

TOWARDS A PATIENT-CENTRED UNDERSTANDING OF ENGAGEMENT IN MEDICAL CARE AMONG ADULTS DIAGNOSED WITH HIV IN SOUTH AFRICA

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DECLARATION

This thesis is submitted in the integrative narrative format, approved by the Faculty of Health sciences.

I, **Tonderai Mabuto**, declare that this thesis is my original work. Where there has been contribution from other people, this has been duly acknowledged. It is being submitted for the degree of Doctor of Philosophy in Public Health in the University of the Witwatersrand, Johannesburg, South Africa. It has not been submitted before for any degree or examination at this or any other University.

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Signature: 

Date: 27 July 2020

DEDICATION

I dedicate this work to future generations,

To those that will live in a world where HIV is no longer a public health threat,

To societies that will receive HIV care services that place them at the centre,

It's a realisable future which starts today.

ACKNOWLEDGEMENTS

This work would not have been possible without my support system - the endurance from my family, the encouragement from my colleagues and the invaluable guidance from my supervisors. I also acknowledge the researchers who have gone before me, those who have created a platform for my own work. The studies for my thesis were supported by generous grants from Fogarty International, United States Agency for International Development, Population Council, and The Aurum Institute.

LIST OF ORIGINAL PAPERS

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ABSTRACT

Background: The availability of simple and well-tolerated antiretroviral therapy (ART) makes early initiation of lifelong HIV treatment practical and safe. However, attempts to identify pragmatic and effective strategies to overcome challenges to early and sustained engagement in HIV medical care in sub-Saharan Africa have yielded limited success. Understanding HIV medical care-seeking behaviour has become an increasingly important area of research, as guidelines and national policies throughout the world are calling for universal access to ART with rapid initiation of therapy after diagnosis.

Methods: This thesis draws upon five studies to identify the contextual factors that influence patient-level decisions for engagement in HIV medical care among adults diagnosed with HIV and to explore how each of the identified factors plays a role in shaping healthcare-seeking decisions. The first study is a quantitative analysis of factors associated with linkage-to-care within 180 days of receiving an HIV diagnosis, among ART-eligible participants diagnosed through community-based mobile HIV testing services (HTS). The second study explores how contextual factors influence the way ART-eligible individuals ascribe meaning to their HIV diagnosis and their perceptions on the value of HIV medical care. The third study is based on in-depth longitudinal interviews to explore how perceptions of clinic-level costs, influence engagement in HIV medical care. The last two studies examine the content and delivery of interpersonal health communication within the context of a pragmatic randomised trial and routine clinic settings. I apply regression techniques for quantitative data and thematic approaches to qualitative data analysis to address my thesis objectives.

Results: This doctoral research adds to the existing literature on linkage-to-care by contextualising individual-level healthcare-seeking decisions within a structured framework that brings together explanatory behaviour models and social-ecological levels. From the quantitative analyses, I learnt that just over half of the participants who knew their eligibility to initiate ART when they were diagnosed, engaged in HIV medical care within the first 180 days of receiving their diagnosis. I identified disclosure of HIV status as a facilitator for linkage-to-care, a greater effect of disclosure on linkage-to-care for men than women. Study findings also highlighted the additional role of repeat HIV testing as a tool for facilitating linkage-to-care among PLHIV aware of their status, who had not engaged in care. On the contrary, being in a relationship was a risk factor for failure to enter care within 180 days of receiving an HIV diagnosis. Our qualitative work further revealed how the 'processing' of the HIV diagnosis and perceptions of the value placed on ART, are still essential factors even among individuals who qualify for ART. From a value-cost perspective, I learnt that the way HIV medical care services are delivered in public sector clinics can escalate the costs of linkage-

to-care and shift the balance further away from care engagement. Worryingly, this also affected people motivated to engage in HIV medical care. Also, our study findings suggest that structured approaches to longitudinal case management support have the potential to improve linkage-to-care. Yet, our review of transcripts of post-test counselling sessions for HIV-positive clients in public sector clinics creates a concerning picture as the content and delivery of post-test counselling falls short of promoting the current goals of universal test and treat.

Conclusion: There is an urgent need to reengineer HIV medical care delivery towards patient-centred approaches which promote the value PLHIV place of medical care while identifying pragmatic approaches to reduce the costs of engaging in medical care. Without addressing costs and assuring perceptions of the value of clinical care, the number of people engaging in HIV medical care is likely to fall short of the 90-90-90 goals.

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ABBREVIATIONS

AHR	Adjusted Hazard Ratio
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral Drugs
CDC	Centres for Disease Control
CFI	Conditional Financial Incentives
CHC	Community Health Care Centres
CI	Confidence Interval
COM-B	Capability Opportunity Motivation Behavioural Framework
DNA	Deoxy-Ribonucleic Acid
F	Female
FDC	Fixed Dose Combination
GPS	Global Positioning System
HIV	Human Immunodeficiency Virus
HIV-1 M	HIV-1 “Major” Subtype
HR	Hazard Ratio
HTS	HIV Testing Services
M	Male
mL	Millilitre
mm ³	Cubic Millimetre
MSM	Men Who Had Sex with Men
MTC	Mother-to-child
n	Number
NGO	Non-Governmental Organisations
NHLS	National Health Laboratory Service
NSP	National Strategic Plan For HIV, TB and STIs 2017 – 2022
OR	Odds Ratio
PEPFAR	President’s Emergency Plan for AIDS Relief
PHC	Primary Health Care Centre
PICT	Provider-Initiated Counselling and Testing
PLHIV	People Living with HIV
PMTCT	Prevention of Mother to Child Transmission

POC	Point-Of-Care
RCT	Randomised Controlled Trial
RD	Risk Difference
RNA	Ribonucleic Acid
RR	Relative Risk
SEARCH	Sustainable East Africa Research in Community Health
SOC	Standard of Care
STI	Sexually Transmitted Infection
TaSP	Treatment as Prevention
TB	Tuberculosis
TDF	Theoretical Domains Framework
UNAIDS	Joint United Nations Programme On HIV/AIDS
US	United States
USAID	United States Agency for International Development
WHO	World Health Organisation
y	Years
ZAR	South African Rand

CHAPTER 1 : INTRODUCTION

1.1 Background

1.1.1 Brief historical overview

What was first reported as a rare immune disorder among a few hundred cases in the early 1980s [1,2], later swept across the rest of the world to become one of the largest epidemics which the world has grappled with over the past four decades. In 1982, this rare immune disorder became known as Acquired Immune Deficiency Syndrome (AIDS) [3], and about a year or two later the etiologic agent for this syndrome was identified as the Human Immunodeficiency Virus (HIV) [4-6]. Since then, more than 75 million people globally have been infected with HIV, and about 32 million people have died of AIDS-related illnesses [7,8]. At the end of 2018, approximately 37.9 million people were living with HIV worldwide, and just over two-thirds of these lived in sub-Saharan Africa [9]. The past couple of decades have witnessed considerable progress in reducing the number of new HIV infections and AIDS-related deaths [9]. However, the global HIV response is currently off-track in meeting the targets set in 2016, when global leaders in the United Nations General Assembly signed a political declaration of accelerating efforts to end the HIV epidemic by 2030 [10].

1.1.2 The lifecycle of HIV in the human host

HIV belongs to the family of retroviruses which insert copies of their genetic material into that of the host cell they invade [11,12]. When HIV enters the human host, it preferentially invades CD4 T-cell lymphocytes (CD4 cells), which have the primary role of stimulating other immune cells to fight infection [13,14]. HIV uses its surface proteins to bind and fuse with the CD4 cell membrane before it enters and infects the host cell. Inside the CD4 cell, HIV converts its genetic material from ribonucleic acid (RNA) to deoxyribonucleic acid (DNA). Through this process, HIV integrates its viral genetic material into that of the CD4 cell [15]. With the viral DNA integrated, the CD4 cell begins to produce viral proteins which form new virus particles that bud off and infect other cells [15]. The infected host CD4 cells become dysfunctional, and after four to eight days of being invaded by HIV, the body's immune system destroys them [16,17]. As the number of CD4 cells begins to decline, the person's immune system becomes weaker [18].

In the very early stages of HIV infection (acute phase), the number of viral particles in the blood may reach levels of $10^5 - 10^9$ viral copies/ml [19]. In response, the body produces HIV-specific antibodies which work through various mechanisms, such as neutralising free viral particles and infected CD4 cells [20]. The body's immune response reduces the amount of virus in the body (viral load) and increases the number of functional CD4 cells [21]. However,

without effective medication to control HIV replication, the viral load will eventually rise to levels that severely compromise the immune system [20,22]. A weak immune system increases the body's susceptibility to diseases from pathogens (known as 'opportunistic infections') that would typically be controlled by a healthy immune system. This late stage of HIV infection is known as AIDS, and without HIV medicine, people with AIDS generally survive about two to three years [22,23].

1.1.3 The diagnosis of HIV

Early identification of people living with HIV (PLHIV) coupled with timely HIV treatment is critical to reducing AIDS-related illness, AIDS-related deaths, and HIV transmission. In most countries, healthcare providers diagnose HIV using point-of-care (POC) rapid diagnostic tests which detect the presence of HIV-specific antibodies in the blood [24,25]. It takes about 3 to 12 weeks after acute infection before POC-HIV tests can accurately diagnose HIV [26]. However, they are cheap, easy to perform, provide accurate results, and most produce results within 15 -20 minutes of starting the test [27].

Over the past decade, HIV programs have employed a mix of community- and clinic-based approaches to promote universal and equitable access to HIV testing services (HTS) [28]. Examples of community-based HTS approaches include mobile-van testing, home-based testing, fixed community HTS sites, self-testing and index partner services. These approaches reach persons less prone to utilise clinic services, those with a low perceived risk of HIV infection, and those who are unlikely to have ever tested for HIV [29-32]. On the other hand, clinic-based testing approaches have become more proactive. In most countries, the recommended practice is for clinic staff to offer HTS to clinic attendees who may not be seeking HIV testing services - commonly referred to as 'provider-initiated counselling and testing' (PICT) [33-35]. There is evidence of high acceptability and uptake of PICT by clinic attendees and a high yield of newly identified HIV-positive persons through this approach [36,37]. More importantly, PICT reaches individuals who are already seeking clinical care and testing and treatment services are co-located in the same facility. Possibly, for this reason, individuals diagnosed through clinic-based HTS are more likely to continue into HIV medical care compared to those diagnosed through community-based HTS [30]. More recently, the roll-out of HIV self-testing in both health facilities and communities has shifted the locus of control from healthcare providers to the general population, which has increased access to HTS even further [38,39].

1.1.4 Antiretroviral therapy

Currently, there is no cure for HIV. However, healthcare providers can clinically manage PLHIV by providing antiretroviral drugs (ARVs) which interfere with the HIV lifecycle in the

human host [40-43]. ARVs mostly target key HIV enzymes required for viral replication: (1) reverse transcriptase enzyme – necessary for the early stages of HIV replication, (2) integrase enzyme – essential for the integration of proviral DNA into host cell DNA, or (3) protease enzyme– necessary for the assembly and maturation of small viral protein chains into infectious viral particles [44-47]. Currently, clinicians use a combination of two or more ARVs from different classes as part of combination antiretroviral therapy (ART) for the management of PLHIV [48].

By 1995, ART was available in several high-income countries. However, the expansion of ART coverage in most low to middle-income countries, only began when the generic manufacturing of ARVs started in 2001 [49,50]. In countries such as South Africa, ART scale-up was further delayed due to lack of political will to support and fund ART programmes [51,52]. With the scale-up of ART globally, AIDS-related illnesses and deaths have declined, particularly in the sub-Saharan African region, which carries the substantial burden of the HIV epidemic. Further, ART has demonstrated by far, the most sizeable impact on reducing HIV transmission in randomised controlled trials [7,53,54]. The prevention benefits of ART have opened the era of new public health ART approaches, commonly referred to as ‘universal test-and-treat’ (UTT) or ‘treat-all’. Under UTT, all persons diagnosed HIV-positive are eligible to initiate ART irrespective of the CD4 count or any other staging criteria previously used to determine when to start ART [55].

The significant increases in both domestic and international funding, have facilitated the expansion of routine HIV programmes in most high-burden countries towards UTT policies [7,9]. The two primary sources of international financing for most high-burden countries are The United States President’s Emergency Plan for AIDS Relief (PEPFAR) and the multilateral Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) [7,9]. Since 2003, PEPFAR has funded the expansion of HIV programmes and still supports about 53 countries towards the goal of ending the HIV epidemic [56]. Domestic investment (private and government) also contributes a significant portion to HIV programme budgets. For example, in eastern and southern Africa, domestic investment accounted for about US\$4.5 billion (42%) of the US\$ 10.6 billion available for HIV programmes in 2017 [9].

1.1.5 Measuring the success of HIV programmes

In 2014, the Joint United Nations Programme on HIV/AIDS (UNAIDS) developed a global blueprint to accelerate the pace towards ending the HIV/AIDS epidemic by 2030 [57]. This blueprint is widely known as the 90-90-90 cascade, and it provides a framework which views HIV medical care services along a cascade or a care continuum, to achieve virologic suppression among people aware that they are living with HIV [57]. Each ‘90’ represents a

specific programme target. The goal of the ‘first 90’ is to ensure that 90% of all PLHIV know their HIV status. The goal of the ‘second 90’ is to ensure that 90% of all PLHIV with diagnosed HIV infection receive ART. Lastly, the goal of the ‘third 90’ is to ensure that 90% of all PLHIV receiving ART, achieve virologic suppression. If the 90-90-90 targets are met, 81% of all PLHIV will be on ART, and 73% of all PLHIV will have virologic suppression (Figure 1-1) [57]. Mathematical models predict that achieving this scenario will avert 28 million new HIV infections globally, between 2015 and 2030. Further, such an impact will translate to annual savings of US\$ 24 billion in HIV medical care and treatment service costs [57].

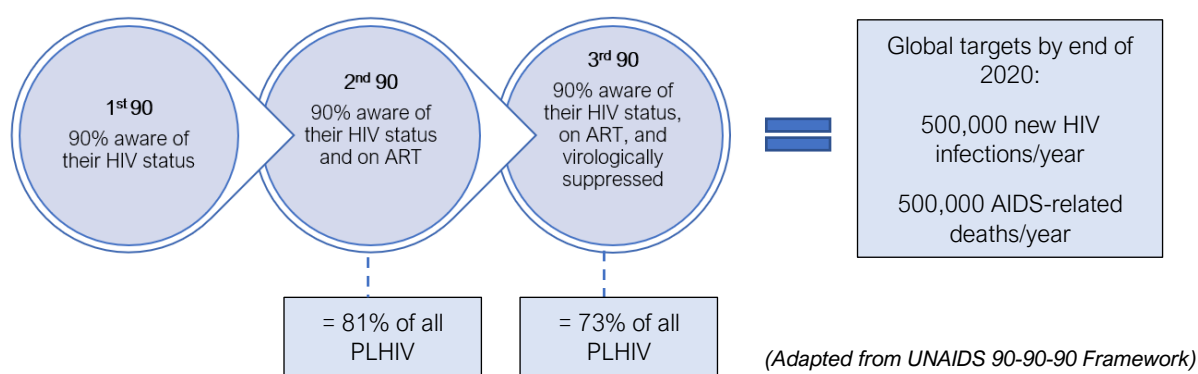


Figure 1-1: Goals for the 90-90-90 cascade

1.1.6 Gaps in linkage-to-care following diagnosis

At the end of 2018, about 79% of PLHIV worldwide were aware that they were living with HIV [9]. Although HTS coverage among men, adolescents, and young adults is still sub-optimal, many countries are on course to achieving the targets of the first-90 [9]. However, most countries are off-track in meeting the goals of second-90 (i.e. ART initiation among PLHIV aware of their status). In this regard, only 78% of PLHIV who knew their status in 2018, were estimated to be receiving ART; translating to a meagre 62% of all PLHIV being on ART (Figure 1-2) [9].

