to various forms of support to PLWHIV. Barriers encountered related to stigma and non-disclosure of HIV status, inadequate support, and health care system challenges. The recommendations that emerged to mitigate these barriers included professionalizing CHW programmes; intensifying health campaigns; strengthening CHW supervision; providing CHWs with the necessary equipment; and improving CHW attitudes. CHW-based HIV care can be improved by prioritising a comprehensive approach above HIV-specific activities, enhancing and standardizing CHW training, strengthening supervision of CHWs, continuously addressing HIV-related stigma, and ensuring sustainable funding for CHW programmes.

6.2 Recommendations

6.2.1 Community-based HIV prevention and HIV counselling and testing services

6.2.1.1 HIV prevention

In 2020, 230 000 (95% CI 150 000 – 310 000) people were newly infected with HIV in South Africa.(3) This equals an incidence of 4.6 (95% CI 2.8 – 6.4) per 1 000 population.(1) This is still one of the highest incidences in the world and is only surpassed by eSwatini with an incidence of 5.3/1 000. In comparison, the incidence was 4.4/1 000 in Botswana and 0.03/1 000 in Germany over the same period.(1) In a study conducted in KwaZulu Natal, the HIV incidence among women aged 20 to 24 years was 8.0 (95% CI 4.9–12.3) per 1 000.(177) In order to control the HIV epidemic by the year 2030, one can not only focus on treatment, but there is also a great need to focus on reducing the HIV incidence (i.e. closing the tap of new infections). Figure 6-1 depicts the relationship between incidence and prevalence in an infection model. Since there is currently no publically-available cure for HIV and since the mortality rate has been drastically reduced by ART, the HIV prevalence will continue to increase unless the incidence can be reduced. Any set of recommendations for HIV care will therefore be amiss if it does not also focus on HIV prevention strategies.

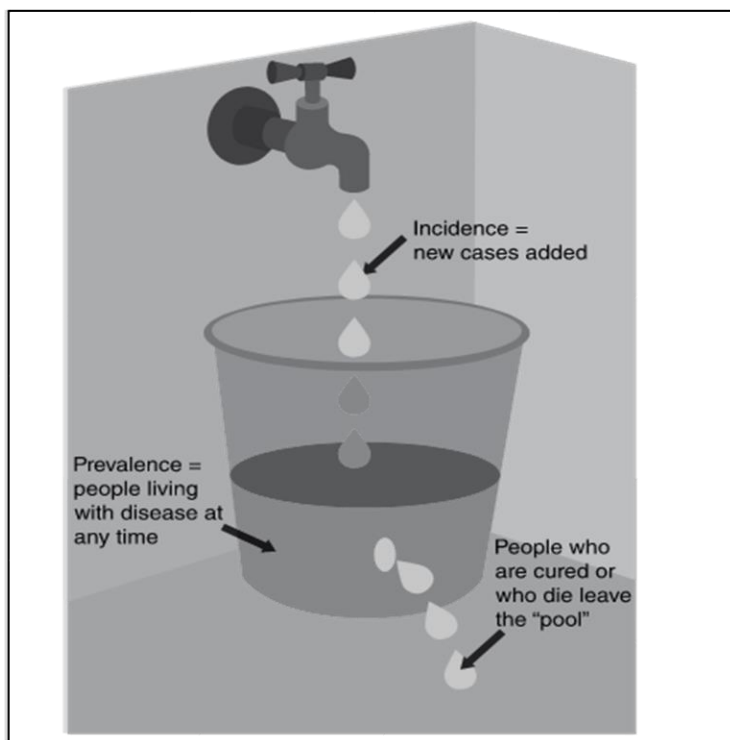


Figure 6-1. The relationship between incidence and prevalence

Reference: Adapted from <https://bettercare.co.za/learn/public-health/images/web/3-1.svg>

For the overall management of HIV in South Africa, it is therefore recommended that CHWs should not only focus on assisting PLWHIV, but their role should also be expanded to those who are HIV negative but at risk of being infected with HIV (Figure 6-2).

As part of a comprehensive HIV prevention strategy, CHWs should play a central role in the distribution of condoms at a household level to those who need them. In three randomised controlled trials conducted in Africa with a combined total of about 11 000 participants, medical male circumcision reduced the risk of female-to-male HIV transmission by more than 50%.(178-180) It is therefore also important for CHWs to educate uncircumcised males about the importance of circumcision and link them to voluntary medical male circumcision services. CHWs can also support post-circumcision healing by providing men with relevant information about the time necessary for healing before sexual activity can be resumed, wound care, warning signs of infection, etc. CHWs should also play a central role in educating household members at risk of HIV infection about prophylaxis available for HIV – for instance pre- and post-exposure prophylaxis and link them to these services if they are needed. CHWs must also focus on educating all household members about HIV/AIDS in general.

6.2.2 HIV testing services

Figure 6-2 depicts the proposed HIV counselling and testing (HCT) pathway. When CHWs are visiting households, as part of a comprehensive healthcare package, they should educate household members about HIV. This health education should also focus on HIV prevention, especially for household members who are at increased risk of HIV infection. They should also offer all household members an HIV test.

Unfortunately, in Tshwane, not all CHWs are trained and certified to conduct HCT. Due to the demand for HCT, there is a growing need to strengthen the training of CHWs in this area and it is therefore recommend that all CHWs be trained and certified as competent to conduct HCT. If a household member is willing to be tested by a CHW and a CHW is competent and well trained with regards to HCT, the CHW can perform the HIV test. Throughout the entire process of HCT, HCWs should ensure that there is an adequate level of privacy. If a household member is willing to be tested for HIV but a CHW is not trained or competent enough to perform the test, a CHW should either refer that patient to the local clinic or call another CHW who is able to conduct HCT to come and do so. This causes an unnecessary delay and could lead to a missed opportunity for early entry into care. This scenario should therefore ideally be prevented.