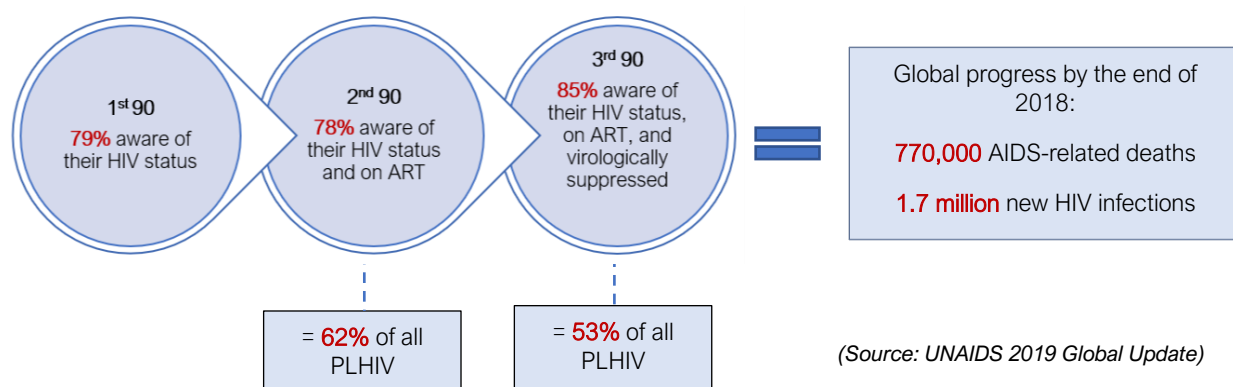


Figure 1-2: State of the global 90-90-90 cascade in 2018

1.1.7 The unique nature of healthcare-seeking decisions

There are essential caveats to the use of the 90-90-90 cascade in guiding the delivery of HIV services. Similar to other biomedical perspectives to healthcare, the 90-90-90 cascade, provides a structure for decision making, and a pathway for actions that need to be performed by the patient to ensure the best outcomes [58,59]. However, an individual's life trajectory following HIV diagnosis rarely moves in a simplified linear manner. Instead, the period following diagnosis is often complicated and involves making several decisions such as appraising the personal significance of living with HIV, whether to respond to the diagnosis, and if so - how to respond to the diagnosis [60,61].

Generally, when people make decisions, they assign more weight to the options that align with their value systems or those that propel them towards the goals they desire to achieve [62]. This notion of 'anticipated or perceived benefit' is widely considered as a primary construct of behavioural intent or action in most health behaviour theories [63,64]. Several qualitative studies have shown how PLHIV place value on ART to re-build their expectations and plans for the future, maintain social- and self-identity, avert social isolation, or relieve disruptive symptoms [65]. Importantly, where close alignment exists between the biomedical benefits of ART and the patient's values or goals, then the expected utility or value of HIV medical care will likely be high [66]. Consequently, this may increase the chances of engagement in HIV medical care. However, the value placed on HIV medical care is insufficient on its own to influence an individual's decision to go to a clinic for medical care [66-68]. Equally important are the the material and psychological costs that an individual perceives they may incur when engaging in HIV medical care [69]. These costs extend beyond financial outlays (e.g. transport costs or lost wages) and may include the risk of involuntary HIV status disclosure and related stigmatization in the community; the internalised shame of being associated with ART or attending clinic; and even the burden of pill taking itself [65,70]. How different individuals identify or assign a weight to these costs is a highly subjective process. Besides, perceptions of costs may be influenced by prior experiences of accessing medical care services; observing or hearing about other people's experiences; as well as the individual's emotional states or their most immediate dominating thoughts at the time of assessing costs [66].

1.1.8 The influence of context on healthcare-seeking decisions

A dynamic interaction exists between the person living with HIV, their environment, and the behaviour they seek to perform [71,72]. Ecological models provide a conceptual base for these interactions and a foundation for the design and evaluation of public health programmes [73-75]. One such model is the social-ecological model which accounts for the

contextual influences on healthcare behaviours at five different levels: individual-level, interpersonal-level, clinic-level, community-level, and policy-level (Figure 1-3) [76].

- Individual-level factors relate to an individual's traits and identities, which include attitude, perceptions of physical health, health self-efficacy, personal beliefs, general chronic illness care, outcome expectancies, and resources such as time and money to get to the clinic [72].
- At the interpersonal level, relationships and the social networks that an individual participates in may mediate the perceptions of values or costs for engaging in HIV medical care [70,77].
- At the clinic level, the accessibility of clinic services and how they are delivered is essential to how individuals assess the costs of engaging in HIV medical care. For example, HIV medical care that requires long waits, or that enacts stigma, increases the costs of care engagement which may outweigh the value placed on HIV medical care [65,78].
- At the community level, individual decision making may be influenced by the community structures and norms that are often important in determining how the individual as a community member behaves and the customs they uphold [72,79].
- Lastly, the institution of policies at various administrative levels, constitute the broadest level of the socio-ecological model. Policies play a critical role on how HIV medical care is delivered (i.e. when to initiate ART, prescription practices for ART, user fees, clinic operating hours, or access to health care by marginalized populations etc.) [80,81].

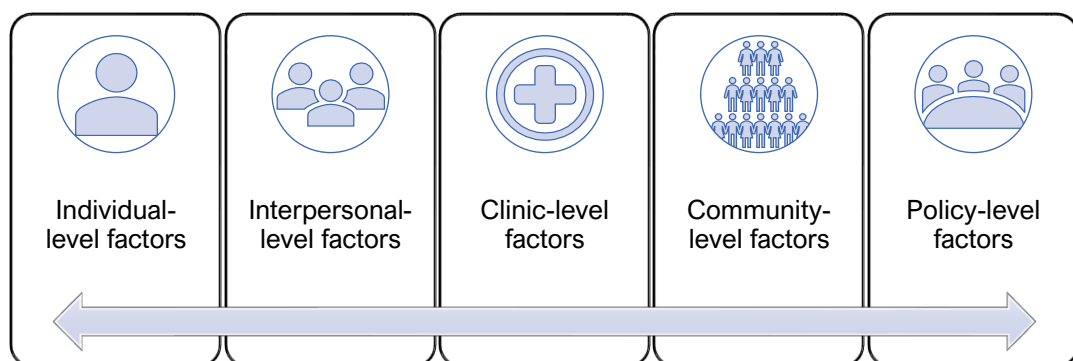


Figure 1-3: Contextual levels of the social-ecological model [76]

1.1.9 Mutual participation in healthcare-seeking decisions

Following HIV diagnosis, healthcare providers have an essential responsibility to discuss with their clients about the available health-protective products such as ART and guide their

clients towards decisions that enhance health. In this regard, healthcare providers need to establish collaborative partnerships with their clients to ensure that they are respectful of their clients' rights to make decisions about their care. In turn, this creates a platform for effective interpersonal communication in the dyad [82,83]. Further, to create an enabling environment for effective interpersonal communication, healthcare providers should seek to understand the client's immediate concerns and most salient needs, in response to the HIV diagnosis. A shared understanding of the client's concerns and needs will allow healthcare providers to provide relevant health education and health promotion messaging. By giving health messaging that is as relevant as possible, healthcare providers maximise the chances of bringing the client to move more rapidly from testing HIV-positive to engaging in care [25,84].

1.2 Justification for the research

Although ending the HIV epidemic as a public health threat over the next decade remains ambitious, it is not out of reach. According to UNAIDS goals, by the end of 2020, less than 500,000 new infections per year and fewer than 500,000 deaths per year are expected globally [9]. However, current global efforts fall short of achieving these targets due to the significant attrition between HIV diagnosis and initial engagement in care, and further losses at later stages of the care continuum [9]. Despite the extensive literature on known barriers and facilitators for linkage-to-care, only a few strategies have been demonstrated to be effective in reducing the substantial attrition that occurs between HIV diagnosis and initial engagement in care [30,70,85-88]. Additional research that provides simplified and alternative conceptualisation to this problem is required to reveal the underlying ways each of these identified barriers and facilitators play the role they do. Such evidence may improve the development of effective interventions which are urgently required to increase the uptake of ART and subsequent virologic suppression among PLHIV.

This research is conducted in South Africa, a country with the largest burden of HIV globally [9]. Based on the most recent national survey conducted in 2017, there were an estimated 231,000 new infections across all ages and 7.9 million people of all ages living with HIV in South Africa [89]. Despite the progress made in South Africa from the time HIV/AIDS was declared an epidemic in 1992; current programme efforts are inadequate to achieve the goals set out in South Africa's National Strategic Plan for HIV, TB and STIs 2017 – 2022 (NSP) [89,90]. These goals include meeting the 90-90-90 targets and reducing the number of new infections to less than 100,000 per year, by the year 2022 [90].

Although South Africa has the most extensive ART programme globally, with about 4.4 million PLHIV on ART; this only represents 71% of the people who know they are living with HIV and only 58% of all PLHIV in South Africa [89]. Equally concerning, men significantly lag in accessing ART compared to women (Figure 1-4). In particular, only an estimated 68% of males aged 15 – 64 years who are aware of their HIV status are on ART (i.e. 53% of all males living with HIV aged 15 -64 years). In comparison, an estimated 72% of females aged 15 – 64 years aware of their HIV status are on ART (i.e. 64% of all females living with HIV aged 15 -64 years) [89]. Once on HIV treatment, about 88% of all ART patients in South Africa achieve virologic suppression (i.e. viral load levels of less than 1000 RNA copies/millilitre (mL)). Still, with low ART coverage, only 62% of all persons who know they are living with HIV are virologically suppressed [89].

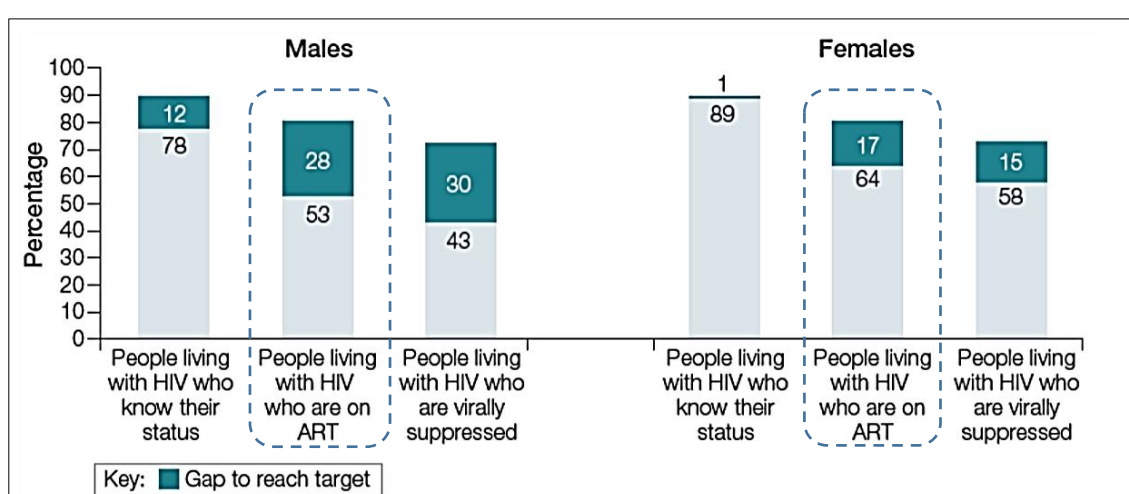


Figure 1-4: 90-90-90 indicators for PLHIV aged 15-64 years, South Africa, 2017 [89]

1.3 Conceptual framework

Conceptualising how persons diagnosed with HIV make healthcare-seeking decisions beyond the biomedical frameworks of HIV pathophysiology, may assist healthcare providers and policymakers in developing effective strategies to improve linkage-to-care. This thesis considers a patient-centred perspective to explore the barriers and opportunities for bridging the gap between HIV diagnosis and linkage-to-care. To explore these issues, we used a conceptual framework built on three core constructs of patient-centred care, described below and illustrated in Figure 1-5 [91].

Construct 1: Each person diagnosed with HIV is unique. A person diagnosed with HIV will subjectively assign a level of personal significance to the HIV diagnosis based on how he or she perceives the HIV diagnosis as a threat to individual values and goals [60,92,93]. The subsequent decisions on whether to engage in HIV medical care, are also based on personal evaluations which consider the values and costs of engaging in HIV medical care [66].

Construct 2: There is a dynamic interaction between the person diagnosed with HIV, their environment, and the behaviour they seek to perform. A person's context mediates their individual healthcare-seeking decisions [63,72,94,95]. From appraising the level of the personal significance of the diagnosis to assessing the values and costs of engaging in medical care, all these decisions are rooted in the person's context. A person's context may include their interpersonal relationships, the community they live in, the availability and accessibility of HIV medical care services, or the policies which govern HIV medical services [72,96-98].

Construct 3: Care that places the patient at the centre through mutual patient-provider collaboration leads to better outcomes. HIV medical care that puts the patient at the centre allows the patient to participate in and take ownership of their care. Such care hinges on strong therapeutic alliances built on effective interpersonal health communication and collaborative provider-client relationships [82,83,99-101].

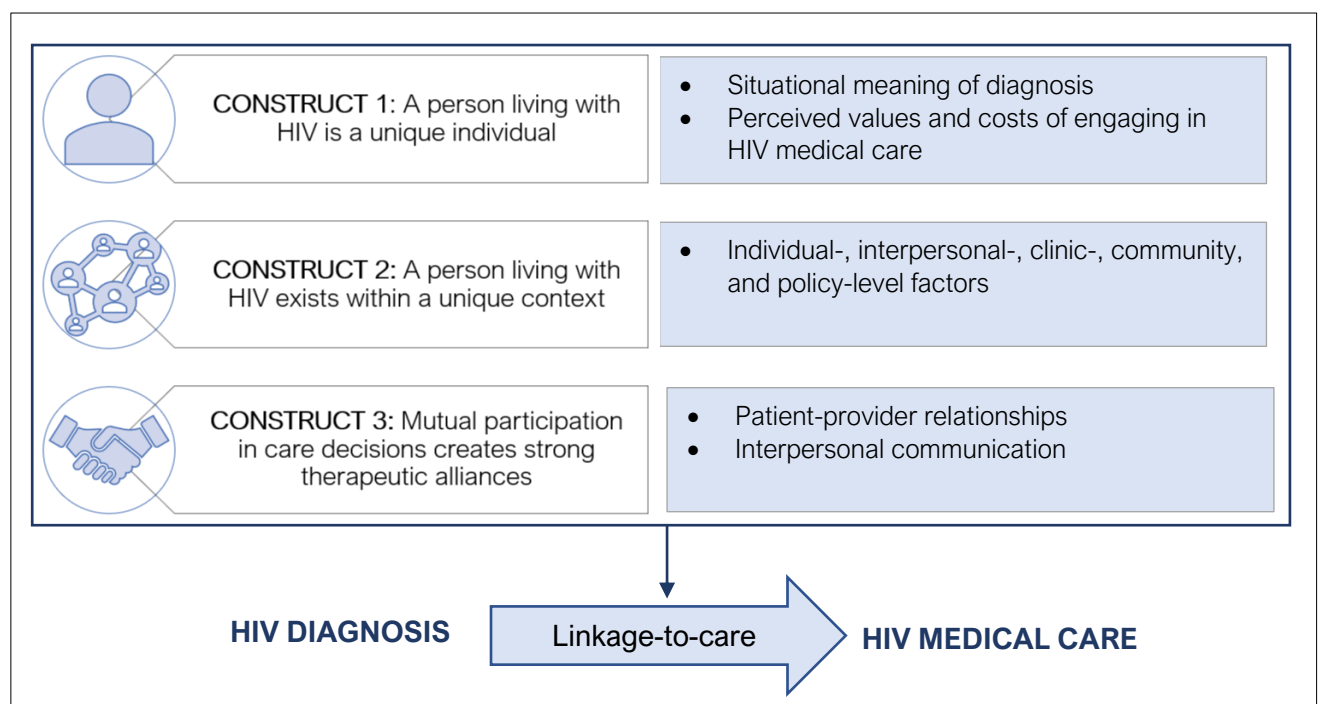


Figure 1-5: Conceptual Framework

As a caveat, this conceptual framework builds on cognitive aspects of individual decision making that can be observed or described. However, unconscious drives, such as emotion or intuition, also drive some healthcare decisions. For such choices, there is no transparent cognitive process for decision making nor a basis of judging whether the decision is perceived to have been the most appropriate [63,64].

1.4 Overall aim and specific objectives

The overarching objective of this study is to identify the individual- and contextual-level factors that influence decisions for individuals diagnosed with HIV to engage in medical care following HIV diagnosis. Further, we seek to explore how the identified factors play the role they do in influencing healthcare-seeking decisions. This will help inform the development and support of public health programmes and policy. The specific objectives are:

1. To determine the factors associated with linkage-to-care within 180 days of receiving an HIV diagnosis among ART-eligible participants diagnosed through community-based mobile HIV testing units.
2. To explore how contextual factors, influence the appraisal of values and costs of engaging in HIV medical care following HIV diagnosis through community-based mobile testing units.
3. To explore how interpersonal health communication between healthcare providers and persons diagnosed with HIV, influence engagement in medical care following HIV diagnosis.

1.5 Structure of the integrating narrative

Following the background provided in this introductory chapter, this thesis has four additional chapters outlined below:

- **Chapter 2** provides a synthesis of reviewed literature on critical components of the problem statement. I examine evidence on the extent of the linkage-to-care gap among PLHIV, factors associated with linkage-to-care, and the outcomes of interventions to improve linkage-to-care. In concluding this chapter, I synthesise key findings from the literature review and situate my study within the context of additional areas of research that are required to move the field forward.
- **Chapter 3** describes the methods used for this thesis. I describe the two primary studies on which form the basis of this thesis, my role on each of the primary studies, the link between this thesis and the primary studies, and the methods used in data analysis.
- **Chapter 4** presents the results from all three study objectives in a manner which provides a broad and coherent picture of issues explored in this thesis.
- **Chapter 5** provides a discussion of the study findings and their implications on HIV medical care service delivery and intervention development. I conclude the chapter outlining the proposed areas for future research.