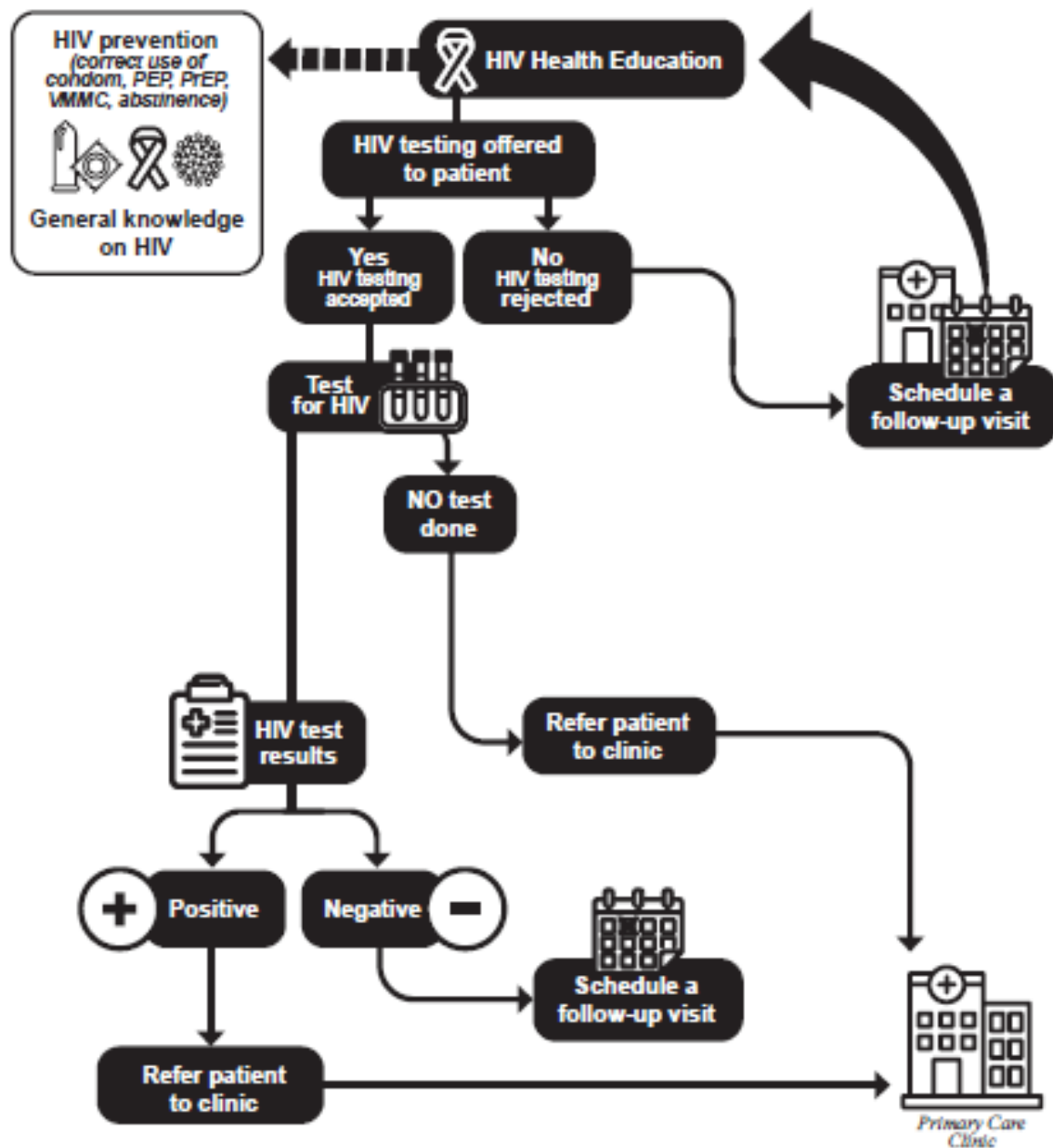


Figure 6-2. Community-based HIV testing services

Once a patient has been tested and the HIV result is negative, the CHW should schedule a follow-up visit to further emphasize the need to prevent HIV infection and explain the available prevention modalities and services. If a household member has tested HIV positive, they must be referred to a health care facility via a linkage officer at the facility level. CHWs should constantly follow-up with the linkage officer to check if the patient arrived at the clinic and was initiated on treatment. If a patient did not arrive at the clinic, a CHW should revisit the household and advise and assist the patient to visit the nearest health facility for treatment initiation.

6.2.3 Role of CHWs and other stakeholders

Results of this project suggest that there is a knowledge gap regarding the role of CHWs amongst community members and health workers. To remedy this situation, the following steps are recommended:

- Part of the morning health talk given by nursing staff in health facilities should include a standardized, brief description of CHWs and their roles.
- The roles of CHWs should be included in relevant topics discussed during continuous professional development programmes for health workers.
- Community campaigns aimed at improving the community's knowledge about HIV and the roles played by CHWs should be conducted.

The results of this project also revealed that there are many stakeholders involved in HIV services at different levels of care. In this regard, the following is recommended:

- Introduce multidisciplinary engagement platforms for all those offering care to PLWHIV. Such engagement must occur on a regular basis and CHWs must be represented. A good example of this approach is from a study done in the Middle East, where a multidisciplinary team consisting of HIV physicians, pharmacists, nurses, counsellors, psychologists and social workers significantly improved treatment outcomes.(181)

6.2.4 Care coordination pathway

Based on the results of this study, it is recommended that every health facility must have a functional WBPHCOT office with a linkage officer who is responsible for linking community-based health services with facility-based health services. This should not only be limited to primary health care facilities, but should ideally also be operative in all the different levels of health care. Similarly, the role of the linkage officers should not be limited to only HIV services, but rather encompass all health services offered in health facilities and community-based health services.

All patients newly-diagnosed with HIV who have not been linked to a CHW should pass through the linkage officer's office on the day of diagnosis, whether initiated on treatment or not. It is important for those not initiated on treatment to be linked to CHWs, as there is a risk that they could be lost to follow up even before they are initiated on treatment. PLWHIV already linked to a CHW should be offered home-based HIV services from the CHW they are

linked to and should be given the opportunity to express their preferences when visited – see Section 6.5.3.1 for details.

6.2.5 Home-based HIV care

Based on the findings of this study, it is recommended that special attention should be paid to the kind and format of services provided as part of home-based HIV care. At minimum, the service package for home-based HIV care by CHWs should include the following services: help with counselling after an HIV test; assist patients with disclosing their HIV status; screen for illnesses related to HIV such as TB and other opportunistic infections; refer patients to a health facility when there is a need; help patients find ways to remember to take their medication every day; teach patients and designated other household members (if patients are comfortable with this) about HIV medication; educate patients and household members (if patients are comfortable with this) about possible side effects of HIV treatment; educate and assist patients and household members with psychosocial well-being (cognitive, emotional, and spiritual strength combined with positive social relationships); deliver medication at home if there is a need; and educate households about the food needed to stay healthy (Figure 6-3).

6.2.6 Patient preferences

In the qualitative and survey study, PLWHIV raised many issues around their preference when visited by CHWs in their household. These preferences include: preferred place of visit i.e. whether PLWHIV are comfortable to be meeting at home or not; visit days; frequency of visits; CHWs they are comfortable with visiting their household – e.g. from the same neighbourhood or not; whether CHWs should be dressed in their official uniform or not; and the services they need the most. Since these preferences could impact the acceptability of receiving such services, it is recommended that CHWs should check PLWHIV's preferences before they are visited in their household. If this is not possible, preferences could be ascertained during the first household visit. CHWs should record and work around patients' preferences to the extent possible.

6.2.7 Stigma, disclosure and confidentiality

It was evident in these studies that stigma and fear of stigmatization are some of the most important barriers that could hinder the delivery of health services by CHWs to PLWHIV. To remedy this, it is recommended that HIV-specific services should be avoided, both in health facilities and at the community level. A more comprehensive package of care (including child

and maternal health, non-communicable diseases, etc.) will not only reduce stigma, but also benefit PLWHIV in the long run, since it is well known that lifestyle diseases and non-AIDS-defining conditions are becoming more important causes of morbidity and mortality as the HIV epidemic matures. CHWs, working together with facility staff members, should identify and deal with factors leading to stigma. Branded cars and clothes that suggest the provision of HIV services should be avoided.

6.2.8 Resources and training

Special attention should also be paid to the resources that are necessary for CHWs to perform home-based HIV services. For example, pamphlets that provide comprehensive and evidence-based, yet accessible information about HIV prevention and treatment should be distributed to households. In a qualitative study (Chapter 2), some CHWs indicated that they needed extra training on HIV-related counselling and testing. Formal and comprehensive training of CHWs must be strengthened and standardized to ensure that all CHWs are competent in providing HIV services. Some CHW HIV programmes remain donor funded with uncertainty about their sustainability in the long-term, as governments might not be able to take over these programmes when donor support ends.(10, 17, 23) It is recommended that more sustainable ways of funding CHW programmes must be created; this should include prioritizing CHW programmes when budgeting for health services.

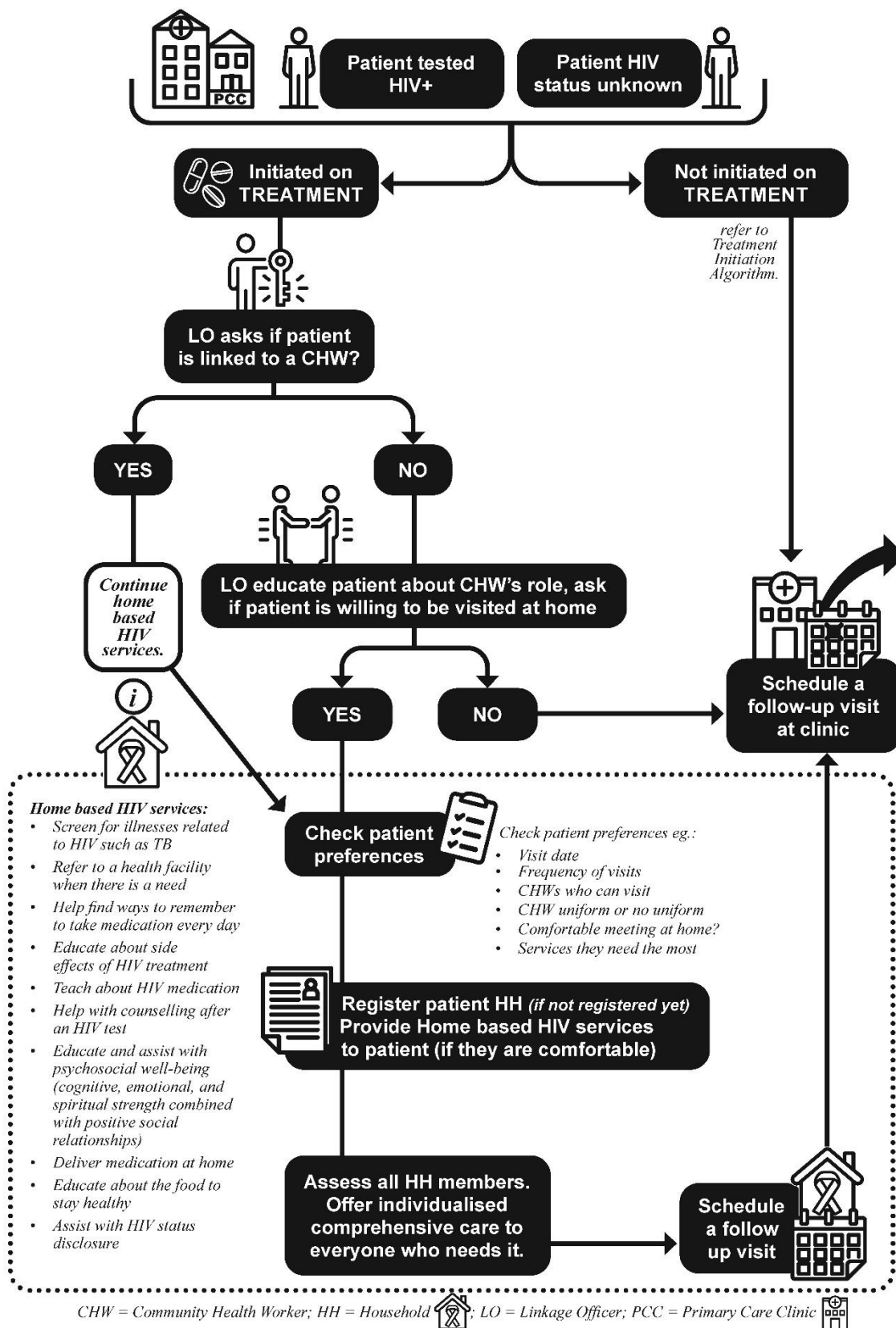


Figure 6-3. Home-based HIV care for PLWHIV

6.2.9 Preventing loss to follow-up.

In a study of PLWHIV in southwest Nigeria, the most common reasons given for defaulting treatment were long distances to the clinic (32%), feeling healthy (30%), having finished ARVs without restocking (23%), and faith/religion (16%).(182) Results from Chapter 4 show that a physical adherence game improves the retention of PLWHIV newly initiated on ART. If the most common reasons for defaulting treatment are known, they can also be addressed preemptively during such a game, potentially making the game even more effective. It is therefore recommended that this intervention should be included as part of the strategy to prevent patients becoming lost to follow-up. In addition, in Chapter 5, delivery of treatment to households for PLWHIV was amongst the activities performed by CHWs. This could assist PLWHIV who have to travel long distances to the clinic and those who tend to finish their ARVs without restocking.

6.2.9.1 *Tracing of patients who become lost to follow-up*

There is an overwhelmingly high number of patients without addresses on Tier.net across Tshwane.(93) This makes it almost impossible to physically trace these patients when they are lost to follow up. It is therefore recommended that:

- Patient addresses should be viewed as an essential tool to keep in contact with patients.
- The number of newly-diagnosed patients without addresses on Tier.net should be incorporated into monthly reports as a required data point. This will assist the Department of Health with understanding the scale of this problem in each of the clinics and inform strategies for resolving it.
- More work needs to be done to identify ways of verifying patient addresses upon treatment initiation.
- Patients diagnosed with HIV who are comfortable with being visited by a CHW should immediately be linked to a CHW. The CHWs should verify the correctness of patients' addresses and report this information back to the facility.

6.2.10 Safety of CHWs

To address fears around safety of WBPHCOT members, links must be created between WBPHCOT and community organizations such as community police forum.

6.2.11 Games

The adherence games are specifically designed for use with groups of people who have recently tested HIV positive, to help them address a range of issues they may face around living positively, such as: stigma, support, disclosure, and treatment adherence.

While previous studies have evaluated digital games for HIV prevention and care (109, 110, 117, 118), there is little information on the effectiveness of physical games that aim to improve patients' adherence to treatment. Physical treatment adherence games could be of special importance in settings where access and knowledge of digital technology are limited. It is therefore recommended that clinics explore ways to implement physical adherence games, such as the Bridges of Hope game, which has now been shown to improve retention of PLWHIV newly initiated on ART.

It is further recommended that the Department of Health should consider adding adherence games as part of the HIV training programme for CHWs and as part adherence clubs. This could help address some of the challenges described in Chapter 2, such as stigma, support, disclosure, and treatment adherence. It will, however, be important to address logistical challenges that could make it difficult for CHWs to work with the lay counsellors who are offering the Games intervention. In this study, these logistical challenges included poor communication and some participants preferring the Games intervention but refusing CHW visits to their households due to perceived stigma.

In future, the Department of Health could consider a similar games approach for other chronic conditions with a high number of patients with poor treatment adherence, such as those on treatment for hypertension and diabetes mellitus.

6.2.12 Recommendations for future research

- More studies should be performed to assess the optimal way of including WBPHCOTs in home-based HIV care as well as how to combine different interventions in a meaningful way.
- Specific operational challenges in implementing WBPHCOT-containing interventions deserve further study.
- In Chapter 2 fears were expressed about the occupational health and safety of CHWs. While there are many guidelines that address this at facility level, there are limited resources addressing the safety of CHWs in the community. It is important for future research to evaluate and explore the occupational health and safety of CHWs at a community level.

- Evaluate the impact of the requirement for identity documents in health facilities, in relation to patients giving incorrect addresses.
- More work is needed to understand and accommodate regional differences and individual preferences for WBPHCOTs.
- More attention should be paid to gender and age differences and preferences for home-based HIV care.

6.3 Conclusion

This 2 x 2 factorial cohort study was the first to demonstrate that a physical adherence game improved the retention of PLWHIV newly initiated on ART and hence has the potential to improve treatment outcomes. In addition, home-based HIV care was largely accepted as an important and positive intervention. To successfully implement effective home-based HIV care in South Africa, it is important to address perceived barriers to such care and involve all stakeholders, from decision makers to CHWs and PLWHIV. Special attention should be paid to integrating WBPHCOTs into clinics and existing support structures, improving training on confidentiality and HCT for CHWs, and rethinking the recruitment, scope of work, and safety of WBPHCOTs.

7 References

1. Joint UN Programme on HIV/AIDS. UNAIDS DATA 2020. Joint United Nations Programme on HIV/AIDS Geneva; 2020.
2. Joint UN Programme on HIV/AIDS. Ending AIDS: Progress towards the 90-90-90 targets. Global AIDS update. 2017.
3. South African National Aids Council. National Strategic Plan on HIV, TB and STIs 2017–2022. SANAC Pretoria. 2017.
4. Bradshaw D, Msemburi W, Dorrington R, Pillay-van Wyk V, Laubscher R, Groenewald P, et al. HIV/AIDS in South Africa: how many people died from the disease between 1997 and 2010? *AIDS*. 2016;30(5):771-8.
5. Ellman T. Demedicalizing AIDS prevention and treatment in Africa. *N Engl J Med*. 2015;372(4):303-5.
6. Cohen S, Guthrie T. Financing the South African national strategic plan for HIV, STIs, and TB 2012-2016: An analysis of funding, funding gaps, and financial considerations. Pretoria, South Africa: SANAC Costing Technical Team & Strategic Development Consultants. 2014.
7. Statistics South Africa. Mid-year population estimates, 2021. In: africa ss, editor. Pretoria2021.
8. Shisana O, Rehle T, Simbayi L, Zuma K, Jooste S, Zungu N, et al. South African national HIV prevalence, incidence and behaviour survey, 2012. 2014.
9. Severe P, Jean Juste MA, Ambroise A, Eliacin L, Marchand C, Apollon S, et al. Early versus standard antiretroviral therapy for HIV-infected adults in Haiti. *N Engl J Med*. 2010;363(3):257-65.
10. Lodi S, Phillips A, Touloumi G, Geskus R, Meyer L, Thiébaud R, et al. Time from human immunodeficiency virus seroconversion to reaching CD4+ cell count thresholds< 200,< 350, and< 500 cells/mm³: assessment of need following changes in treatment guidelines. *Clinical infectious diseases*. 2011;53(8):817-25.
11. Patten GE, Cox V, Stinson K, Boule AM, Wilkinson LS. Advanced HIV disease at antiretroviral therapy (ART) initiation despite implementation of expanded ART eligibility guidelines during 2007–2012 in Khayelitsha, South Africa. *Clinical infectious diseases*. 2014;59(3):456-7.
12. HIV-Causal Collaboration. When to initiate combined antiretroviral therapy to reduce mortality and AIDS-defining illness in HIV-infected persons in developed countries: an observational study. *Annals of internal medicine*. 2011;154(8):509.
13. World Health Organization. Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: recommendations for a public health approach June 2013. Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: recommendations for a public health approach June 20132013. p. 272-.
14. Babiker AG, Emery S, Fätkenheuer G, Gordin FM, Grund B, Lundgren JD, et al. Considerations in the rationale, design and methods of the Strategic Timing of AntiRetroviral Treatment (START) study. *Clinical Trials*. 2013;10(1_suppl):S5-S36.
15. Temprano ANRS 12136 Study Group. A trial of early antiretrovirals and isoniazid preventive therapy in Africa. *New England Journal of Medicine*. 2015;373(9):808-22.
16. Hammer SM, Squires KE, Hughes MD, Grimes JM, Demeter LM, Currier JS, et al. A controlled trial of two nucleoside analogues plus indinavir in persons with human immunodeficiency virus infection and CD4 cell counts of 200 per cubic millimeter or less. *N Engl J Med*. 1997;337(11):725-33.
17. Gulick RM, Mellors JW, Havlir D, Eron JJ, Gonzalez C, McMahon D, et al. Treatment with indinavir, zidovudine, and lamivudine in adults with human immunodeficiency virus infection and prior antiretroviral therapy. *N Engl J Med*. 1997;337(11):734-9.
18. Tanser F, Barnighausen T, Grapsa E, Zaidi J, Newell M-L. High coverage of ART associated with decline in risk of HIV acquisition in rural KwaZulu-Natal, South Africa. *Science*. 2013;339(6122):966-71.
19. Eisinger RW, Dieffenbach CW, Fauci AS. HIV Viral Load and Transmissibility of HIV Infection: Undetectable Equals Untransmittable. *JAMA*. 2019;321(5):451-2.