CHAPTER 2 : LITERATURE REVIEW

2.1 Introduction

This literature review will focus on published findings from research studies and routine HIV programmes in sub-Saharan African settings; a region which accounts for more than half of the global HIV epidemic, and the context in which I conducted my research. As a point of departure, I commence the chapter by highlighting some caveats that are essential in interpreting these review findings, mostly relating to the heterogeneity of outcome measurement and ascertainment – a significant limitation in HIV care continuum research. Further, this review will provide a synthesis of linkage-to-care outcomes reported across various settings, factors associated with linkage-to-care, and the results of interventions to improve linkage-to-care. In concluding this chapter, I provide an overview of the broad themes arising from the literature review and situate this doctoral research within the additional areas of research required to fill evidence gaps.

2.2 Considerations for interpreting literature review findings

There are several terms used to describe the transition from HIV diagnosis to engagement in HIV medical care services. The most commonly used terms are linkage-to-care, entry-into-care, enrolment in care or engagement in care. Although some studies ascribe nuances to these terms, they generally imply a visit with an HIV medical provider following diagnosis, commonly at a fixed health facility (e.g. community clinics). However, this is slowly changing with increasing decentralization of HIV medical care service delivery to the community. In this thesis, I use these terms interchangeably to denote initial engagement in HIV medical care after HIV diagnosis.

There are limitations to the inferences in comparing linkage-to-care findings across studies. Firstly, there is variation across studies and programmes in the end-points and time intervals used to measure linkage-to-care. For example, time intervals used for reporting linkage-to-care, mostly range from the same day of HIV diagnosis (Day 0) to 12 months after HIV diagnosis [30,70,85-88,102]. In 2015, the World Health Organisation (WHO) published recommendations to standardise definitions and metrics of linkage-to-care [103]. WHO made recommendations for the following end-points: (1) the first clinic attendance date with HIV medical care, (2) CD4 count date, (3) ART start date, or (3) viral load date; and the reporting of these outcomes over a three-month (90 days) interval from the time of HIV diagnosis. Although the 90-day cut-off is not based on empiric evidence of its predictive ability for mortality or virologic suppression; it provides a balance between prompt ART initiation and allowing a person to adjust to their diagnosis and complete the referral processes to HIV

medical care services. However, regardless of the WHO recommendations, metrics for linkage-to-care remain variable.

Secondly, there is variation in how studies define who they include in their denominator or study population when evaluating linkage-to-care outcomes. For example, some studies only follow up people who are receiving an HIV diagnosis for the first time (i.e. newly-diagnosed). In contrast, others include all PLHIV diagnosed with HIV (i.e. both newly and previously diagnosed) who are not engaged in care. Although these differences appear subtle, findings from a recent systematic review show that studies which include both newly- and previously diagnosed participants report higher proportions of participants who enter care compared with studies that restrict eligibility to newly-diagnosed PLHIV [102].

Thirdly, there is significant variation in the ascertainment of linkage-to-care outcomes across studies, with many studies relying on the participant's self-report on whether they entered care or not. Due to social desirability bias and the inherent inaccuracies of asking participants to recall dates of events, participant self-report may overestimate both the proportion of participants who engage in HIV medical care and the timeliness with which the linkage happens [104]. Where linkage-to-care is verified, most studies rely on the patient's paper or electronic medical records. However, most studies cite incomplete patient records and challenges in accessing these records as challenges in reporting on verified linkage-to-care outcomes [97,105-107].

Lastly, several studies only describe the proportion of PLHIV linked to care at specific time points, without evaluating the time it takes from HIV diagnosis to initial engagement in care nor the cumulative probabilities of linkage-to-care over time [86,88,102,107]. Without time-to-event analyses, the seemingly high proportions of PLHIV engaged in HIV medical care at a single time point, mask the challenges of delays in linkage-to-care.

2.3 State of linkage-to-care in sub-Saharan Africa

Countries in sub-Saharan Africa which bear the brunt of the HIV epidemic, are confronted with challenges of PLHIV who delay or fail to engage in HIV medical care following diagnosis. In 2018, UNAIDS estimated that there were 20.6 million PLHIV in Eastern and Southern Africa; of these, 85% were aware of their HIV status, yet only 67% of those aware of their status were on ART [9]. From the same report, there were about 5 million PLHIV in Western and Central Africa; of these, 64% were aware of their status, and only 51% of these were on ART [9]. Several countries in Eastern and Southern Africa have conducted national household surveys in recent years, to assess progress towards achieving the 90-90-90 targets. Studies conducted in Eswatini (Swaziland), Lesotho, Malawi, South Africa, Tanzania,

Uganda, Zambia, and Zimbabwe suggest that some of these countries may be on course to meeting the UNAIDS target of 90% of those aware of their HIV status on ART. Across the eight countries, the proportion of PLHIV aware of their HIV status and on ART ranged from 70.6% - 90.9% [108-114].

Notwithstanding the progress that some countries have made in improving linkage-to-care, there is an essential caveat to the interpretation of findings which report the proportion of people on ART at a single time point. Such results paint an incomplete picture of the challenges that most countries still face with delays in linkage-to-care. It could be that PLHIV eventually initiate ART, but they may not be doing so early enough. This view is supported by evidence from systematic reviews of studies from sub-Saharan Africa, which show how people diagnosed with HIV have consistently linked to care at CD4 count levels well below the policy thresholds [115,116]. Notably, these delays in entering care are associated with an increased risk of mortality (including early death after starting ART), and longer time to virologic suppression, which increases the risk of onward transmission [117-120].

2.4 HIV testing approaches and linkage-to-care outcomes

Where people receive their HIV diagnosis, whether in the community or at a health facility (e.g. clinic or hospital), is essential when examining linkage-to-care issues [30,121,122]. Many health facilities that offer HTS have the convenience of having both diagnosis and treatment services in the same facility. However, the client may still need to move to another section of the facility to receive HIV medical care services. In contrast, most community-based HTS approaches require an HIV-positive client to go to a health facility for HIV medical care services after diagnosis. Unlike facility-based HTS clients who are already engaged in the medical system; when community HTS clients receive an HIV diagnosis, they are usually not seeking clinical care and may not otherwise utilise services from health facilities. Among the few studies and systematic reviews that have compared linkage-to-care outcomes between community-based and facility-based HTS approaches, most have reported inferior linkage-to-care outcomes among persons diagnosed through community-based HTS [30,121-123]. However, community-based HTS approaches remain valuable in reaching persons less prone to utilise clinic services, those who have a low perceived risk of being infected by HIV, and those who are unlikely to have ever tested for HIV [29,102,124].

One study conducted in South Africa, during the early stages of mobile HTS expansion, found that mobile HTS clients were less likely to link to care compared to clinic HTS clients (10% vs 72%, Odds Ratio (OR) = 0.05, 95% Confidence Interval (CI) = 0.03-0.07) [121]. Similarly, from rural communities in Tanzania, participants who tested through clinic-based HTS were almost twice as likely to enter care within the first six months of HIV diagnosis

compared to those who tested through mobile HTS (Hazard ratio (HR) = 1.78; 95% CI = 1.52–2.07) [123]. Also, it took clinic HTS clients a median of one day (Interquartile range (IQR) = 1–7.5 days) to enter care, compared with a median of 6 days (IQR = 3–11 days) among community HTS clients. Another study in Uganda reported similar results of a higher proportion of clinic HTS clients linking to care within three months compared to clients who had tested through home-based HTS (Risk difference (RD) = 12.1%; 95% CI = 7.8%–16.5%) [125]. Although facility-based HTS approaches appear to link more people into care compared with community-based HTS approaches; the reported outcomes are still sub-optimal for a population that is already seeking clinical services and engaged in the medical system [121,123,125]. Besides, findings from several studies suggest that clinic attendees who are offered HTS by healthcare providers, may be less likely to enter care after an HIV-positive diagnosis compared with clinic attendees who request HTS on their own [30]. Therefore, interventions are also required to optimise linkage-to-care among persons who are diagnosed in health facilities.

2.5 Factors associated with linkage-to-care

Understanding the factors which influence linkage-to-care, is an important starting point for identifying areas amenable for public health intervention. In this regard, ecological frameworks offer a wide lens to characterise these factors. Ecological frameworks are based on the premise that multiple levels of factors influence health behaviours, and these factors are interactive and reinforcing on each other [72]. This multi-level focus on health behaviour dates to the initial work of Bronfenbrenner in 1977 [126], which was refined by McLeroy et al. in 1988, into five levels of influence: individual-, interpersonal-, institutional-, community- and policy factors [95]. This view on health behaviour is also supported by other widely applied theories such as Bandura's social cognitive theory of 1986 which posits that the behaviour of an individual both influences and is influenced by personal factors and the social environment in which they exist [127]. Importantly, ecological frameworks simply offer a structure for characterizing factors associated with health behaviour, but do not postulate the mechanisms through which the factors interact in producing the observed behaviour. In this section, I review existing knowledge on factors associated with linkage-to-care organized according to McLeroy's five levels of the social-ecological model.

2.5.1 Individual factors

Individual-level factors occur at the level of a person diagnosed with HIV. At this level, the sex and age of persons diagnosed with HIV are among the most commonly reported factors associated with linkage-to-care. Most studies show that men are less likely to engage in care compared to women, and consistently demonstrate a positive trend of a higher likelihood of

linkage-to-care with increasing age [70,128]. Additional insights from qualitative studies suggest that men and younger individuals may be more prone to the stigma, which is a commonly reported correlate of delayed linkage-to-care [65]. Although there are various conceptualisations of stigma across studies, they mostly encompass emotions of fear, guilt and shame. Harboursing personal stigmatizing beliefs (internalized stigma), concerns of being prejudiced or discriminated based on HIV status (anticipated stigma), or experiences of discrimination on their HIV status (enacted stigma), are consistently reported as significant barriers to timely linkage-to-care [65,129,130]. In contrast, PLHIV who have high social support and voluntarily disclose their HIV status are more likely to engage in care by enlisting support from their social networks [98,131,132].

Also, how a person perceives their health status at the time of diagnosis is a commonly cited risk factor for linkage-to-care. PLHIV who have signs and symptoms of advanced immunodeficiency are more likely to enter care compared with individuals who are asymptomatic or perceive themselves to be healthy [70,98,105,133]. Findings from qualitative findings suggest that PLHIV who see themselves as being healthy, are likely to place less value in the future benefits of engaging in care to preserve their health [98,134,135]. This barrier is particularly crucial for community-based HTS approaches which are likely to identify asymptomatic PLHIV and reach younger individuals who are more prone to discounting the future value of engaging in HIV medical care services.

Non-medical care practices based on cultural and religious beliefs are widely practiced in sub-Saharan Africa and are a competing alternative to medical HIV medical care services [136,137]. Studies have reported how some PLHIV ascribe alternative aetiologies (e.g. being bewitched, or merely having bad blood) to AIDS-related illnesses, while others consider medical care as a futile solution to coping with HIV [65,134,138,139]. In several studies, PLHIV who start by seeking non-medical care services, eventually enter medical care usually at advanced stages of HIV disease [140-142].

Other individual-level factors reported to be associated with poor linkage-to-care include beliefs about the adverse side effects of ART, such as weight gain, changes in skin tone, or hallucinations [143]. Also, the skills and confidence required to navigate healthcare systems; availability of time and money to get to the health facility; and levels of education, are also reported to influence linkage-to-care outcomes [65,70,128].

2.5.2 Interpersonal factors

Interpersonal factors pertain to the relationships between a person diagnosed with HIV and others within their sphere of activity or life-space. A person can be linked to these people via

general communication, family relation, work, or other interests. PLHIV who disclose their status can leverage various forms of support from their social relationships, and this is usually associated with early engagement in care [98,144]. Supportive ties can assist with emotional support; tangible help or services such as transport money for clinic visits (instrumental support); provision of information or advice (informational support); or dialogue that allows the person to reflect on their health behaviours (appraisal support) [65,145].

Interpersonal relationships also include the interactions between PLHIV and their healthcare providers. Strong relationships between the patient and their healthcare provider are associated with high patient satisfaction and improved utilisation of medical services [146,147]. In HIV medical care, one of the first opportunities to develop these relationships is during the counselling sessions provided during the HIV testing encounter. After that, on-going support from healthcare providers which assists PLHIV to navigate the health care system and adapt to their diagnosis also promotes early linkage-to-care [84,148].

Other studies have also described the role of perceived social pressure that people diagnosed with HIV place upon themselves to enter care following disclosure of the HIV-positive status (i.e. subjective norms) [149-151]. Also, the weight of immediate examples that a person thinks about when contemplating engaging in care, carries an outsized impact on behaviour [65]. In this regard, studies have reported how individuals are positively influenced by people who they know to have engaged in HIV medical care and have become healthier or averted other highly disvalued states (e.g. economic unproductivity or social isolation). Conversely, if the immediate examples relate to negative experiences, it may lead to delays in linkage-to-care [65,98,138,152].

2.5.3 Institutional factors

Institutional factors pertain to structures and processes within HIV medical care facilities that influence utilisation of available care services. Generally, consumers of healthcare services subjectively assign value to different attributes of healthcare service delivery [153-155]. The commonly assessed traits which influence the utilisation of services include the reliability of healthcare services, as well as the responsiveness and empathy of healthcare providers [155]. The extent to which a person believes that their expectations from the healthcare experience will be met, is vital in forming their perceptions of the quality of healthcare services, and whether they will readily engage with the services [156-158]. In particular, long waiting times, multiple clinic visits, lack of privacy and/or confidentiality, and demeaning attitudes by service providers, raise barriers for timely linkage-to-care [65,70,128]. On the other hand, healthcare providers often attribute service delivery deficiencies to the low number of clinic staff who operate beyond recommended clinician to patient ratios. This

situation keeps worsening as current ART guidelines allow more PLHIV to access ART [159-161].

During the early days of the public sector ART rollout in sub-Saharan Africa, clinic-level factors contributed significantly to the low uptake of ART. High user fees for accessing ART, the small number of clinics offering ART, and few clinic staff trained to initiate and manage ART patients, were among the commonly cited barriers to engagement in care [162-164]. Although there have been substantial improvements in resolving these challenges, the delivery of HIV medical care services in sub-Saharan Africa continues to raise barriers to clinic attendance [128,165]. Even more worryingly, these barriers dissuade early engagement in care among individuals who are highly motivated to engage in HIV medical care services.

2.5.4 Community factors

Community-level factors pertain to how a person's membership in larger groups influences their health behaviours. Importantly, communities have norms which inform how a member should behave, whether stated or implied [149,166-168]. In some communities, negative perceptions of a local clinic spread by word-of-mouth may influence PLHIV in the community to seek HIV medical care services from distant clinics delaying entering care [65,78,97,169,170]. Also, people who live in communities where there is high HIV stigma, often take steps to avoid being seen at local clinics to circumvent disclosure. In extreme instances, PLHIV in such communities may fail to enter care, delay accessing care while looking for distant clinics, or end up accessing non-allopathic care which may be more private [65,129,171].

Cultural and gender norms in communities are also associated with linkage-to-care outcomes. In some communities, gender norms attached to masculinity inhibit men from early care engagement [172-175]. On the other hand, reported gendered norms attached to femininity might prompt women to seek care early [176]. Also, community belief systems in predestination or fatalism may reduce perceived value in care among community members [143,177,178]. Broadly, there is limited published literature on the influence of community-level factors on linkage-to-care. The limited amount of research can be attributed to the lack of standardised methods to quantify essential aspects of community-level influences (e.g. social and gender norms) on health behaviour. Also, there is a lack of validated theoretical models that can be used to conceptualise mechanisms through which community factors may influence linkage-to-care [179].

2.5.5 Policy factors

Policy factors pertain to overarching guidelines which influence how HIV medical care services are delivered and the extent to which the services reach the target population. Essentially, policies have the critical role of creating an enabling or inhibiting environment for timely access to HIV medical care services. For example, policies which extend clinic operating hours, integrate chronic care in clinics, and increase the capacity of healthcare workers have the potential to increase timeliness of linkage-to-care. However, the impact of policies on the HIV care continuum remains an under-studied area in South Africa. [65,159,180,181].