20. Albert J, Berglund T, Gisslén M, Gröön P, Sönnernborg A, Tegnell A, et al. Risk of HIV transmission from patients on antiretroviral therapy: A position statement from the Public Health Agency of Sweden and the Swedish Reference Group for Antiviral Therapy. *Scand J Infect Dis.* 2014;46(10):673-7.
21. Grobler A, Cawood C, Khanyile D, Puren A, Kharsany AB. Progress of UNAIDS 90-90-90 targets in a district in KwaZulu-Natal, South Africa, with high HIV burden, in the HIPSS study: a household-based complex multilevel community survey. *The Lancet HIV.* 2017;4(11):e505-e13.
22. Joint UN Programme on HIV/AIDS. Understanding fast-track: accelerating action to end the AIDS epidemic by 2030. UNAIDS Geneva; 2015.
23. Kaufmann GR, Elzi L, Weber R, Furrer H, Giulieri S, Vernazza P, et al. Interruptions of cART limits CD4 T-cell recovery and increases the risk for opportunistic complications and death. *AIDS.* 2011;25(4):441-51.
24. Azia IN, Mukumbang FC, Van Wyk B. Barriers to adherence to antiretroviral treatment in a regional hospital in Vredenburg, Western Cape, South Africa. *South Afr J HIV Med.* 2016;17(1):1-8.
25. Rosen S, Fox MP, Gill CJ. Patient retention in antiretroviral therapy programs in sub-Saharan Africa: a systematic review. *PLoS medicine.* 2007;4(10):e298.
26. Reda AA, Biadgilign S. Determinants of adherence to antiretroviral therapy among HIV-infected patients in Africa. *AIDS Res Treat.* 2012;2012.
27. National Department of Health. National consolidated guidelines for the prevention of mother-to-child transmission of HIV (PMTCT) and the management of HIV in children, adolescents and adults. aidsfree.usaid.gov/sites/default/files/tx_south-africa_pmtct_2015.pdf. 2015.
28. Osler M, Boule A. Three interlinked electronic registers (TIER. Net) Project. Working Paper; 2010.
29. Thomas BE, Suresh C, Lavanya J, Lindsley MM, Galivanche AT, Sellappan S, et al. Understanding pretreatment loss to follow-up of tuberculosis patients: an explanatory qualitative study in Chennai, India. *BMJ Glob Health.* 2020;5(2):e001974.
30. Larson BA, Brennan A, McNamara L, Long L, Rosen S, Sanne I, et al. Early loss to follow up after enrolment in pre-ART care at a large public clinic in Johannesburg, South Africa. *Tropical Medicine & International Health.* 2010;15:43-7.
31. Brinkhof MW, Pujades-Rodriguez M, Egger M. Mortality of patients lost to follow-up in antiretroviral treatment programmes in resource-limited settings: systematic review and meta-analysis. *PloS one.* 2009;4(6):e5790.
32. Mills EJ, Nachega JB, Buchan I, Orbinski J, Attaran A, Singh S, et al. Adherence to antiretroviral therapy in sub-Saharan Africa and North America: a meta-analysis. *JAMA.* 2006;296(6):679-90.
33. Shubber Z, Mills EJ, Nachega JB, Vreeman R, Freitas M, Bock P, et al. Patient-reported barriers to adherence to antiretroviral therapy: a systematic review and meta-analysis. *PLoS Med.* 2016;13(11):e1002183.
34. Langebeek N, Gisolf EH, Reiss P, Vervoort SC, Hafsteinsdóttir TB, Richter C, et al. Predictors and correlates of adherence to combination antiretroviral therapy (ART) for chronic HIV infection: a meta-analysis. *BMC Med.* 2014;12(1):142.
35. Heestermans T, Browne JL, Aitken SC, Vervoort SC, Klipstein-Grobusch K. Determinants of adherence to antiretroviral therapy among HIV-positive adults in sub-Saharan Africa: a systematic review. *BMJ global health.* 2016;1(4):e000125.
36. Ochieng-Ooko V, Ochieng D, Sidle JE, Holdsworth M, Wools-Kaloustian K, Siika AM, et al. Influence of gender on loss to follow-up in a large HIV treatment programme in western Kenya. *Bull World Health Organ.* 2010;88:681-8.
37. Bauleth MF, Van Wyk B, Ashipala DO. Factors associated with poor adherence amongst patients receiving antiretroviral therapy at the Oshakati intermediate hospital in Namibia. *International Journal of Healthcare.* 2016;2(2):89.
38. Bauleth MF. Factors associated with poor adherence amongst patients receiving antiretroviral therapy at the intermediate hospital Oshakati in Namibia. 2011.

39. Ndubuka NO, Lim HJ, van der Wal DM, Ehlers VJ. Health-related quality of life of antiretroviral treatment defaulters in Botswana. *South Afr J HIV Med.* 2016;17(1):1-6.
40. Miller CM, Ketlhapile M, Rybasack-Smith H, Rosen S. Why are antiretroviral treatment patients lost to follow-up? A qualitative study from South Africa. *Trop Med Int Health.* 2010;15(s1):48-54.
41. Mberi MN, Kuonza LR, Dube NM, Nattey C, Manda S, Summers R. Determinants of loss to follow-up in patients on antiretroviral treatment, South Africa, 2004–2012: a cohort study. *BMC Health Serv Res.* 2015;15(1):259.
42. Harrison D. The National Health Services Commission, 1942-1944-its origins and outcome. *South African Medical Journal.* 1993;83(9):679-84.
43. Marcus T. A practical guide to doing community oriented primary care. Lynnwood :: Minuteman Press; 2015.
44. Sodo P, Bosman A. Progress of the municipal ward-based primary healthcare outreach teams in Vhembe, Limpopo Province. *Strengthening Health Systems.* 2017;2(1):18-22.
45. Marcus T. Community oriented primary care L2: Primary care. Cape Town: Pearson. 2013.
46. Karel. Why policy is failing community health workers — Soul City Institute for Social Justice. 2014.
47. Braun R, Catalani C, Wimbush J, Israelski D. Community health workers and mobile technology: a systematic review of the literature. *PLoS One.* 2013;8(6):e65772.
48. Mwai GW, Mburu G, Torpey K, Frost P, Ford N, Seeley J. Role and outcomes of community health workers in HIV care in sub-Saharan Africa: A systematic review. *J Int AIDS Soc.* 2013;16(1).
49. Schneider H, Blaauw D, Gilson L, Chabikuli N, Goudge J. Health Systems and Access to Antiretroviral Drugs for HIV in Southern Africa: Service Delivery and Human Resources Challenges. *Reproductive health matters.* 2006;14(27):12-23.
50. Mukanga D, Babirye R, Peterson S, Pariyo G, Ojiambo G, Tibenderana J, et al. Can lay community health workers be trained to use diagnostics to distinguish and treat malaria and pneumonia in children? Lessons from rural Uganda. *Trop Med Int Health.* 2011;16(10):1234-42.
51. Wouters E, Van Damme W, Van Loon F, van Rensburg D, Meulemans H. Public-sector ART in the Free State Province, South Africa: Community support as an important determinant of outcome. *Social Science & Medicine.* 2009;69(8):1177-85.
52. Zachariah R, Teck R, Buhendwa L, Labana S, Chinji C, Humblet P, et al. How can the community contribute in the fight against HIV/AIDS and tuberculosis? An example from a rural district in Malawi. *Trans R Soc Trop Med Hyg.* 2006;100(2):167-75.
53. Igumbor J, Scheepers E, Ebrahim R, Jason A, Grimwood A. An evaluation of the impact of a community-based adherence support programme on ART outcomes in selected government HIV treatment sites in South Africa. *AIDS Care.* 2011;23(2):231-6.
54. Zachariah R, Teck R, Buhendwa L, Fitzerland M, Labana S, Chinji C, et al. Community support is associated with better antiretroviral treatment outcomes in a resource-limited rural district in Malawi. *Trans R Soc Trop Med Hyg.* 2007;101(1):79-84.
55. Grimwood A, Fatti G, Mothibi E, Malahlela M, Shea J, Eley B. Community adherence support improves programme retention in children on antiretroviral treatment: a multicentre cohort study in South Africa. *Journal of the International AIDS Society.* 2012;15(2):17381.
56. Howell K. Games for health conference 2004: issues, trends, and needs unique to games for health. *Cyberpsychology & Behavior.* 2005;8(2):103-9.
57. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. *Ann Intern Med.* 2011;155(2):97-107.
58. Kharrazi H, Lu AS, Gharghabi F, Coleman W. A scoping review of health game research: Past, present, and future. *GAMES FOR HEALTH: Research, Development, and Clinical Applications.* 2012;1(2):153-64.
59. Conserve DF, Issango J, Kilale AM, Njau B, Nhigula P, Memiah P, et al. Developing national strategies for reaching men with HIV testing services in Tanzania: results from the male catch-up plan. *BMC Health Serv Res.* 2019;19(1):317.