2.6 Interventions to improve linkage-to-care

In this section, I review the published literature on interventions to improve timely linkage-to-care. Most of the studies included in this review required PLHIV to meet the CD4 or WHO staging eligibility criteria before ART initiation. My view is that studies conducted before the treat-all era are still crucial in guiding the development of effective interventions. I hold this view because simply making ART available to all PLHIV, through treat-all approaches without considering lessons from the prior era of CD4 count-based eligibility, will not adequately address the perennial challenges of poor engagement in HIV medical care.

2.6.1 Integration of HIV testing services with point-of-care CD4 testing

For many years, the CD4 count test has been central to the management of HIV patients. Clinicians have used the CD4 count as a guide for when to start ART, to assess the risk of opportunistic infections, and to manage prophylaxis for opportunistic infections [182,183]. Also, the CD4 count has been an essential tool in guiding health messaging to promote patient healthcare-seeking behaviours in routine programmes [184,185]. However, in most sub-Saharan African countries, the process of completing CD4 count testing has often required multiple clinic visits, which have raised barriers to early care engagement [65,186-188]. In light of this, several studies have evaluated the use of POC-CD4 technologies at the time of diagnosis to maximise opportunities of health promotion at the time of diagnosis, and to reduce the patient's workload required to initiate HIV medical care [88,189,190]. Although most high-HIV burden countries now start ART for PLHIV regardless of CD4 count [191], the CD4 count will continue to be an essential clinical component in ART initiation algorithms, particularly in the management of PLHIV who present with advanced HIV disease.

A handful of randomized trials in SSA have evaluated the effectiveness of POC-CD4 testing on linkage-to-care from community-based HTS approaches. In a South African study conducted in mobile HTS units operating in an urban area, clients offered POC-CD4 testing

were more likely to report linkage-to-care within eight weeks of diagnosis compared with clients referred for facility-based CD4 count testing (59.4% vs 46.7%; RR = 1.23; 95% CI =1.00-1.57) [192]. The Thol'impilo trial conducted in South Africa from March 2013 to October 2014, was also based in mobile HTS units and evaluated the effectiveness of POC-CD4 on linkage-to-care in rural and urban areas from which the mobile units operated. Compared with usual care, providing POC-CD4 testing did not improve both self-reported linkage-to-care (POC-CD4 arm = 52% vs. usual care arm = 50%; HR = 1.0; 95% CI =0.89-1.20) nor verified linkage-to-care (POC-CD4 arm = 31% vs. usual care arm =29%; HR = 1.0; 95% CI =0.86-1.30) within the first 90 days of diagnosis [193]. In another trial, TB household contacts in a rural and urban district of South Africa were offered home-based HTS and POC-CD4 testing. The study found no evidence of an increase in 3-month linkage-to-care between participants in the POC-CD4 arms compared to those referred to clinics for CD4 count testing (RR = 1.37; 95% CI = 0.68–2.76) [194]. In another study conducted among participants from rural South Africa and Uganda communities diagnosed through community-based HTS, there were also no differences in 9-month linkage-to-care outcomes between participants in the POC-CD4 arm and usual care arm (RR =1.02; 95% CI = 0.99-1.05) [195]. However, in western Kenya success with POC-CD4 testing was reported from a community-based cluster-randomized trial which showed improvements in verified linkage-to-care among participants in the POC-CD4 group compared to the usual care group (58% vs 34%; HR = 2.14; 95% CI= 1.67-2.74) [196].

Only a few studies in sub-Saharan Africa have evaluated the use of POC-CD4 testing on improving linkage-to-care among PLHIV diagnosed through facility-based HTS. The few numbers of studies may be attributed to the availability of CD4 testing services on-site, although results are generally not available immediately. Nonetheless, four clinic-based studies, three in South Africa and another in Mozambique found that POC-CD4 increased the proportion of patients who started ART compared with laboratory-based CD4 testing approaches [197-200].

There is no clear reason for the outcome differences across these studies. However, it is possible that in studies that observed no difference in linkage-to-care outcomes, the additional costs associated with going to a referral clinic may have outweighed the value of HIV medical care generated from the CD4 count [66]. Also, participants aware of their ineligibility for ART at the time of diagnosis, may have perceived low value in entering HIV medical care [87,201]. None of the studies explored the client's understanding of CD4 counts as a barrier to linking to care. To improve timely linkage-to-care, POC-CD4 testing may need

to be coupled with effective health communication strategies to influence healthcare seeking decisions [202].

2.6.2 Community-based HIV testing services coupled with ART initiation

Coupling community-based HTS approaches with immediate ART initiation services may contribute to timely linkage-to-care by addressing individual- and clinic-level barriers to initial care engagement faced by individuals who are mostly healthy and less likely to utilise services at fixed health facility sites. In Lesotho, 278 adults who were diagnosed with HIV through home-based HTS from 60 rural villages and 17 urban areas were randomly assigned to receive same-day ART in their homes or referral to the nearest health facility for HIV medical care [203]. ART eligible participants in the same-day group were issued with a one-month ART supply and were required to visit their clinic within 2 to 4 weeks for their first check-up and ART refills. Within the first 90 days of HIV diagnosis, 68.6% of participants in the same-day ART group, compared with 43.1% in the standard care group had linked to care (absolute difference = 25.6%; 95% CI = 13.8%-36.3%) [203]. Home-based ART initiation after HIV self-testing, among participants in a cluster randomised trial in Malawi, also showed improvements in linkage-to-care. In this trial, nurses provided ART-eligible participants in the home-based ART initiation arm with a two-week ART supply. They then referred them to the nearest health facility for ongoing HIV medical care. The intervention resulted in a three-fold increase in ART initiation compared with usual care (64% vs. 36%; RR= 2.94; 95% CI = 2.10-4.12) [204]. Similar models have shown success in Nigeria, and among hard to reach key population groups such as female sex workers [205].

2.6.3 Facility-based HIV testing services coupled with rapid ART initiation

Although facility-based HTS reaches individuals who are already seeking clinical care and ready to engage with the medical care system, the need for repeat clinic visits and other process delays may result in delayed care engagement [65,70,78]. Given these barriers, several studies have evaluated interventions to accelerate ART initiation. The RapIT trial conducted in two public sector clinics in South Africa, between May 2013 and August 2014, is one of the early trials to evaluate the effectiveness of algorithms to accelerate ART initiation in routine clinical settings in sub-Saharan Africa [206]. In this trial, ART-eligible participants assigned to the intervention arm were issued with a four-week supply of ART on the day of diagnosis and then asked to return to the clinic for routine monitoring and prescription refills. Three months after study enrolment, a higher proportion of participants in the rapid initiation group had initiated ART compared with the usual care group (97% vs 72%; risk difference = 25%; 95% CI = 19%–33%). Another study was conducted between March 2017 and April 2017 in three urban outpatient clinics in South Africa and three hospital clinics in Kenya

[207]. Among the participants in South Africa, 78% of participants in the rapid initiation arm, started ART within 28 days of diagnosis, compared with 68% in the usual care arm (risk difference =10%; 95% CI = 3%-17%). Among the participants in Kenya, 94% of participants in the rapid initiation arm, started ART within 28 days of diagnosis, compared with 89% in the usual care arm (risk difference = 6%; 95% CI = 0.5%-11%) [207]. In Uganda, a similar study conducted in 20 public sector health facilities between April 2013 and August 2015, found that participants in the rapid ART initiation group were 27% more likely to start ART compared with the usual care group (90% vs.70%; RR = 1.27; 95% CI = 1.25-1.30) [208]. In considering the evidence on the effectiveness and feasibility of accelerated ART in sub-Saharan African settings, WHO issued recommendations in 2016 for countries to adopt policies of initiating ART within seven days of HIV diagnosis, including same-day ART initiation [209].

2.6.4 ART for all people living with HIV

Three randomised control trials have been conducted in sub-Saharan Africa to evaluate the effectiveness of treat-all approaches in reducing population-level HIV incidence [210-212]. In March 2012, one of the first trials was launched in a largely rural area in South Africa – the ANRS 1229 Treatment as Prevention (TaSP) Trial [210]. Communities were randomly assigned to receive ART immediately or according to CD4 eligibility criteria as per national guidelines. After diagnosis, participants in both arms were referred to trial clinics for HIV medical care. Twelve months after enrolment, linkage-to-care was low and not significantly different between the two arms at all follow-up time points (Table 2-1). Besides, there was no difference in HIV incidence between the two arms[210].

Table 2-1: Linkage-to-care outcomes in the ANRS 1229 TaSP Trial

Cumulative linkage-to-care outcomes	Intervention	Control
By 3 months	37.1%	36.5%
By 6 months	47.6%	47.4%
By 12 months	62.6%	63.6%

From 2013 to 2017, another community randomised trial (the SEARCH Trial) was conducted in rural Uganda and Kenya to evaluate the effectiveness of immediate ART initiation on HIV incidence. In this trial, a higher proportion of participants in the immediate ART initiation arm linked to care, compared with participants in the usual care arm, at all study follow-up visits (Table 2-2) [211]. Despite superior linkage-to-care outcomes in the intervention arm, the proportion of participants who entered care by 3-months was below the 90% UNAIDS target for the 'second 90', and this target was not achieved even after 36 months of follow-up [211].

Table 2-2: Linkage-to-care outcomes in the SEARCH Trial

Cumulative linkage-to-care outcomes	Intervention	Control
By 3 months	60%	17%
By 6 months	73%	30%
By 12 months	80%	40%
By 36 months	83%	50%

The third community randomised trial (the POP-ART Trial) to evaluate the effectiveness of immediate ART initiation on HIV incidence, was conducted in 21 urban and peri-urban communities in South Africa and Zambia. Similar to findings from the SEARCH trial, a high proportion of participants assigned to immediate ART successfully entered care [212]. However, the linkage-to-care outcomes in the intervention arm were similar to those observed among care as usual participants who did not know whether they would start ART when they got to the clinic (81% vs 79.9%, respectively) [212].

Findings from the population-level studies reviewed in this section, highlight how simply offering treatment for all PLHIV, will not achieve the anticipated population-level prevention benefits without effective interventions to improve linkage-to-care.

2.6.5 Case management and counselling

Case management and counselling interventions to improve linkage-to-care are the most commonly described in the literature [86,106]. Three randomised control trials in South Africa have evaluated the effectiveness of case management interventions to promote early linkage-to-care [202,213,214].

In the Sizanani trial, trained case managers provided strengths-based case management support – a facilitation approach which helps clients to achieve desired outcomes by building on their strengths and resources [213]. Over 16 weeks, case managers provided up to five telephonic sessions and sent up to four short message reminders encouraging participants to make clinic visits. In the intervention arm, 22% of ART-eligible participants completed three months of ART compared with 28% of ART-eligible participants in the usual care arm. In this study, the reliance on telephonic sessions may have compromised the strength of provider-client relationships leading to ineffective case management support in improving linkage-to-care [213].

In a similar study conducted in South Africa, from March 2013 to October 2014, 603 participants were randomly assigned to receive on-going strengths-based case management support over five sessions within 90 days from the time of enrolment [202]. The case

management support was a mix of telephonic and in-person meetings, whichever was convenient to the participant. Based on verified outcomes using health records, care facilitation resulted in a 40% increase in linkage-to-care by 90 days compared with the usual care arm which did not receive additional linkage support (care facilitation = 38% vs usual care = 29%; HR = 1.4; 95% CI = 1.1-1.7) [202].

In a third trial conducted in South Africa and Uganda, participants who were assigned to receive case management at the clinic (RR=1.09; 95% CI = 1.05-1.13) or home (RR=1.04; 95% CI = 1.00 - 1.09) had slightly improved linkage-to-care outcomes compared with participants receiving usual care [214]. Other studies evaluating multi-component intervention packages which include on-going case management have also reported improvements in linkage-to-care [215-217].

Some studies have explored the use of peer counsellors to facilitate linkage-to-care, based on the premise that counselling support provided by PLHIV who have experiences with linking to care, can create stronger provider-client relationships through shared experiences. Two separate studies conducted in Tanzania and Swaziland evaluated the effectiveness of a similar peer counselling intervention on linkage-to-care [218,219]. In these studies, peer counsellors escorted clients to the clinic, conducted weekly telephone calls, provided disclosure counselling, and provided psychosocial support to resolve patient barriers to care engagement. In both studies, almost all PLHIV had linked to care in the follow-up period. In another study conducted in rural Uganda, participants who received peer counselling support were more likely to engage in care by nine months compared with participants who did not receive peer support (83% vs 53%, respectively) [220].

The success of care facilitation interventions described in this section underscores the centrality of interpersonal communication between patients and their healthcare providers in promoting favourable healthcare-seeking behaviour towards utilisation of available medical services.

2.6.6 Conditional financial incentives

Conditional financial incentives (CFI), have the potential to promote linkage-to-care by reducing the real or perceived economic costs of linking to care (e.g. travel costs, or opportunity costs), or increasing the value of linkage-to-care because of the near-immediate reward attached to it. However, for a person to derive value from the CFI, the intervention should address a barrier that exists, and the CFI should hold enough economic value to serve as an incentive.

In a study conducted in South Africa among ART-eligible adults diagnosed through mobile HTS, participants in the intervention arm were offered a South African Rand (ZAR)300 voucher (approximately US\$23) which could be exchanged for cash if they started ART within three months [221]. At the time of study implementation, the financial incentive was worth about a third of the average household monthly spend on food in the area where the mobile HTS units operated. The study found no difference in 3-month linkage-to-care (intervention = 63% vs. usual care = 72.5%) nor ART initiation outcomes (intervention = 63% vs. usual care = 72.5%) between the two study arms. Additional findings from in-depth interviews revealed that participants faced multiple clinic barriers which could not be addressed by the financial incentive and that some participants were uncertain whether they would receive the incentive [221].

In another study conducted in South Africa among PLHIV diagnosed through mobile HTS in rural and urban areas, participants in one of the intervention arms received vouchers that they could exchange for cash for up to 3 clinic visits within the first 90 days of enrolment [202]. The CFIs were standardized at US\$6 for urban or peri-urban and US\$10 for rural residents. After reporting a clinic visit, participants received their vouchers through cell phone transfer, automated teller machine, or a designated grocery store chain. The study found that conditional transport vouchers did not improve linkage-to-care within the first three months of diagnosis compared with standard of care (31% vs 29%; HR = 1.1; 95% CI: 0.88 to 1.3), and the intervention did not address the significant barriers to care engagement [202].

Studies in Mozambique and Eswatini, which evaluated multi-component linkage-to-care intervention strategies found no incremental benefit on linkage-to-care outcomes when including a non-financial incentive valued from US\$8 to US\$15 [222,223]. Similar null effects of CFIs on linkage-to-care outcomes have also been reported from randomised trials in the US [224]. However, some success in reducing the time to ART and improving retention in care has been reported from studies using CFI in India, the Democratic Republic of the Congo, and Uganda [225-227]. It is possible that in the studies where CFIs were effective, the financial incentives addressed major costs of care engagement or they carried enough weight to promote the participants' perceived value of initial or sustained engagement in medical care [66,228].

2.7 Theoretical perspectives on healthcare-seeking behaviour

2.7.1 Health behaviour theories

Theoretical perspectives on how people make decisions in adopting new health behaviours, such as seeking care after HIV diagnosis, may reveal the underlying mechanisms in which

the extensive catalogue of linkage-to-care barriers and facilitators play the role they do. Theories offer a systematic approach to understanding events or situations by illustrating the relationships between different concepts and constructs which explain or account for the event or situation [229]. However, to adequately understand a process, such as healthcare-seeking behaviour, more than one theory may be required; in which case, theoretical models or frameworks are developed [230]. Although the nuances to the terms: 'theory', 'model', and 'framework', cannot be disregarded; they are used interchangeably across different settings and disciplines [231,232].

Most health behaviour theories are adapted from various disciplines such as sociology, consumer behaviour and psychology [233]. Explanatory behaviour change models are a category of health behaviour theories which conceptualise the processes and associated influential factors, that come into play as individuals adopt new behaviours in response to the event or stimuli (e.g. HIV diagnosis) [233]. Importantly, most explanatory models conceptualise the cognitive processes of behaviour change based on a person's mental actions or processes, such as thinking, judging, remembering and problem-solving [149,234-236]. Despite their frequent and longstanding use of these cognitive-based theories, a major criticism is that they fail to account for unconscious drives which may influence health behaviours [237,238]. For example, in some cases, a person's decisions may be intuitive or emotional with no transparent mental process of decision making or a basis of judging whether it is 'correct' [63,238]. Notwithstanding these limitations, most of the cognitive-behavioural models are robust with multiple applications across several health conditions and disciplines [239-241].

2.7.2 The value-cost perspective in health behaviour theories

There are numerous health behaviour change models, with overlapping theoretical constructs among most of them, and various conceptualizations of the same constructs [63]. Such overlaps create challenges in selecting and applying health behaviour models to characterize problems with targeted health behaviours, and it weakens the base for intervention development. Encouragingly, there have been moves towards synthesizing similar theoretical constructs into theoretical domains that are non-overlapping, to aid intervention design and evaluation. For example, the Theoretical Domains Framework (TDF), and the Capability Opportunity Motivation Behavioural Framework. (COM-B) were developed from a synthesis of over 30 behaviour theories and outline key domains which may be applied to understand health behaviour change [63,238].