60. Lester RT, Ritvo P, Mills EJ, Kariri A, Karanja S, Chung MH, et al. Effects of a mobile phone short message service on antiretroviral treatment adherence in Kenya (WelTel Kenya1): a randomised trial. *The Lancet*. 2010;376(9755):1838-45.
61. B Nachega J, C Marconi V, U van Zyl G, M Gardner E, Preiser W, Y Hong S, et al. HIV treatment adherence, drug resistance, virologic failure: evolving concepts. *Infectious Disorders-Drug Targets (Formerly Current Drug Targets-Infectious Disorders)*. 2011;11(2):167-74.
62. Moneyham L, McLeod J, Boehme A, Wright L, Mugavero M, Seal P, et al. Perceived barriers to HIV care among HIV-infected women in the Deep South. *J Assoc Nurses AIDS Care*. 2010;21(6):467-77.
63. Mwai GW, Mburu G, Torpey K, Frost P, Ford N, Seeley J. Role and outcomes of community health workers in HIV care in sub-Saharan Africa: a systematic review. *Journal of the International AIDS Society*. 2013;16(1):18586.
64. Jinabhai C, Marcus T, Chaponda A. Rapid appraisal of ward based outreach teams. Pretoria: Albertina Sisulu Executive Leadership Programme in Health. 2015.
65. Marcus TS, Reji E, Ngcobo S. Peer-learning reviews to improve Gauteng community-oriented primary care: Findings from AitaHealth™-enabled ward-based outreach teams. *African Journal of Primary Health Care & Family Medicine*. 2020;12(1):1-10.
66. Marcus TS. COPC—A practical guide. Pretoria (South Africa): Department of Family Medicine, University of Pretoria. 2018.
67. Naidoo N, Railton J, Jobson G, Matlakala N, Marincowitz G, McIntyre JA, et al. Making ward-based outreach teams an effective component of human immunodeficiency virus programmes in South Africa. *South Afr J HIV Med*. 2018;19(1).
68. Liamputtong P. Focus group methodology: Principle and practice: Sage Publications; 2011.
69. Hennink MM, Kaiser BN, Weber MB. What influences saturation? Estimating sample sizes in focus group research. *Qualitative health research*. 2019;29(10):1483-96.
70. Castleberry A, Nolen A. Thematic analysis of qualitative research data: Is it as easy as it sounds? *Currents in Pharmacy Teaching and Learning*. 2018;10(6):807-15.
71. World Health Organization. Global tuberculosis report 2019: World Health Organization; 2019.
72. Bristow CC, Podewils LJ, Bronner LE, Bantubani N, van Der Walt M, Peters A, et al. TB tracer teams in South Africa: knowledge, practices and challenges of tracing TB patients to improve adherence. *BMC public health*. 2013;13(1):801.
73. O'Hara LM, Yassi A, Zungu M, Malotle M, Bryce EA, Barker SJ, et al. The neglected burden of tuberculosis disease among health workers: a decade-long cohort study in South Africa. *BMC infectious diseases*. 2017;17(1):547.
74. Mwisongo A, Mehlomakhulu V, Mohlabane N, Peltzer K, Mthembu J, Van Rooyen H. Evaluation of the HIV lay counselling and testing profession in South Africa. *BMC Health Serv Res*. 2015;15(1):278.
75. Chung MH, Richardson BA, Tapia K, Benki-Nugent S, Kiarie JN, Simoni JM, et al. A randomized controlled trial comparing the effects of counseling and alarm device on HAART adherence and virologic outcomes. *PLoS Med*. 2011;8(3):e1000422.
76. Otiso L, McCollum R, Mireku M, Karuga R, de Koning K, Taegtmeyer M. Decentralising and integrating HIV services in community-based health systems: a qualitative study of perceptions at macro, meso and micro levels of the health system. *BMJ Global Health*. 2017;2(1).
77. Katz IT, Dietrich J, Tshabalala G, Essien T, Rough K, Wright AA, et al. Understanding treatment refusal among adults presenting for HIV-testing in Soweto, South Africa: a qualitative study. *AIDS Behav*. 2015;19(4):704-14.
78. Treves-Kagan S, Steward WT, Ntswane L, Haller R, Gilvydis JM, Gulati H, et al. Why increasing availability of ART is not enough: a rapid, community-based study on how HIV-related stigma impacts engagement to care in rural South Africa. *BMC Public Health*. 2015;16(1):87.

79. Jennings JD, Ciaravino SG, Ramsey FV, Haydel C. Physicians' attire influences patients' perceptions in the urban outpatient orthopaedic surgery setting. *Clinical Orthopaedics and Related Research*®. 2016;474(9):1908-18.
80. Grant M, Wilford A, Haskins L, Phakathi S, Mntambo N, Horwood CM. Trust of community health workers influences the acceptance of community-based maternal and child health services. *African journal of primary health care & family medicine*. 2017;9(1):1-8.
81. Hai NK, Lawpoolsri S, Jittamala P, Huong PTT, Kaewkungwal J. Practices in security and confidentiality of HIV/AIDS patients' information: A national survey among staff at HIV outpatient clinics in Vietnam. *PLoS One*. 2017;12(11):e0188160.
82. O'Donovan J, O'Donovan C, Kuhn I, Sachs SE, Winters N. Ongoing training of community health workers in low-income and middle-income countries: a systematic scoping review of the literature. *BMJ open*. 2018;8(4):e021467.
83. Chellaiyan VG, Raut DK, Khokhar A. Integrated counseling and HIV testing centers of Delhi: An evaluation. *Journal of family medicine and primary care*. 2018;7(4):791.
84. Naik SB. Death in the hospital: Breaking the bad news to the bereaved family. *Indian journal of critical care medicine : peer-reviewed, official publication of Indian Society of Critical Care Medicine*. 2013;17(3):178-81.
85. Steege R, Taegtmeyer M, McCollum R, Hawkins K, Ormel H, Kok M, et al. How do gender relations affect the working lives of close to community health service providers? Empirical research, a review and conceptual framework. *Social Science & Medicine*. 2018;209:1-13.
86. Ponthieu A, Incerti A. Continuity of care for migrant populations in southern Africa. *Refugee Survey Quarterly*. 2016;35(2):98-115.
87. Hunter JR, Chandran TM, Asmall S, Tucker J-M, Ravhengani NM, Mokgalagadi Y. The Ideal Clinic in South Africa: progress and challenges in implementation. *South African health review*. 2017;2017(1):111-23.
88. Schneider H, Schaay N, Dudley L, Goliath C, Qukula T. The challenges of reshaping disease specific and care oriented community based services towards comprehensive goals: a situation appraisal in the Western Cape Province, South Africa. *BMC Health Serv Res*. 2015;15(1):436.
89. Shand T, Thomson-de Boor H, van den Berg W, Peacock D, Pascoe L. The HIV blind spot: men and HIV testing, treatment and care in sub-Saharan Africa. *IDS Bulletin*. 2014;45(1):53-60.
90. Massyn N, Barron P, Day C, Ndlovu N, Padarath A. *District Health Barometer, 2018/19*. Durban: Health Systems Trust. 2020.
91. Naledi T, Barron P, Schneider H. Primary health care in SA since 1994 and implications of the new vision for PHC re-engineering. *South African health review*. 2011;2011(1):17-28.
92. Schneider H, Sanders D, Besada D, Daviaud E, Rohde S. Ward-based primary health care outreach teams in South Africa: developments, challenges and future directions. *South African health review*. 2018;2018(1):59-65.
93. Ngcobo S, Rossouw T. "They come and knock at the gate until the neighbours see". Perceived barriers and benefits of implementing HIV care at the community level in Tshwane district: A qualitative study. *PloS one*. 2020;15(10):e0240740.
94. Handford CD, Rackal JM, Tynan AM, Rzeznikewiz D, Glazier RH. The association of hospital, clinic and provider volume with HIV/AIDS care and mortality: systematic review and meta-analysis. *AIDS care*. 2012;24(3):267-82.
95. Lehmann U, Sanders D. *Community health workers: what do we know about them. The state of the evidence on programmes, activities, costs and impact on health outcomes of using community health workers* Geneva: World Health Organization. 2007:1-42.
96. Pallant J. *SPSS survival manual: A step by step guide to data analysis using IBM SPSS*: Routledge; 2020.
97. Kaai S, Sarna A, Luchters S, Geibel S, Munyao P, Mandaliya KN, et al. Changes in stigma among a cohort of people on antiretroviral therapy: findings from Mombasa, Kenya. *Population Council*. 2007.