More recently, Hoffmann et al. (2016) proposed a simplified explanatory model based on key theoretical domains which are likely to have an outsized impact on influencing a person's

decision-making process on whether or not to engage in HIV medical care [66]. In contrast to the TDF and COM-B frameworks, the model by Hoffmann et al. (hereafter referred to as the value-cost model), suggests the nature of the relationships that exist between the theoretical domains in influencing behaviour change. Fundamentally, the value-cost model is based on the premise that people consciously or unconsciously place value on specific states of being, outcomes, or material assets above others [62,127]. In other words, people seek resources that they perceive to be useful in protecting what they value and furthering the goals that they desire to achieve. When applied to decisions for seeking healthcare (in this case – HIV medical care), the extent to which PLHIV, perceive engaging HIV medical care services to hold them from or move them towards these valued states, determines their level of engagement with healthcare services.

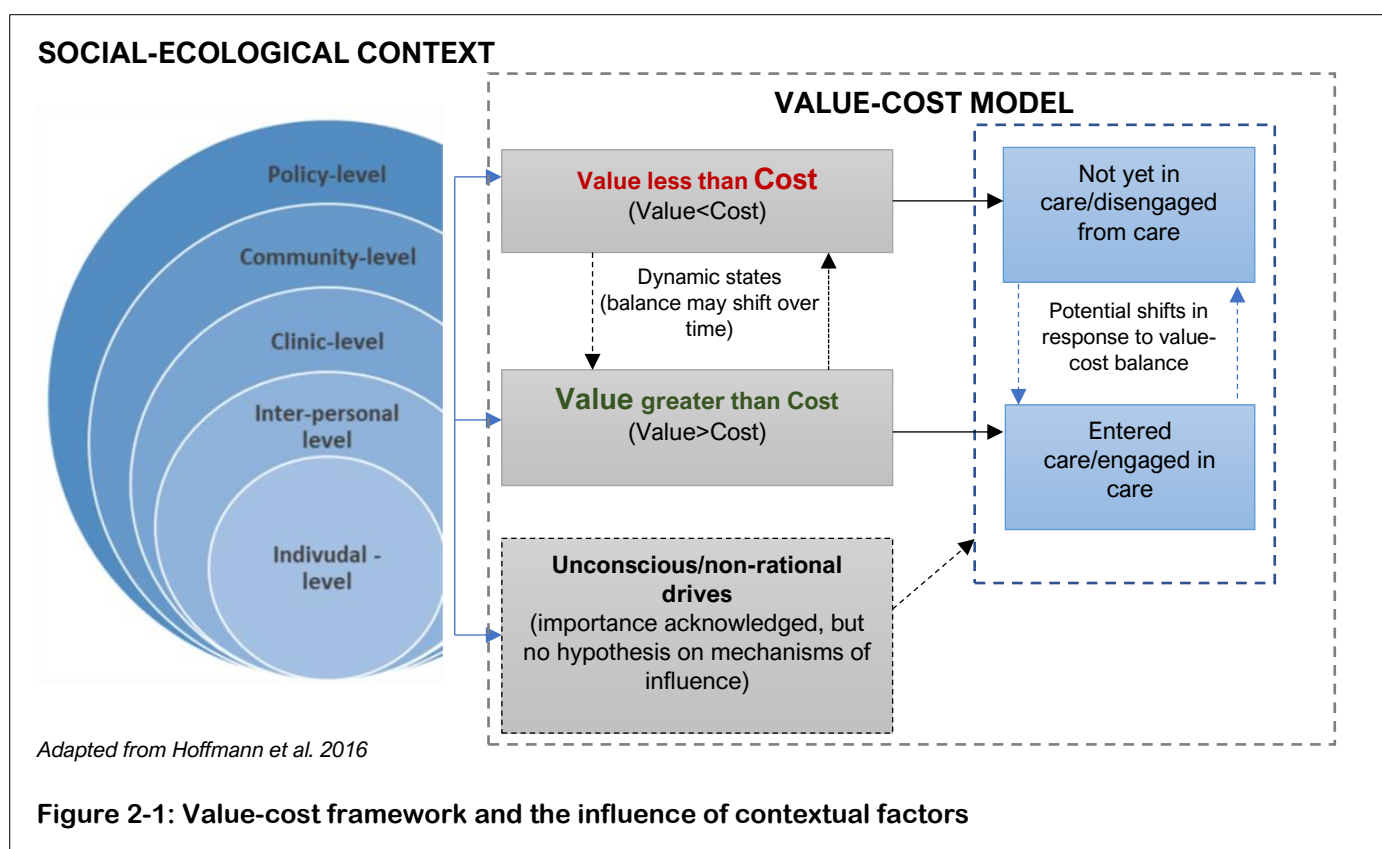
Equally important are a person's perceptions of the material and psychological costs of engaging in HIV medical care. Notably, the theoretical constructs of values and costs are central to most health behaviour models or frameworks used in health behaviour research (Table 2-3) [63,68,94,234,238]. According to the value-cost model, linkage-to-care is highly likely when a person's perceived value of HIV exceeds the costs of engaging in care. In contrast, when the perceived costs of engagement in care exceed the anticipated value, linkage-to-care may not occur, or disengagement from care is likely. Lastly, when value and costs are nearly equal, a person may be ambivalent to care engagement, leading to cycling in and out of care.

Table 2-3: Examples of health behaviour models that have constructs on value and costs

Theoretical models/frameworks	A conceptualisation of value-cost constructs
Explanatory models	
Health belief model [234]	People form positive intentions to perform a behaviour if they believe that the perceived benefits outweigh the costs of acting.
The Theory of Planned Behaviour [149]	A person's intention to engage in a behaviour is influenced by the degree to which they form a favourable or unfavourable evaluation of performing the behaviour. This evaluation includes consideration of the outcomes of acting and the value placed on the beliefs about whether people of importance approve engagement in the planned behaviour
Social Cognitive Theory [94]	People have expectations when they perform a health behaviour. Before acting, people consider the likely consequences (health or

	non-health related) which are derived from previous experiences or the subjective value placed on the outcome.
Stage Models	
Transtheoretical Model [68]	As people transitions across the different stages of behaviour, they weigh out the ‘pros’ and ‘cons’ of changing behaviour.
Frameworks	
Theoretical Domains Framework [63]	One of the eight essential criteria for a person to perform a behaviour is that the person believes the benefits or anticipated positive outcomes of performing the behaviour outweigh the costs or expected negative consequences.

A person’s context also mediates their perceptions of values and costs of engaging in HIV medical care (Figure 2-1). Similar to other simplified theoretical frameworks such as TDF and COM-B, the value-cost model also acknowledges the importance of unconscious or non-rational drives to individual healthcare-seeking decisions. However, none of the frameworks makes any hypotheses on the mechanism through which these factors play the role they do.



2.7.3 Cognitive biases and healthcare-seeking decisions

Evidence from the fields of decision-making sciences and behavioural economics suggests that people also make healthcare-seeking decisions that consistently, and systematically depart from what may be considered rational judgements or decisions [228,242,243]. These are referred to as cognitive biases, and they often play a significant role in how individuals assess the balance of values and costs of engaging in HIV medical care [244]. There are three cognitive biases commonly described in HIV medical care literature and appear to have an outsized impact on healthcare-seeking decisions.

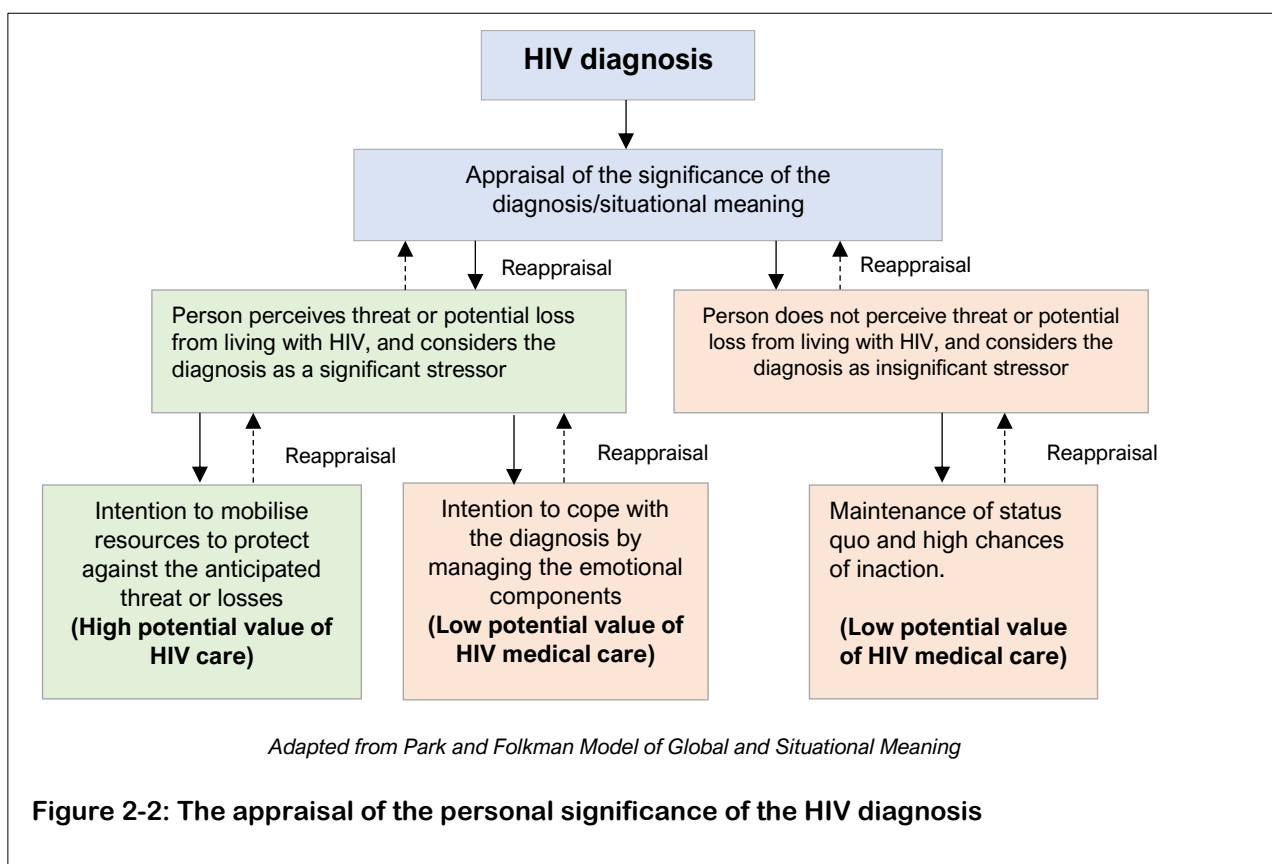
- **Present bias or temporal discounting** occurs when a person perceives less value in a future result compared to the value they place on their current state [245,246]. This bias plays out in HIV medical care-seeking behaviour when individuals are more likely to seek medical care when they are experiencing HIV-related symptoms, compared to when they are asymptomatic. Conversely, maintaining health or longevity can have little immediate value. In contrast, pregnant women living with HIV may place more weight on the future value of preventing HIV transmission to their unborn infant compared to the value they ascribe to their present states, overcoming the effect of present biases.
- **Status quo bias** plays out when people prefer to maintain the current state of affairs. In maintaining the status quo, people may decide not to take any action in response to the diagnosis or they may default to decisions that they may have made previously (e.g. denial of diagnosis if they had previously tested for HIV before). In some cases, PLHIV may choose to maintain the status quo regardless of whether they perceive value in HIV medical care or whether the anticipated costs of care engagement are negligible [228,247,248].
- **Availability bias** plays out as individuals recalling the most dramatic outcome (either good or bad) for a situation [94,249]. For example, individuals who know someone living with HIV who has become much healthier while taking ART may exaggerate the value of ART. In contrast, having heard of or knowing someone with severe ART side effects may lead to exaggerated perceptions of the risk of ART. Also, prior experience or knowledge of poor clinic services can lead to an unrealistic higher anticipated cost of engaging in HIV medical care [78].

2.7.4 Subjective appraisal of the potential value of HIV medical care

Theoretical perspectives from the field of medical sociology offer insights into some of the foundations upon which PLHIV appraise the “value” of HIV medical care as a resource worth mobilising for adapting to or coping with the HIV diagnosis [60,61]. Such perspectives are

valuable for the value-cost model (and other theories cited in Table 2-3), where “value” is a key theoretical construct for health behaviour. Broadly, when people experience unwanted or aversive life events, such as receiving an HIV diagnosis, they assess the potential threat of the event (also known as the stressor or stimulus) to what they value and the goals they desire to achieve. This is commonly referred to as the “significance” or the “situational meaning” of the HIV diagnosis [60,93,250,251]. Persons who assign less weight to the significance of the diagnosis may not perceive any need to adapt by altering their behaviour, perceptions, or emotional responses. On the other hand, persons who consider the diagnosis to be hugely significant may start exploring and evaluating what they can do in response to the HIV diagnosis.

Some people will consider mobilising resources to mitigate the anticipated losses from AIDS-related illness, AIDS-related deaths or HIV transmission to their sexual partners (all examples of problem-focused coping). Options include seeking medical care, alternatives to medical care such as institutional or non- institutional religions, or self-care practices such as consultations at local pharmacies [252]. Other people may consciously or unconsciously reassess their goals, based on their knowledge and understanding of living with HIV, which can lead to “pruning” or reducing aspirations [60,253,254]. Also, some people will attempt to alleviate distress from the HIV diagnosis by minimizing, or preventing, the emotional components associated with the anticipated losses to their valued states of being (emotion-focused coping) [255,256]. People who respond to the diagnosis in the manner, often distance themselves from the HIV diagnosis by denying that they are living with HIV or elevate beliefs of fatalism or destiny [143,257]. When patients have a rapport with their healthcare providers, it creates opportunities for healthcare providers to explore most of the appraisal processes described above. In turn, this allows healthcare providers to communicate relevant health messages which promote the value of health behaviours based on what they know about their patient [101].



2.7.5 Patient-centred care

Thus far, this review has highlighted the subjective nature of individual-level decision making for health behaviour change, and the critical role played by the individual's contextual environment in influencing these decisions. Traditional biomedical approaches to health behaviour change, which focus on disease and treatment, excluding the psychosocial and environmental influence, are less likely to be effective in promoting early engagement in care. Instead, patient-centred approaches which seek to model services in line with patient values, needs, and preferences, are more likely to be effective in promoting behaviour change [258-260]. In part, this is supported by findings from studies reviewed in this chapter which show most success in the category of interventions that provide individualised on-going counselling and linkage support provided on a foundation of patient-provider relationships.

The concept of placing the patient at the centre of healthcare delivery (patient-centred care) has taken centre stage in health communication studies and discussions in health service delivery over the past few decades [91,261,262]. In 1969, Balint et al., published the first article on patient-centred medicine to offer an alternative approach to medical thinking, beyond a narrow focus on disease-centred thinking [259]. The patient-centred paradigm advocated for a shift towards forming an 'overall diagnosis' based on examining the whole patient (i.e. using everything known about the patient, such as their family situation or their occupation) and acknowledging that each patient is unique. Since then, there is consensus

among researchers and health practitioners that the nature of the interaction between patients, their healthcare providers, and the way services are delivered, is central to health behaviour change and achieving favourable health outcomes [258,263,264].