98. Samuels F, Simbaya J, Sarna A, Geibel S, Ndubani P, Kamwanga J. Engaging communities in supporting HIV prevention and adherence to antiretroviral therapy in Zambia. Washington, DC: Population Council. 2008.
99. Nyblade L, MacQuarrie K, Kwesigabo G, Jain A, Kajula L, Philip F. Horizons Final Report. Washington: Population Council. 2008.
100. Stutterheim SE, Sicking L, Baas I, Brands R, Roberts H, van Brakel WH, et al. Disclosure of HIV Status to Health Care Providers in the Netherlands: A Qualitative Study. *The Journal of the Association of Nurses in AIDS Care : JANAC*. 2016;27(4):485-94.
101. Edwards J, Palmer G, Osbourne N, Scambler S. Why individuals with HIV or diabetes do not disclose their medical history to the dentist: a qualitative analysis. *British dental journal*. 2013;215(6):E10.
102. Ingram M, Sabo S, Rothers J, Wennerstrom A, de Zapien JG. Community Health Workers and Community Advocacy: Addressing Health Disparities. *Journal of Community Health*. 2008;33(6):417-24.
103. Rosenthal EL. A summary of the national community health advisor study. Baltimore, MD: Annie E Casey Foundation. 1998.
104. Mutasa-Apollo T, Ford N, Wiens M, Socias ME, Negussie E, Wu P, et al. Effect of frequency of clinic visits and medication pick-up on antiretroviral treatment outcomes: a systematic literature review and meta-analysis. *Journal of the International AIDS Society*. 2017;20(Suppl 4):21647-.
105. Vawda Y, Gray A. South African health review 2018. Health Systems Trust; 2018.
106. World Health Organization. Global tuberculosis report 2018: World Health Organization; 2018.
107. Moosa A, Gengiah TN, Lewis L, Naidoo K. Long-term adherence to antiretroviral therapy in a South African adult patient cohort: a retrospective study. *BMC Infectious Diseases*. 2019;19(1):775.
108. LeMessurier J, Traversy G, Varsaneux O, Weekes M, Avey MT, Niragira O, et al. Risk of sexual transmission of human immunodeficiency virus with antiretroviral therapy, suppressed viral load and condom use: a systematic review. *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne*. 2018;190(46):E1350-e60.
109. Castel AD, Qasmieh S, Greenberg D, Ellenberger N, Howell TH, Griffith C, et al. Digital Gaming to Improve Adherence Among Adolescents and Young Adults Living With HIV: Mixed-Methods Study to Test Feasibility and Acceptability. *JMIR serious games*. 2018;6(4):e10213.
110. Whiteley L, Mena L, Craker LK, Healy MG, Brown LK. Creating a Theoretically Grounded Gaming App to Increase Adherence to Pre-Exposure Prophylaxis: Lessons From the Development of the Viral Combat Mobile Phone Game. *JMIR serious games*. 2019;7(1):e11861.
111. Zhonggen Y. A Meta-Analysis of Use of Serious Games in Education over a Decade. *International Journal of Computer Games Technology*. 2019;2019:4797032.
112. Dilts R. From coach to awakener: Meta Publications Capitola, CA.; 2003.
113. Sanderson PM. Verbalizable knowledge and skilled task performance: Association, dissociation, and mental models. *J Exp Psychol Learn Mem Cogn*. 1989;15(4):729.
114. Naidoo N, Railton J, Jobson G, Matlakala N, Marincowitz G, McIntyre JA, et al. Making ward-based outreach teams an effective component of human immunodeficiency virus programmes in South Africa. 2018. 2018;19(1).
115. Hayes RJ, Donnell D, Floyd S, Mandla N, Bwalya J, Sabapathy K, et al. Effect of Universal Testing and Treatment on HIV Incidence - HPTN 071 (PopART). *The New England journal of medicine*. 2019;381(3):207-18.
116. Health NDo. National consolidated guidelines for the prevention of mother-to-child transmission of HIV (PMTCT) and the management of HIV in children, adolescents and adults. aidsfree.usaid.gov/sites/default/files/tx_south-africa_pmtct_2015.pdf. 2015.
117. Hightow-Weidman LB, Muessig KE, Bauermeister JA, LeGrand S, Fiellin LE. The future of digital games for HIV prevention and care. *Curr Opin HIV AIDS*. 2017;12(5):501-7.

118. LeGrand S, Muessig KE, McNulty T, Soni K, Knudtson K, Lemann A, et al. Epic Allies: Development of a Gaming App to Improve Antiretroviral Therapy Adherence Among Young HIV-Positive Men Who Have Sex With Men. *JMIR serious games*. 2016;4(1):e6-e.
119. Fox MP, Bor J, Brennan AT, MacLeod WB, Maskew M, Stevens WS, et al. Estimating retention in HIV care accounting for patient transfers: A national laboratory cohort study in South Africa. *PLoS Med*. 2018;15(6):e1002589.
120. Rich ML, Miller AC, Niyigena P, Franke MF, Niyonzima JB, Socci A, et al. Excellent clinical outcomes and high retention in care among adults in a community-based HIV treatment program in rural Rwanda. *Journal of acquired immune deficiency syndromes (1999)*. 2012;59(3):e35-42.
121. Ramjee G, Coumi N, Dladla-Qwabe N, Ganesh S, Gappoo S, Govinden R, et al. Experiences in conducting multiple community-based HIV prevention trials among women in KwaZulu-Natal, South Africa. *AIDS Research and Therapy*. 2010;7(1):10.
122. Kanfers S, Vitoria M, Doherty M, Socias ME, Ford N, Forrest JI, et al. Comparative efficacy and safety of first-line antiretroviral therapy for the treatment of HIV infection: a systematic review and network meta-analysis. *The lancet HIV*. 2016;3(11):e510-e20.
123. World Health Organization. Updated recommendations on first-line and second-line antiretroviral regimens and post-exposure prophylaxis and recommendations on early infant diagnosis of HIV: interim guidelines: supplement to the 2016 consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection. World Health Organization; 2018.
124. Crawford TN, Sanderson WT, Thornton A. Impact of poor retention in HIV medical care on time to viral load suppression. *Journal of the International Association of Providers of AIDS Care (JIAPAC)*. 2014;13(3):242-9.
125. World Health Organization. HIV Drug Resistance Report 2019. 2019: WHO; 2019.
126. Bisson GP, Rowh A, Weinstein R, Gaolathe T, Frank I, Gross R. Antiretroviral failure despite high levels of adherence: discordant adherence–response relationship in Botswana. *Journal of acquired immune deficiency syndromes (1999)*. 2008;49(1):107.
127. Woldeesenbet SA, Kufa T, Barron P, Chirombo BC, Cheyip M, Ayalew K, et al. Viral suppression and factors associated with failure to achieve viral suppression among pregnant women in South Africa. *AIDS (London, England)*. 2020;34(4):589-97.
128. Joint United Nations Programme on HIV/AIDS. Geneva, Switzerland; 2018. North American, Western and Central Europe: AIDS epidemic update regional summary. 2019:1-16.
129. Teeraananchai S, Kerr S, Amin J, Ruxrungtham K, Law M. Life expectancy of HIV-positive people after starting combination antiretroviral therapy: a meta-analysis. *HIV medicine*. 2017;18(4):256-66.
130. Joint UN Programme on HIV/AIDS. Fast-track commitments to end AIDS by 2030. UNAIDS Geneva, Switzerland; 2016.
131. South African National Aids Council. The National Strategic Plan (NSP) 2017-2022: SANAC; 2017 [Available from: <http://sanac.org.za/about-sanac/the-national-strategic-plan-nsp-2012-2016-in-a-nutshell/>].
132. Murray KR, Dulli LS, Ridgeway K, Dal Santo L, de Mora DD, Olsen P, et al. Improving retention in HIV care among adolescents and adults in low-and middle-income countries: A systematic review of the literature. *PloS one*. 2017;12(9).
133. Magingxa MM, Ngubo T. COMMUNITY HEALTH WORKERS A BRIEF DESCRIPTION OF. 2011.
134. Olaniran A, Smith H, Unkels R, Bar-Zeev S, van den Broek N. Who is a community health worker? - a systematic review of definitions. *Global health action*. 2017;10(1):1272223-.
135. Naidoo N, Railton J, Jobson G, Matlakala N, Marincowitz G, McIntyre JA, et al. Making ward-based outreach teams an effective component of human immunodeficiency virus programmes in South Africa. *Southern African Journal of Hiv Medicine*. 2018;19(1).
136. Schneider H, Lehmann U. Lay health workers and HIV programmes: implications for health systems. *AIDS care*. 2010;22(sup1):60-7.

137. Kredt T, McCaul M, Volmink J. Task-shifting from doctors to non-doctors for initiation and maintenance of antiretroviral therapy. 2015.
138. Mdege ND, Chindove S, Ali S. The effectiveness and cost implications of task-shifting in the delivery of antiretroviral therapy to HIV-infected patients: a systematic review. *Health policy and planning*. 2013;28(3):223-36.
139. Callaghan M, Ford N, Schneider H. A systematic review of task-shifting for HIV treatment and care in Africa. *Human resources for health*. 2010;8(1):8.
140. Mays N, Pope C, Popay J. Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field. *Journal of health services research & policy*. 2005;10(1_suppl):6-20.
141. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Annals of internal medicine*. 2009;151(4):264-9.
142. Lewin S, Munabi-Babigumira S, Glenton C, Daniels K, Bosch-Capblanch X, van Wyk BE, et al. Lay health workers in primary and community health care for maternal and child health and the management of infectious diseases. *Cochrane database of systematic reviews*. 2010(3).
143. Higgins JP, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, et al. *Cochrane handbook for systematic reviews of interventions*: John Wiley & Sons; 2019.
144. De Neve JW, Garrison-Desany H, Andrews KG, Sharara N, Boudreaux C, Gill R, et al. Harmonization of community health worker programs for HIV: A four-country qualitative study in Southern Africa. *PLoS Med*. 2017;14(8):e1002374.
145. Suri A, Gan K, Carpenter S. Voices from the field: perspectives from community health workers on health care delivery in rural KwaZulu-Natal, South Africa. *The Journal of infectious diseases*. 2007;196 Suppl 3:S505-11.
146. Rachlis B, Naanyu V, Wachira J, Genberg B, Koech B, Kamene R, et al. Community Perceptions of Community Health Workers (CHWs) and Their Roles in Management for HIV, Tuberculosis and Hypertension in Western Kenya. *PloS one*. 2016;11(2):e0149412.
147. Nxumalo N, Goudge J, Manderson L. Community health workers, recipients' experiences and constraints to care in South Africa - a pathway to trust. *Aids Care-Psychological and Socio-Medical Aspects of Aids/Hiv*. 2016;28:61-71.
148. Naidoo N, Zuma N, Khosa NS, Marincowitz G, Railton J, Matlakala N, et al. Qualitative assessment of facilitators and barriers to HIV programme implementation by community health workers in Mopani district, South Africa. *PloS one*. 2018;13(8):e0203081.
149. Loeliger KB, Niccolai LM, Mtungwa LN, Moll A, Sheno SV. "I Have to Push Him with a Wheelbarrow to the Clinic": Community Health Workers' Roles, Needs, and Strategies to Improve HIV Care in Rural South Africa. *AIDS patient care and STDs*. 2016;30(8):385-94.
150. Heunis JC, Wouters E, Norton WE, Engelbrecht MC, Kigozi NG, Sharma A, et al. Patient- and delivery-level factors related to acceptance of HIV counseling and testing services among tuberculosis patients in South Africa: a qualitative study with community health workers and program managers. *Implementation science : IS*. 2011;6:27.
151. Wanga I, Helova A, Abuogi LL, Bukusi EA, Nalwa W, Akama E, et al. Acceptability of community-based mentor mothers to support HIV-positive pregnant women on antiretroviral treatment in western Kenya: a qualitative study. *BMC pregnancy and childbirth*. 2019;19(1):288.
152. van Heerden A, Harris DM, van Rooyen H, Barnabas RV, Ramanathan N, Ngcobo N, et al. Perceived mHealth barriers and benefits for home-based HIV testing and counseling and other care: Qualitative findings from health officials, community health workers, and persons living with HIV in South Africa. *Social science & medicine (1982)*. 2017;183:97-105.
153. Pellicchia U, Baert S, Nundwe S, Bwanali A, Zamadenga B, Metcalf CA, et al. "We are part of a family". Benefits and limitations of community ART groups (CAGs) in Thyolo, Malawi: a qualitative study. *Journal of the International AIDS Society*. 2017;20(1):21374.
154. Magidson JF, Joska JA, Regenauer KS, Satinsky E, Andersen LS, Seitz-Brown CJ, et al. "Someone who is in this thing that I am suffering from": The role of peers and other facilitators for task sharing

- substance use treatment in South African HIV care. *International Journal of Drug Policy*. 2019;70:61-9.
155. Mottiar S, Lodge T. The role of community health workers in supporting South Africa's HIV/AIDS treatment programme. *African Journal of AIDS Research*. 2018;17(1):54-61.
 156. Busza J, Dauya E, Bandason T, Simms V, Chikwari CD, Makamba M, et al. The role of community health workers in improving HIV treatment outcomes in children: lessons learned from the ZENITH trial in Zimbabwe. *Health Policy and Planning*. 2018;33(3):328-34.
 157. Alamo S, Wabwire-Mangen F, Kenneth E, Sunday P, Laga M, Colebunders RL. Task-shifting to community health workers: evaluation of the performance of a peer-led model in an antiretroviral program in Uganda. *AIDS patient care and STDs*. 2012;26(2):101-7.
 158. Gusdal AK, Obua C, Andualem T, Wahlström R, Chalker J, Fochsen G, et al. Peer counselors' role in supporting patients' adherence to ART in Ethiopia and Uganda. *AIDS care*. 2011;23(6):657-62.
 159. Cataldo F, Seeley J, Nkhata MJ, Mupambireyi Z, Tumwesige E, Gibb DM. She knows that she will not come back: tracing patients and new thresholds of collective surveillance in PMTCT Option B. *BMC health services research*. 2018;18(1):76.
 160. Geldsetzer P, Francis JM, Sando D, Asmus G, Lema IA, Mboggo E, et al. Community delivery of antiretroviral drugs: a non-inferiority cluster-randomized pragmatic trial in Dar es Salaam, Tanzania. *PLoS medicine*. 2018;15(9).
 161. Ware NC, Wyatt MA, Geng EH, Kaaya SF, Agbaji OO, Muyindike WR, et al. Toward an understanding of disengagement from HIV treatment and care in sub-Saharan Africa: a qualitative study. *PLoS Med*. 2013;10(1):e1001369; discussion e.
 162. Tuller DM, Bangsberg DR, Senkungu J, Ware NC, Emenyonu N, Weiser SD. Transportation costs impede sustained adherence and access to HAART in a clinic population in southwestern Uganda: a qualitative study. *AIDS Behav*. 2010;14(4):778-84.
 163. Louw JM, Rantloane B, Christian CS. Home delivery of medication as part of reducing congestion in primary healthcare in Tshwane District Health Services. 2020.
 164. Ruud KW, Srinivas SC, Toverud E-L. Knowledge of HIV and its treatment among health care providers in South Africa. *International Journal of Clinical Pharmacy*. 2014;36(2):352-9.
 165. Ingram M, Reinschmidt KM, Schachter KA, Davidson CL, Sabo SJ, De Zapien JG, et al. Establishing a professional profile of community health workers: results from a national study of roles, activities and training. *J Community Health*. 2012;37(2):529-37.
 166. Carr RL, Gramling LF. Stigma: a health barrier for women with HIV/AIDS. *Journal of the Association of Nurses in AIDS Care*. 2004;15(5):30-9.
 167. Simbayi L, Zuma K, Cloete A, Jooste S, Zimela S, Blose S, et al. The people: living with HIV stigma index: South Africa 2014: summary report. 2015.
 168. Katz IT, Ryu AE, Onuegbu AG, Psaros C, Weiser SD, Bangsberg DR, et al. Impact of HIV-related stigma on treatment adherence: systematic review and meta-synthesis. *Journal of the International AIDS Society*. 2013;16:18640.
 169. Daftary A, Padayatchi N, Padilla M. HIV testing and disclosure: a qualitative analysis of TB patients in South Africa. *AIDS care*. 2007;19(4):572-7.
 170. Friedland BA, Gottert A, Hows J, Baral SD, Sprague L, Nyblade L, et al. The People Living with HIV Stigma Index 2.0: generating critical evidence for change worldwide. *AIDS*. 2020;34:S5-S18.
 171. Loeliger KB, Niccolai LM, Mtungwa LN, Moll A, Shenoi SV. Antiretroviral therapy initiation and adherence in rural South Africa: community health workers' perspectives on barriers and facilitators. *AIDS care*. 2016;28(8):982-93.
 172. Huisman ER, Morales E, van Hoof J, Kort HS. Healing environment: A review of the impact of physical environmental factors on users. *Building and environment*. 2012;58:70-80.
 173. Duffin E. Average household size worldwide, by region 2019: Statistica; 2019 [Available from: <https://www.statista.com/statistics/1090668/average-household-size-worldwide-by-region/>].