2.8 Summary of literature review

There is a large body of evidence from studies in sub-Saharan Africa, exploring linkage-to-care outcomes and interventions to promote early engagement in care [30,87,102,265-267]. Although comparisons across studies are a challenge, findings from this literature review, strongly suggest that there have been modest shifts towards early linkage-to-care, despite improved accessibility to ART over the years. These review findings are particularly crucial for community-based HTS approaches, such as mobile HTS, that identify PLHIV in earlier stages of HIV and reach populations that are less likely to interact with traditional health services; yet subsequent engagement is poor. While these findings are often generalised to all mobile HTS clients; there is a lack of prospective cohort studies evaluating linkage-to-care outcomes specifically among ART-eligible persons diagnosed with HIV in routine mobile HTS programmes. Individuals who know that they are eligible for ART at the time of diagnosis through mobile HTS may be more motivated to enter HIV medical care - one of the promises of treat-all approaches. However, there is a lack of prospective studies exploring the potential and pitfalls of treat-all approaches in routine mobile HTS programmes, beyond mathematical modelling and findings from controlled research environments. In line with this evidence gap, **we sought to evaluate linkage-to-care outcomes and identify factors associated with linkage-to-care within 180 days of receiving an HIV diagnosis among ART-eligible persons diagnosed through mobile HTS (Objective 1)**

More theory-grounded qualitative research is required to understand how the catalogue of factors reported from quantitative studies, play the role they do with influencing linkage-to-care. However, the complexity of different theoretical models and significant overlap, limits their application and weakens the base for intervention development. No single model can incorporate the level of detail required to explain sources of HIV medical care-seeking behaviour or to determine what will or will not be an effective linkage intervention [230]. However, the value-cost model offers a simplified and alternative patient-centred approach for characterizing the barriers and facilitators for care engagement and pragmatic views of developing strategies to bridge identified gaps [66]. Further, while there has been an increase in qualitative research over the years, there is a lack of studies that provide a longitudinal perspective of how identified barriers and facilitators may change over time. The failure to account for potential shifts of a person's contextual environment over time may create simplistic views on the care engagement process, leading to the development of ineffective

interventions [60,66,91]. Therefore, in this thesis, we also sought **to explore how contextual factors, influence the appraisal of values and costs of engaging in HIV medical care following HIV diagnosis through community-based mobile testing units (Objective 2).**

There are mixed results on the success of interventions which lead to early linkage-to-care. Among most of the interventions reported to be effective, the proportion of PLHIV who link to care is less than the global target of 90%. The most success is published from the category of interventions which provide interpersonal health communication through on-going counselling or case management support [66,215,219,268]. Effective interpersonal communication can bring aspects of client autonomy and shared decision making to health communication, which maximises the chances of health behaviour change [146,269].

However, most of the published literature describes the effect of communication strategies on specific outcomes without description or analysis of the communication transcripts, which limits the guidance for quality improvement efforts in routine programmes [270-275].

Therefore, in this thesis, we sought **to explore how interpersonal health communication between healthcare providers and persons diagnosed with HIV, influence engagement in medical care following HIV diagnosis (Objective 3).** Findings from this work will expand the body of knowledge on: (1) the core elements of interpersonal health communication which influence HIV medical care-seeking behaviour, and (2) developing best practices in counselling approaches to promote care engagement.

CHAPTER 3 : METHODOLOGY

3.1 Introduction

Two studies contributed to the data used for this thesis (hereafter referred to as parent studies). The study setting is described first because of the overlap between the geographical areas of the parent studies. This chapter provides an overview of the parent studies, including their aims, design, setting, and population. Further in the chapter, I provide details of the methodologies applied for each study objective.

3.2 Study setting

The parent studies were conducted in two districts in South Africa: (1) Ekurhuleni District, an urban/peri-urban district in Gauteng Province, and (2) Sekhukhune District, a rural district in Limpopo Province (Figure 3-1). Urban, peri-urban, and rural areas were included to maximize generalizability.

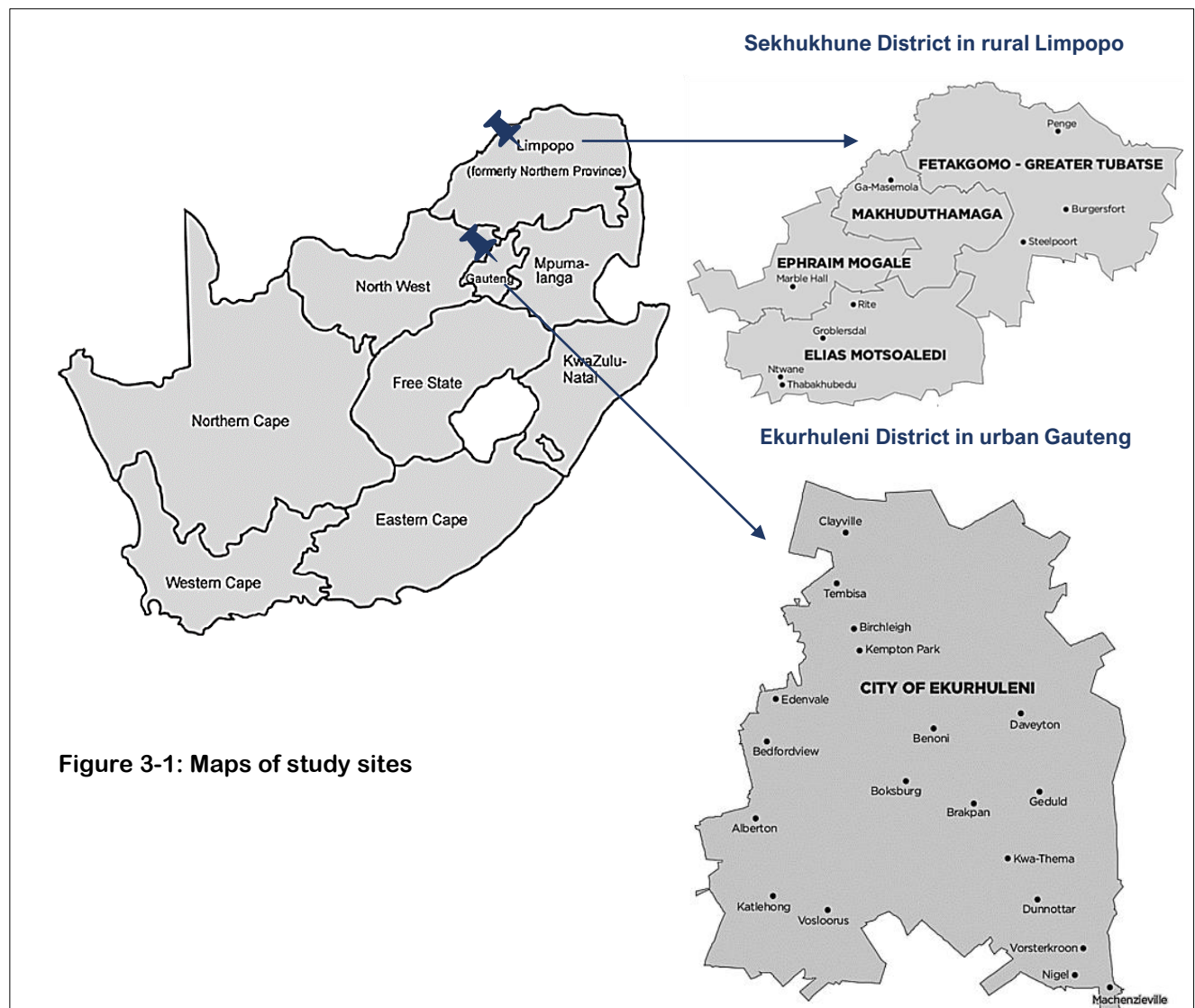


Figure 3-1: Maps of study sites

3.2.1 Ekurhuleni District

Ekurhuleni district is one of the six districts of Gauteng Province, and one of the eight metropolitan municipalities in South Africa. The district is a manufacturing hub and a popular destination for work seekers [276]. In 2016, an estimated 3,379,104 people were residing in the district, with a population density of 1,609 people per km² [277]. Notably, the rate of population growth in the district has far outpaced the rate of economic growth, which has resulted in a significant proportion of the population living in poverty. In 2018, about a third of the district's labour force was unemployed, and 26% of the households had no source of income [276]. The district has 119 unplanned or informal settlements mostly comprising of informal structures not approved for a permanent dwelling. These informal settlements are home to an estimated 164,599 households [276].

Ekurhuleni has one of the highest district-level HIV prevalence estimates in South Africa and is among the 27 priority districts that account for 82% of the HIV burden in South Africa [278]. In 2018, an estimated 15% of the district's population was living with HIV [279]. There are 99 public sector clinics which serve the people in Ekurhuleni, and all provide services for HIV testing and treatment [276]. The district receives additional funding from PEPFAR to support HIV programme delivery provided through non-governmental organisations (NGOs). The Aurum Institute is one such NGO, which provides technical assistance (e.g. training and mentoring of clinic staff). It employs additional clinic staff who directly participate in the delivery of HIV services (e.g. provision of HIV testing services and management of ART patients). From 2008 to 2017, The Aurum Institute was funded by PEPFAR to provide mobile HTS services in Ekurhuleni District. The mobile HTS units were deployed in communities, workplaces, commercial shopping areas, and at special events as part of routine service delivery.

3.2.2 Sekhukhune District

Sekhukhune district is the smallest of the five districts of Limpopo Province. In 2016, an estimated 1,169,762 people were residing in the district, with a population density of 86 people per km² [280]. Further, only 51% of the labour force is employed; and the average annual household income is ZAR14,600, which is about half the national average [280]. Mining, trade, and agriculture drive the district's economy. However, it is one of the poorest areas in South Africa; it is predominantly rural and has underdeveloped public transport and road networks, which means that most people walk long distances to access services [281].

Sekhukhune has one of the lowest district HIV prevalence estimates in South Africa, with an estimated 7.5% of the population living with HIV [279]. There are 89 public sector clinics which serve the people, and all provide services for HIV testing and treatment [281]. From

2008 to 2017, the Aurum Institute was funded by PEPFAR to provide mobile HTS services in Sekhukhune District. The mobile HTS units were deployed in communities, workplaces (e.g. mines and commercial farms), commercial shopping areas, and at special events as part of routine service delivery.

3.3 Parent studies

In this section, I provide an overview of the parent studies: (1) Thol'impilo Study, and (2) Post-test Counselling Evaluation. Thol'impilo is a metaphor in one of the South African indigenous languages, which denotes 'embracing life'. The notion of embracing life, linked to the central theme of the study related to individual-level decisions and actions to seeking medical care. The Thol'impilo Study had two phases, with each stage conducted as a separate sub-study.

- **Phase 1** was a longitudinal qualitative study to explore healthcare-seeking behaviours following HIV diagnosis.
- **Phase 2** was a pragmatic randomised control trial to evaluate the effectiveness of interventions to accelerate linkage-to-care.

3.3.1 Thol'impilo longitudinal qualitative study

The study sought to qualitatively explore the healthcare-seeking decisions and behaviours towards engagement in HIV medical care over six months from the time of diagnosis. Table 3-1 provides an overview of study procedures, and Figure 3-2 is an illustration of the study visit sequence.

Table 3-1: Overview of Thol'impilo longitudinal qualitative study

Study setting	• The study was conducted in Ekurhuleni District and Sekhukhune District. • Study enrolment and follow up occurred from January 2012 to July 2015.
Study design and population	• This was a longitudinal qualitative study, in which participants diagnosed with HIV, were prospectively followed for repeat in-depth interviews at 30, 90, and 180 days after consenting to participate in the study. • Clients testing HIV-positive at mobile HTS units were consecutively invited to participate in the study, immediately following post-test counselling. • Clients were eligible to participate in this study if they: • were issued with an HIV diagnosis from one of the mobile HTS units • ≥18 years old • capable of providing informed consent • not reporting current engagement in HIV-related care (receiving ART or other regular ongoing HIV-related care).

	- Trained interviewers used a semi-structured guide for in-depth interviews. The interview guides covered topics including: - the meaning of HIV to the individual - barriers to engagement in care - experiences with the health care system - beliefs and knowledge about HIV - individual health perceptions. - Immediately after every interview, study staff compiled field notes documenting personal reflections of each interview to describe the interview context and methodological issues. - Interviews were audio-recorded and conducted in four local languages (Sesotho, Sepedi, isiZulu or Xhosa), in-person in a private room or telephonically. - The interviews lasted about one hour, and participants were issued USD6 in cash to cover costs for travel and time, in keeping with local practice. To enhance the quality of probing and clarity of the interview guide, transcripts from randomly selected audio-recordings were transcribed and reviewed at three different time-points before completion of data collection.
Ethical considerations:	The institutional review board of the University of the Witwatersrand, South Africa (M110722), approved the study.
Contribution to the study	- I was the Principal Investigator for the Thol'impilo Longitudinal Qualitative Study, funded by the Fogarty supported South Africa Tuberculosis (TB) and AIDS Training Grant. - I was involved in the applying for study funding, development of study protocol, development of data collection tools (including interview guide), supervision of participant enrolment and follow-up, and supervision of translation and transcription activities.

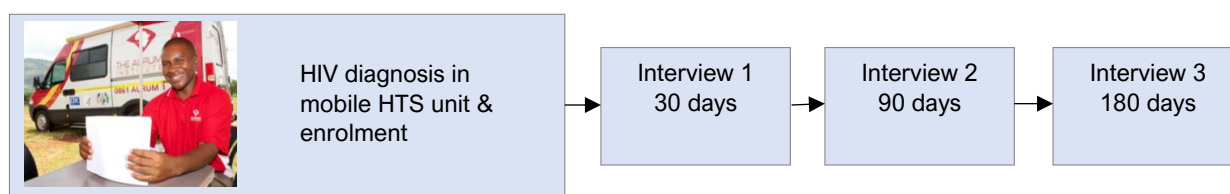


Figure 3-2: Study visit sequence for Thol'impilo longitudinal qualitative study

3.3.2 Thol'impilo intervention study

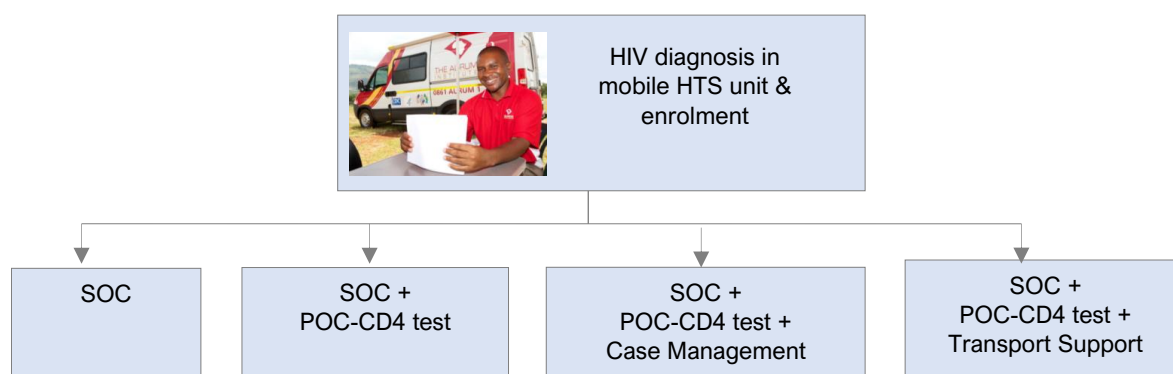
The study sought to identify pragmatic widely implementable strategies to accelerate engagement in medical care following HIV diagnosis from mobile HTS units. Table 3-2

provides an overview of study procedures, and Figure 3-3 is an illustration of the four study arms.

Table 3-2: Overview of Thol'impilo intervention study

Study setting	• The study was conducted in Ekurhuleni District and Sekhukhune District. • Study enrolment occurred between March 2013 and October 2014, during which time the South African Department of Health CD4 threshold for ART initiation was ≤ 350 cells/mm³. This criterion changed to ≤ 500 cells/mm³ in January 2015.
Study design and population	• The Thol'impilo intervention study was a pragmatic, unmasked, individually randomized trial with four arms. Clients testing HIV-positive from mobile HTS units in Sekhukhune and Ekurhuleni districts were consecutively invited to participate in the study following post-test counselling. HTS clients received small incentives for HIV testing (value \$0.25-\$1.00). • Clients were eligible to participate if: • they were ≥ 18 years old • able to provide informed consent • planned to remain in South Africa for at least six months • not reporting current HIV-related care (receiving ART or other regular ongoing HIV-related care). • Individuals with previous positive HIV tests or who previously received HIV medical care but no longer engaged in care were eligible to participate. • At study enrolment, participants were randomly allocated to receive either routine referral to HIV clinic of their choice (standard of care), or three additional interventions: (1) POC- CD4 testing, (2) POC-CD4 testing and case management, or (3) POC-CD4 and transportation assistance vouchers. The details of the trial design are published elsewhere [202]. • All participants were followed up by telephone and/or home visits at 90, and 180 days to assess disclosure of HIV status and self-reported linkage to HIV medical care. • Self-reported linkage-to-care at any public or private health facility in South Africa was verified by the study team, who visited the facility to perform case note abstraction using clinical charts, registers and/or electronic records. If no records were found, the participant was re-contacted to clarify which facility they had attended and possible names they may have used. Additional searches were then performed using this information. National Health Laboratory Service (NHLS) data, (matched on name, date of birth,

	clinic and date range), were searched for further evidence of linkage-to-care for all participants, irrespective of self-report. Individuals were defined as having verified linkage-to-care if any evidence of registering for or receiving HIV medical care was found, including but not limited to ART initiation.
Ethical considerations:	The study was approved by the institutional review board of the University of the Witwatersrand, South Africa (M120829).
Contribution to the study	I was Co-Investigator and Study Manager for the Thol'impilo Intervention Study funded by the United States Agency for International Development (USAID). As co-investigator, I was involved in conceptualising the study design and developing the research proposal for funding. I also participated in the development of data collection tools. As a study manager, I supervised all field activities concerning training of study staff, participant enrolment, participant follow-up and data collection.



HTS = HIVtesting services. SOC = standard of care; POC-CD4 = point-of-care CD4 test

Figure 3-3: Overview of study arms in the Thol'impilo Intervention Study

3.3.3 Post-Test Counselling Evaluation

This study sought to describe how health facility-based HTS counsellors conducted post-test counselling sessions focusing on health communication that either supported or raised a barrier to ART initiation. Table 3-3 provides an overview of the study procedures.

Table 3-3: Overview of Post-test Counselling Evaluation

Study setting	- The post-test counselling evaluation was conducted from January 2017 to June 2017, in ten public sector health facilities in the Ekurhuleni District of South Africa. - The study sites consisted of six primary health care centres (PHC), three community health care centres (CHC) and one district-level hospital. Facilities were selected in coordination with the district-level Department
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	of Health to achieve geographic diversity. All facilities included in the study had HIV counselling and testing personnel (lay counsellors) and routinely provided HTS free of charge according to the 2015 National HIV Counselling and Testing guidelines. Under these guidelines, HIV testing is an opt-in service requiring informed consent with pre- and post-test counselling in a confidential private setting. HIV testing followed an algorithm based on approved rapid point-of-care blood tests that use finger-prick capillary blood samples.
Study design and population	• We audio-recorded 160 post-test counselling sessions with clinic patients who had received HIV testing, equally distributed across participating study sites. Counsellors and the patients provided written, informed consent to participate in the study. The counsellors were consented once, for participation in this study. They also had an option of voluntary withdrawal from the study, and re-consenting if willing to re-join the study. Study participants consented to the audio-recording of the counselling session after providing the consent required for routine HIV testing and before the start of the testing procedures. • Enrolment was restricted to patients who underwent HIV testing at the selected study sites, ≥18 years of age, and provided informed consent for participation. To protect confidentiality and encourage the participation of patients in this study; only information on the patient's sex was collected.
Ethical considerations:	• The study was approved by the University of the Witwatersrand Human Research Ethics Committee (160101), the Johns Hopkins University School of Medicine Institutional Review Board, and the Ekurhuleni District Research Committee.
Contribution to the study	• I served as the local Principal Investigator for the study, contributing to the development of the study protocol, development of data collection tools, supervision of data collection activities, and data analysis. USAID funded this study.

3.4 The link between thesis objectives and data sources

Figure 3-4 below shows the connection between the thesis objectives and the parent studies.

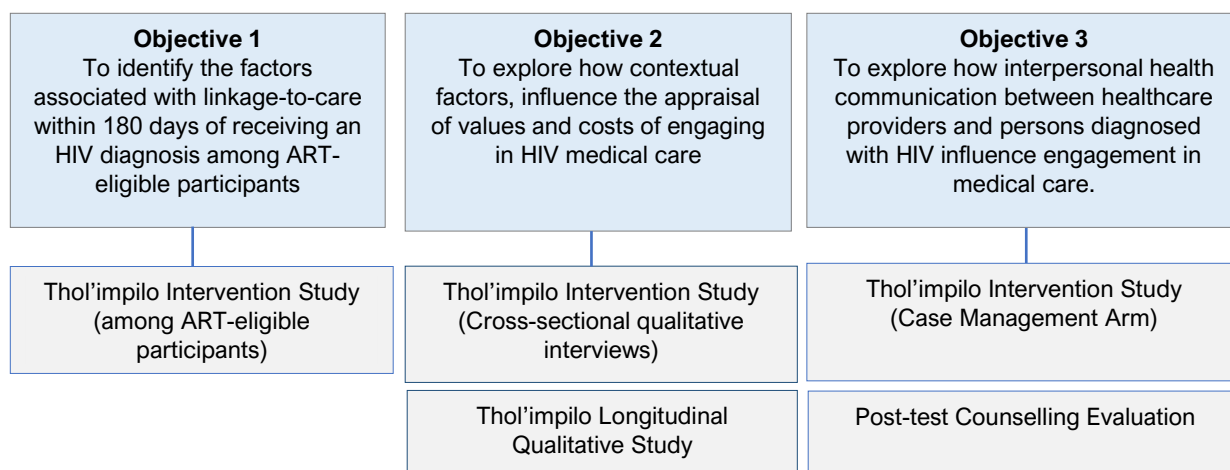


Figure 3-4: Illustration of the link between study objectives and primary studies

3.5 Methods

3.5.1 Objective 1: Evaluation of factors associated with linkage-to-care

Using data from the Thol'impilo Intervention Study (described in Table 3-1), we sought to identify factors associated with linkage-to-care within 180 days of receiving an HIV diagnosis, among ART-eligible participants diagnosed through community-based mobile testing units.

Study population: Participants in three of the four arms of the Thol'impilo Intervention Study were offered POC-CD4 testing immediately after receiving their diagnosis. POC-CD4 measurement used a portable battery-powered POC-CD4 test platform (PIMA, Alere Inc., Waltham, MA) which used capillary blood to provide CD4 count enumeration within 20 minutes (Figure 3-5). After testing, the participant received printed results and counselling on the health implications.



Figure 3-5: PIMA CD4 count machine used to provide POC-CD4 testing

According to the guidelines operational at the time participant enrolment and referral for HIV medical care in the Thol'impilo Intervention Study, participants were eligible to start ART if their CD4 counts were ≤ 350 cells/mm³ [282]. Other criteria for ART initiation stipulated by the guidelines (e.g. being pregnant, having advanced HIV disease (WHO stage 3 or 4), and having active Tuberculosis (TB) disease) were not assessed at the time of diagnosis. Evaluating these additional ART criteria were not part of routine mobile HTS procedures.

For this analysis, we included individuals from the Thol'impilo Intervention Study who: (1) had a POC-CD4 test done, (2) received POC-CD4 test results and counselling regarding ART eligibility at the time of study enrolment, and (3) had a POC-CD4 count ≤ 350 cells/mm³. Using these criteria, we established a sub-group of participants who knew they were eligible to start ART on the day of HIV diagnosis. By selecting participants who knew they were eligible for ART, it allows for contextualisation of the study findings within the current treat-all era, where all persons diagnosed with HIV are eligible for ART.

Explanatory variables: Data on participant socio-demographics were collected at study enrolment. Table 3-4 outlines the variables and categorization of variables). Continuous variables such as age and CD4 count were categorized in age groups and CD4 count strata, respectively. During follow-up interviews, participants reported if they had disclosed their HIV status, and if so, the date when they disclosed. Data on disclosure were used to generate an updated explanatory variable for disclosure of HIV before engagement in care. Calculations of the distance from a participant's residence and the nearest clinic used global positioning system (GPS) coordinates of the place of residence (based on an estimate using Google Earth®) and the GPS coordinates of the nearest clinic or favoured clinic as stated by the participant. We used this approach (i.e. Euclidean distance) as it was superior to both self-report and the road distance (i.e. Manhattan Distance Method) in a study from East Africa [283].

Table 3-4: Overview of socio-demographic factors included in the analysis

Variable	Categorisation	Rationale for inclusion
Age (years)	18 – 30; 31-40; >40	Several studies report an association between age and linkage-to-care. In most studies, younger age is associated with poor linkage-to-care [70,128].
Sex	Male; Female	Several studies report an association between sex and linkage-to-care. In most studies, being male is associated with poor linkage-to-care [70,128].
Country of origin	South Africa; Other	Participants from countries outside of South Africa may experience raised barriers such as the lack of self-efficacy in navigating the health system, or fear of clinic-enacted discrimination based on nationality [284].

District where the participant was enrolled	Urban/peri-urban; Rural	There may exist contextual differences in how care is generally accessed or delivered between urban/peri-urban and rural districts [279]. This variable serves as a proxy for these contextual differences which cannot be fully accounted for by the information collected in this study.
Employment status	Employed; Unemployed	Employed participants (part-time, full-time, or self-employed) may experience higher opportunity costs for engaging in HIV medical care which may result in delayed entry-into-care [70,128].
Number of workdays per week	0; 5 days; 6-7 days	
Highest level of education	None/primary; Secondary/higher	Differences in education level may influence the extent to which participants engage with and derive value from the health education messages (i.e. biomedical benefits of ART or the interpretation of CD4 count results) presented at the time of diagnosis [285,286].
Type of dwelling	Formal; Informal	The nature of the dwelling was used as a marker for the socioeconomic status [287]. Informal dwellings were considered as housing in unplanned settlements (informal settlements) or housing not in compliance with building regulations (i.e. temporary housing structures in the backyard of a formally allocated piece of land)[288].
Distance to referral clinic (km)	≤5; 5-20; >20	Long distances to the referral clinic and the costs associated with travel may raise barriers for linkage-to-care [283,289].
Planned mode of travel to the referral facility	Walk; Taxi/other types of land transport	
CD4 count cells/mm ³ at the time of diagnosis	≤ 100; 101-200; 201-300; > 300	The CD4 count represented a measure of HIV disease progression of HIV. Participants with lower CD4 counts are likely to enter care earlier than those with higher CD4 counts [70,128,290].

Reason for the HIV test	Suspected exposure to HIV infection; Routine test	The value that a person places in knowing their status may also motivate them to engage in HIV medical care after an HIV-positive diagnosis [291]. In this study, participants who suspected exposure to HIV infection included those who reported HIV testing because they had not used condoms during sexual intercourse, mistrust of partners' sexual behaviour, or whose sexual partners had disclosed that they were living with HIV.
The place where HTS was done	Community; Workplace	In this analysis, workplace-based HTS was differentiated from HTS conducted in the general community, commercial shopping areas, or during community events. Findings from previous studies suggest high levels of stigma associated with workplace-based HTS; this may influence linkage-to-care outcomes [30,292].
Previous HIV test and result	No test; Negative; Positive	The study population includes previously diagnosed PLHIV who have never engaged in care. The differences in linkage-to-care by previous testing history have important implications for HIV programmes [70,293].
Relationship status	Not in a relationship; In a relationship	We assessed the role of interpersonal relationships (i.e. being in a relationship or not) in hindering or facilitating early engagement in care. Participants who engage support from their immediate social relationships may enter care earlier compared to those without the self-efficacy to do so. On the contrary, PLHIV who are not in relationships may find it easier to make decisions about their care without the need for additional consultation, which may promote earlier care engagement [65,70].
Knowledge of partner's status	Yes, No	
Willing to disclose status to other people	Yes, No	
Disclosed HIV status (collected during follow-up interviews)	Yes, No	

Study outcomes: The primary outcome was verified entry-into-care within 180 days of enrolment. We used verified entry-into-care because, some participants in the parent study acknowledged that they had incorrectly reported entering care, due to social desirability [202]. We extended the follow-up period beyond the WHO-recommended 90-day period for assessing linkage-to-care, to allow for comparison of our findings with other linkage-to-care studies with longer follow-up times. Verified time to entry-into-care was the first date of care documented in a written or electronic clinic or laboratory records. All participants who reported entry-into-care had verification of self-report. Also, electronic clinical and laboratory records were queried for participants who were unable to be contacted via telephone or home visits. Participant records (HIV registers, CD4 count registers, and clinic files) were abstracted after identifying the record through a name and date of birth. Among participants reporting entry-into-care, if no records were located, the participant was contacted to ask whether they entered care, at which clinic, and what name they used to register for care. Finally, national identification numbers were periodically matched with the South African national vital statistics registry to identify participants who had died and whose death was not otherwise reported.

Statistical analysis: We excluded from this analysis, participants who reported linkage at private health practices if the study team were unable to access records at those health practices). The constructed cohort was followed up for 180 days from the time of enrolment; participants without verified entry-into-care were censored at death or at 180 days after enrolment, whichever occurred first. The baseline characteristics of the cohort were stratified by 180-day verified linkage-to-care outcomes. Frequencies (n) and proportions (%), were determined for all categorical variables. Associations between baseline variables and time to linkage-to-care were analysed using Cox regression and Kaplan Meier proportions [294,295]. Ordered categorical variables were tested for a linear trend and departures from a linear trend using the likelihood ratio test [296]. Univariable regression models between each variable and the primary outcome were performed first. Variables which were associated with entry-into-care at $p < 0.2$, were added to a preliminary multivariable Cox regression model. We used stepwise backward elimination procedures to identify variables for retention in the final multivariable model at $p < 0.05$. All hazard ratios were reported at 0.05 (5%) significance level. Proportional hazards were assessed by testing for interactions between each variable and follow-up time (0-90 days versus 90-180 days per WHO recommended timelines for evaluating linkage-to-care). We used Stata 14.0 for all analyses (STATA Corp., 2015. Stata Statistical Software: Release 14. College Station, TX: StataCorp LP).

3.5.2 Objective 2: Exploring the influence of contextual factors on linkage-to-care

For this objective, I sought to qualitatively explore how contextual factors influence PLHIV in their appraisal of values and costs for engaging in HIV medical care following HIV diagnosis. This objective has two sub-objectives outlined below. For each sub-objective, I provide further details on the data sources, study population and data analysis methods.

- **Sub-objective 1:** To explore how contextual factors influence the way ART-eligible individuals ascribe meaning to their HIV diagnosis and their perceptions on the value of HIV medical care.
- **Sub-objective 2:** To explore how perceptions of clinic-level costs by PLHIV, influence engagement in HIV medical care.

a) Objective 2: Sub-objective 1

We used qualitative data collected from participants in the Thol'impilo Intervention Study (described in Table 3-2), to explore how contextual factors influence the way ART-eligible individuals ascribe meaning to their HIV diagnosis and their values of HIV medical care. We selected participants who knew they were eligible for ART, to contextualise our study findings to the current treat-all approaches for all PLHIV diagnosed HIV-positive.

Study population: In the parent study (Thol'impilo Intervention Study), trained interviewers conducted in-depth interviews from April 2014 to October 2014, with randomly selected participants in each of the four study arms. Participants for in-depth interviews were selected in April 2014, about 12 months after participant enrolment had commenced. Using follow-up data collected up to April 2014, participants who had been under follow-up for at least 120 days (about 80% of the final sample size) and had self-reported 90-day linkage-to-care outcomes, were considered for selection. From this list, 30 participants were randomly for interviewing from each of the four study arms (i.e. standard of care, POC-CD4 only, POC-CD4 and case management, POC-CD4 and transport support).

Study staff contacted the selected participants to invite them to participate in the interviews and obtain informed consent. Interviews were audio-recorded and conducted in four local languages (Sesotho, Sepedi, isiZulu or Xhosa), in-person or telephonically. Trained interviewers used a semi-structured guide which covered topics including participant responses to the HIV diagnosis, coping with the HIV diagnosis, barriers to engagement in care, experiences with the health care system, beliefs and knowledge about HIV, and individual health perceptions. Interviews lasted about one hour, and participants were issued with an equivalent of US\$6 (ZAR50) in cash to cover costs for travel and time, in keeping with

local practice. Immediately after each interview, study staff compiled field notes documenting personal reflections to describe the interview context and methodological issues.

For this study, we selected all interview audio recordings for participants that were issued with a POC-CD4 test result and were eligible for ART under the national treatment guidelines at the time of enrolment (CD4 count ≤ 350 cells/mm³) and informed of their eligibility for ART. A total of 115 out of a targeted 120 participants in the Thol'impilo Intervention Study had in-depth interviews conducted and audio-recorded. Of the 115 interviews conducted, 85 (74%) were among participants assigned to one of the study arms with POC-CD4 testing. Using participant information collected at enrolment, we further excluded 35 of the 80 interviews from data analysis: 30 participants were ineligible for ART (CD4 count >350 cells/mm³), and 5 participants left the testing site without being issued their CD4 results. A total of 50 participants were included in the final analysis (Figure 3-6).