174. Rodriguez NM, Casanova F, Pages G, Claire L, Pedreira M, Touchton M, et al. Community-based participatory design of a community health worker breast cancer training intervention for South Florida Latinx farmworkers. *PloS one*. 2020;15(10):e0240827.
175. Maloney KM, Bratcher A, Wilkerson R, Sullivan PS. Electronic and other new media technology interventions for HIV care and prevention: a systematic review. *Journal of the International AIDS Society*. 2020;23(1):e25439.
176. Ballard M, Bancroft E, Nesbit J, Johnson A, Holeman I, Foth J, et al. Prioritising the role of community health workers in the COVID-19 response. *BMJ Glob Health*. 2020;5(6).
177. Karim QA, Kharsany AB, Frohlich JA, Werner L, Mashego M, Mlotshwa M, et al. Stabilizing HIV prevalence masks high HIV incidence rates amongst rural and urban women in KwaZulu-Natal, South Africa. *International journal of epidemiology*. 2011;40(4):922-30.
178. Auvert B, Taljaard D, Lagarde E, Sobngwi-Tambekou J, Sitta R, Puren A. Randomized, controlled intervention trial of male circumcision for reduction of HIV infection risk: the ANRS 1265 Trial. *PLoS medicine*. 2005;2(11):e298.
179. Bailey RC, Moses S, Parker CB, Agot K, Maclean I, Krieger JN, et al. Male circumcision for HIV prevention in young men in Kisumu, Kenya: a randomised controlled trial. *The lancet*. 2007;369(9562):643-56.
180. Gray RH, Kigozi G, Serwadda D, Makumbi F, Watya S, Nalugoda F, et al. Male circumcision for HIV prevention in men in Rakai, Uganda: a randomised trial. *The Lancet*. 2007;369(9562):657-66.
181. Elgalib A, Al-Sawafi H, Kamble B, Al-Harthi S, Al-Sariri Q. Multidisciplinary care model for HIV improves treatment outcome: a single-centre experience from the Middle East. *AIDS care*. 2018;30(9):1114-9.
182. van der Elst EM, Smith AD, Gichuru E, Wahome E, Musyoki H, Muraguri N, et al. Men who have sex with men sensitivity training reduces homophobia and increases knowledge among Kenyan healthcare providers in coastal Kenya. *Journal of the International AIDS Society*. 2013;16(Suppl 3):1-9.

8 Appendices

Appendix 1 : Ethics approval certificate



Faculty of Health Sciences

The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.

- FWA 00002567, Approved ~~dd~~ 22 May 2002 and Expires 03/20/2022.
- IRB 0000 2235 IORG0001762 Approved ~~dd~~ 22/04/2014 and Expires 03/14/2020.

16 October 2018

Approval Certificate New Application

Ethics Reference No.: 580/2018

Title: Effect of a ward-based outreach team and adherence game interventions on retention in care and virological suppression of HIV-infected patients newly initiated on antiretroviral treatment in Tshwane

Dear Mr S Ngoobo

The **New Application** as supported by documents received between 2018-10-02 and 2018-10-16 for your research, was approved by the Faculty of Health Sciences Research Ethics Committee on its quorate meeting of 2018-09-26.

Please note the following about your ethics approval:

- Ethics Approval is valid for 1 year and needs to be renewed annually by 2019-10-16.
- Please remember to use your protocol number (580/2018) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, monitor the conduct of your research, or suspend or withdraw ethics approval.

Ethics approval is subject to the following:

- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

Additional Conditions:

- ☐ Recommend conditional approval, pending receipt of permission letters from CEO from the 48 clinics and add in the ICD, will the participant be compensated for taking part in the study

We wish you the best with your research.

Yours sincerely

Dr R Sommers

MBChB MMed (Int) MPharmMed PhD

Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by

Research Ethics Committee
Room 4-60, Level 4, Tswelopele Building
University of Pretoria, Private Bag X323
Arcadia 0007, South Africa
Tel +27 (0)12 356 3084
Email deepeka.bahari@up.ac.za
www.up.ac.za

Fakulteit Gesondheidswetenskappe
Lefapha la Disaense tša Maphelo



Faculty of Health Sciences

Institution: The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.

- FWA 00002567, Approved dd 22 May 2002 and Expires 03/06/2023.
- IORG #: IORG0001762 OMB No. 0560-0279 Approved for use through February 28, 2022 and Expires: 03/04/2023.

Faculty of Health Sciences Research Ethics Committee

15 October 2021

Approval Certificate Annual Renewal

Dear Mr S Ngcobo

Ethics Reference No.: 580/2018

Title: Effect of a ward-based outreach team and adherence game interventions on retention in care and virological suppression of HIV-infected patients newly initiated on antiretroviral treatment in Tshwane

The Annual Renewal as supported by documents received between 2021-09-15 and 2021-10-13 for your research, was approved by the Faculty of Health Sciences Research Ethics Committee on 2021-10-13 as resolved by its quorate meeting.

Please note the following about your ethics approval:

- Renewal of ethics approval is valid for 1 year, subsequent annual renewal will become due on 2022-10-15,
- Please remember to use your protocol number (580/2018) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, monitor the conduct of your research, or suspend or withdraw ethics approval.

Ethics approval is subject to the following:

- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

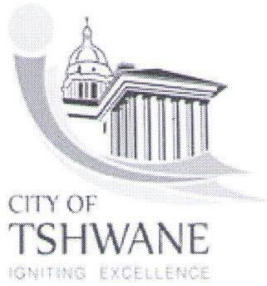
We wish you the best with your research.

Yours sincerely

On behalf of the FHS REC, Professor Werdlie (CW) Van Staden
MBChB, MMed(Psych), MD, FCPsych(SA), FTCL, UPLM
Chairperson: Faculty of Health Sciences Research Ethics Committee

¹⁸ The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes, Second Edition 2015 (Department of Health)

Appendix 2: Approval from City of Tshwane



Annexure 1

DECLARATION OF INTENT FROM SKILLS DEVELOPMENT FOR TSHWANE MUNICIPAL CLINICS

I give permission to **Mr Sanele Ncobo** to do his Research On **Effect of a ward-based outreach team and adherence game interventions on retention in care and virological suppression of HIV-infected patients newly initiated on antiretroviral treatment in Tshwane**

Other comments or conditions prescribed by the PHC Manager to the Researcher are

Kindly make arrangements with the facility Managers for appointments and introduction of the study. Clinic list attached with contact details

Ms Pinkie Lesolang

Deputy Director: Skills Development

Date: 2018.10.29.

Appendix 3: Clearance certificate from Tshwane Research Committee



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Enquiries: Mpho Moshime-Shabagu
Tel: +27 12 451 9036
E-mail: Mpho.Moshime@gauteng.gov.za

TSHWANE RESEARCH COMMITTEE: CLEARANCE CERTIFICATE

MEETING: 10/2018
PROJECT NUMBER: 71/2018
NHRD REFERENCE NUMBER: GP_201809_030

TOPIC: Effect of a ward-based outreach team and adherence game interventions on retention in care and virological suppression of HIV-infected patients newly initiated on antiretroviral treatment in Tshwane

Name of the Researcher: Mr. Ngcobo Sanele
Name of Supervisor: Prof Theresa Rossouw
Facility: Tshwane District & City of Tshwane Facilities
Name of the Department: University of Pretoria

NB: THIS OFFICE REQUEST A FULL REPORT ON THE OUTCOME OF THE RESEARCH DONE AND

NOTE THAT RESUBMISSION OF THE PROTOCOL BY RESEARCHER(S) IS REQUIRED IF THERE IS DEPARTURE FROM THE PROTOCOL PROCEDURES AS APPROVED BY THE COMMITTEE.

DECISION OF THE COMMITTEE: APPROVED

.....
Ms. Mpho Moshime-Shabagu
Acting Chairperson: Tshwane Research Committee

Date: 11/05/18

.....
Mr. Mothomone Pitsi
Chief Director: Tshwane District Health

Date: 2018.11.05

Appendix 4: Approval from PHC manager for Tshwane provincial clinics

Annexure 1



DECLARATION OF INTENT FROM THE PHC MANAGER FOR TSHWANE PROVINCIAL CLINICS

I give preliminary permission to **Mr. Sanele Ngcobo** to do his or her research on
“Effect of a ward-based outreach team and adherence game interventions on retention in care and virological suppression of HIV-infected patients newly initiated on antiretroviral treatment in Tshwane” in **Tshwane District Health Facilities**

I know that the final approval will be from the Tshwane Regional Research Ethics Committee and that this is only to indicate that the clinic/hospital is willing to assist.

Other comments or conditions prescribed by the PHC Manager to the Researcher are

Kindly have an entry meeting with Facility Manager before starting with your study for Local Government, kindly contact the COT Management.

M. MAKHUDU (Mr.)
PRIMARY HEALTH CARE: TSHWANE
Date: 26/10/2018