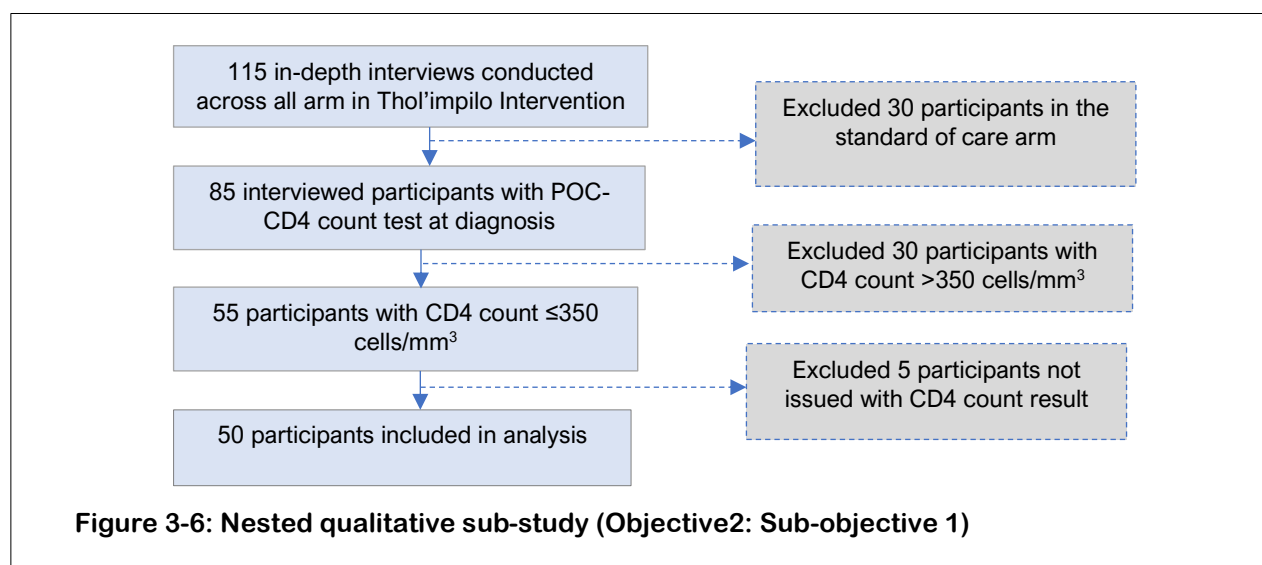
Data analysis: All in-depth interviews selected for this analysis were transcribed and translated into English. We removed all participant identifying information or details of where participants received care from the transcripts. We saved files using a study identification number issued by study staff at enrolment. For quality assurance of the translation process, transcribers conducted peer reviews of each other's transcripts. This process was supervised by the team leader, who also randomly sampled transcripts to assess the quality of transcripts after peer review by transcribers. Query resolution was through discussions among the transcribers and team leaders either in-person, via email or telephonically.

After completion of transcription, myself (TM), and two co-investigators experienced in qualitative research (NM and MH), read and summarised all interview transcripts to familiarise with the data. All data were managed and analysed using NVivo 10™ (QSR International Pty Ltd., Melbourne, Australia, Version 10, 2012) – a qualitative data management and analysis software package. Next, TM, NM, and MH collaboratively developed a preliminary analytical framework/codebook of broad codes based on:

1. How individuals construct their own subjective/situational 'meaning' of medical diagnoses [60]
2. Individual perceptions of values and costs of engaging in HIV medical care [66]
3. Contextual influences at a social-ecological level [95].

This process led to the development of broad codes such as the appraisal of the HIV diagnosis, the personal significance of the HIV diagnosis, the perceived value of seeking HIV medical care, perceived costs of seeking HIV medical care, and contextual influences on appraisal processes.

After assigning definitions to each broad code to ensure consistency in coding, all three researchers applied the broad codes to a few transcripts, and where indicated, revised the codebook to ensure that the broad codes captured relevant patterns from the participant narratives with minimal overlap [297]. Next, using an inductive approach to qualitative data analysis, the three researchers collaboratively developed ‘fine’ codes by reviewing all coded excerpts to create a list of sub-themes emerging from the data [297]. All sub-themes were always compared to the definition of the broader code to ensure that they remained relevant to the coding framework.



b) Objective 2: Sub-objective 2

Using data from the Thol'impilo Longitudinal Qualitative Study (described in Table 3-1), we sought to explore how participant perceptions of clinic-level costs influence engagement in HIV medical care following HIV diagnosis.

Study population: From January 2012 to February 2013, 61 participants were enrolled and followed-up for in-depth longitudinal interviews. Clients testing HIV-positive at mobile HTS units were consecutively invited to participate in the study, immediately following post-test counselling. Clients were eligible to participate in this study if they were:

- Issued with an HIV diagnosis from one of the mobile HTS units
- ≥18 years old
- Capable of providing informed consent
- Not currently engaged in HIV-related care (receiving ART or other regular ongoing HIV-related care).

Data analysis: All in-depth interviews selected for this analysis were transcribed and translated into English. We removed all participant identifying information or details of where

participants received care from the transcripts. We saved files using a study identification number issued by study staff at enrolment. For quality assurance of the translation process, transcribers conducted peer reviews of each other's transcripts. This process was supervised by the team leader, who also randomly sampled transcripts to assess the quality of transcripts after peer review by transcribers. Query resolution was through discussions among the transcribers and team leaders either in-person, via email or telephonically.

After completion of transcription, myself (TM) and a senior co-investigator (CJH), read and summarised all interview transcripts to familiarise ourselves with the data. All data were managed and analysed using NVivo 10™ (QSR International Pty Ltd., Melbourne, Australia, Version 10, 2012) – a qualitative data management and analysis software package. Following the initial reading of all transcripts, TM and CJH categorised all participants according to the participant's self-reported 90-day linkage-to-care status using information obtained during the 90-day or 180-day interviews. We classified participants in this manner to contextualise identified themes with different linkage-to-care outcomes. Participants were categorised into three sub-groups, which included additional sub-categories outlined below. Importantly, the same qualitative data analysis methods described further in this section were applied to all participant subgroups.

- **Sub-group 1: Failure to enrol in care within the first three months of diagnosis**

This group included participants who: (1) reported not attempting to make any clinic visits within 90 days of diagnosis, (2) failed to enrol in HIV medical care after making clinic visits within 90 days of diagnosis, and (3) attempted clinic visits or enrolled in care after 90 days of diagnosis.

- **Sub-group 2: Disengagement from care after initial enrolment**

This group included participants who: (1) disengaged from care after initial enrolment within three months of diagnosis and never returned to care during the 180-day follow-up period, and (2) cycled in and out of HIV medical care during the 180-day follow-up period.

- **Sub-group 3: Early enrolment and sustained engagement in care**

This group included participants who: (1) enrolled in care within the first 90 days of diagnosis and remain in care at the clinic where they started HIV medical care, and (2) enrolled in care within the first 90 days of diagnosis and remain in care with a change in clinics over the 180-day follow-up period.

Next, TM and CJH collaboratively developed a preliminary analytical framework/codebook of broad codes based on the 'value-cost' framework [66], and social-ecological levels of influence on healthcare-seeking behaviour with a particular focus on clinic-level factors [95].

After assigning definitions to each broad code to ensure consistency in coding, TM and CJH applied the broad codes to a few transcripts, and where indicated, revised the codebook to ensure that the broad codes captured relevant patterns from the participant narratives with minimal overlap [297]. This process led to the development of broad codes which covered broad topics listed below:

- The perceived value of HIV medical care
- The perceived value of non-medical HIV care
- Anticipated costs of linkage to HIV medical care
- Experienced costs of linkage to HIV medical care
- Social-ecological influences on the appraisal of values
- Costs on linkage to HIV medical care.

Participant's transcripts were coded separately for each interview attended (i.e. 30, 90, and 180-day interview). Next, using an inductive approach to qualitative data analysis, TM and CJH collaboratively developed 'fine' codes by reviewing all coded excerpts to create a list of sub-themes emerging from the data [297]. All sub-themes were constantly compared to the definition of the broader code to ensure that they remained relevant to the coding framework.

Considering the dynamic nature of individual perceptions on the values and costs of engagement in HIV medical care over time [66], we performed additional analyses by creating a matrix of themes for each participant at the different interview time-points (i.e. 30 days, 90 days and 180 days). From this analysis, we explored individual trajectories over the three interviews with a focus on identifying shifts in the value-cost balance and the influence of care engagement over time.

3.5.3 Objective 3: Exploring interpersonal health communication and linkage-to-care

For this objective, I sought to explore how interpersonal health communication between healthcare providers and persons diagnosed with HIV, influence engagement in medical care following HIV diagnosis. This objective had two sub-objectives outlined below. For each sub-objective, I provide further details on the data sources, study population and data analysis methods.

- **Sub-objective 1:** To describe the content and delivery of structured interpersonal health communication provided through a case management intervention to facilitate linkage-to-care
- **Sub-objective 2:** To explore the extent to which the content and delivery of interpersonal health communication provided by lay counsellors during post-test

counselling sessions in routine public sector health facilities, align to the goals of universal test and treat.

a) Objective 3: Sub-objective 1

We used data collected from the strengths-based case management sessions conducted as part of the Thol'impilo Intervention Study (described in Table 3-2), to describe the content and delivery of structured interpersonal health communication provided through a case management intervention to facilitate linkage-to-care.

Case management approach: Longitudinal case management sessions were provided telephonically or in-person at a mutually convenient and safe location for both the case manager and client (Figure 3-7). Two case managers worked in each study district (i.e. Ekurhuleni and Sekhukhune Districts). The case managers had formal qualifications as either a social worker or an auxiliary social worker. The case managers received additional training on adherence counselling, disclosure counselling, ART guidelines that were in operation during the study period, strengths-based counselling approaches and motivational interviewing techniques.



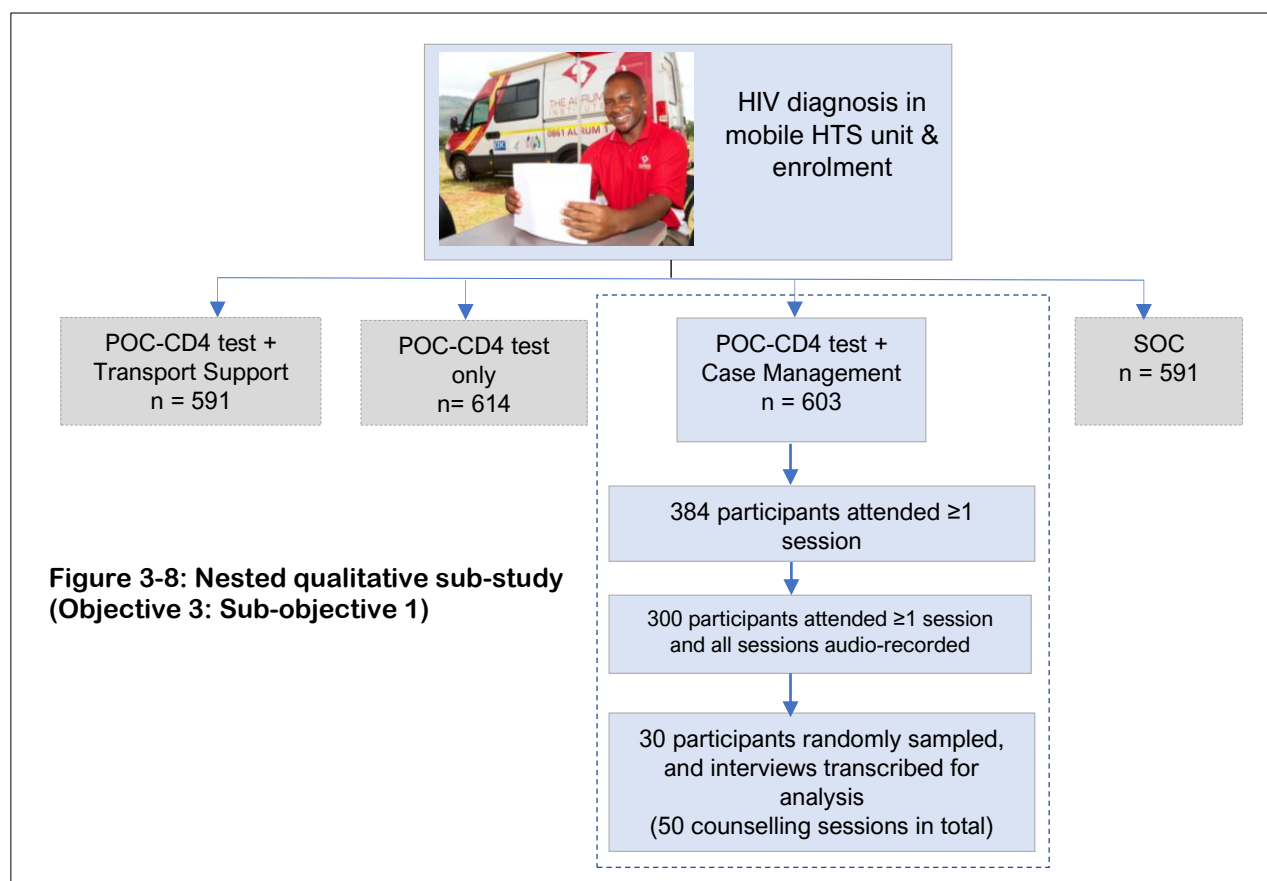
Figure 3-7: Case Manager conducting in-person session with client

Case managers received training to explore immediate client perceptions on the significance of the diagnosis; explore client perceptions on the value of engaging in care and identify context-specific costs associated with seeking HIV clinical care. Also, case managers were encouraged to focus on identifying client strengths, promoting self-efficacy and optimism, adjusting to client resistance with regards to recommendations of healthcare-seeking behaviour, tactfully highlighting discrepancies between the client's values and their

current behaviour, and to express empathy at all times. A senior counsellor mentor provided on-going reflective feedback to the case managers through one-on-one appraisals of audio-recordings and group discussions of case studies. The client was offered five case management sessions which followed a structured curriculum progressing from identifying client goals to determining strengths, and finally entry-into-care. Meetings were discontinued once the five sessions had lapsed, 90 days had passed since enrolment, the participant had entered into care, or the participant requested stopping. Case managers were encouraged to audio-record all case management sessions, provided that the participant consented to the recording. In some instances, when case management sessions happened in public places,

audio-recordings of the meeting were not conducted because of the high background noise, or to avoid drawing attention to the participant with the recorder placed in front of them.

Study population: Of the 603 participants assigned to the case management intervention in the Thol'impilo Intervention study, 384 (64%) attended at least one case management session, and of these, 300 (78%) had all their case management sessions audio-recorded. For this study, we randomly selected 15 participants from each of the two study districts (Ekurhuleni and Sekhukhune Districts) intending to balance the study sample by participant's sex, rural/urban residence, and ART eligibility at the time of diagnosis (CD4 count ≤ 350 and >350 cells/mm³). The audio-recordings of all 30 participants were translated and transcribed; however, transcripts from two rural participants were excluded from analysis after participants disclosed to the case manager that they were in care before enrolment. From the 28 participants (15 urban and 13 rural participants), a total of 50 transcripts were analysed; 30 from in-person sessions and 20 from telephonic sessions (Figure 3-8).



Data analysis: All case management sessions selected for this analysis were transcribed and translated into English. We removed all participant identifying information or details of where participants received care from the transcripts. We saved files using a study identification number issued by study staff at enrolment. For quality assurance of the translation process, transcribers conducted peer reviews of each other's transcripts. This process was supervised

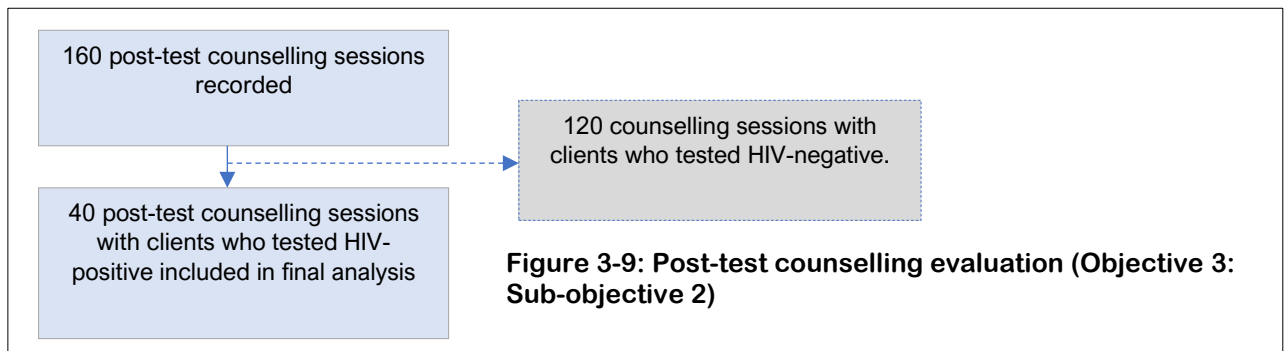
by the team leader, who also randomly sampled transcripts to assess the quality of transcripts after peer review by transcribers. Query resolution was through discussions among the transcribers and team leaders either in-person, via email or telephonically.

A preliminary coding structure was generated *a priori* from principles of patient-centred counselling techniques upon which the intervention was built [84]. After assigning definitions to each broad code to ensure consistency in coding, TM and CJH applied the broad codes to a few transcripts, and where indicated, revised the codebook to ensure that the broad codes captured relevant patterns from the participant narratives with minimal overlap [297]. This process led to the development of codes which covered broad topics such as rapport between the case manager and client, case manager-client collaboration, identifying participant goals, the value of HIV medical care, barriers to HIV medical care, and discontinuation of sessions. Next, using an inductive approach to qualitative data analysis, TM and CJH collaboratively developed ‘fine’ codes by reviewing all coded excerpts to create a list of sub-themes emerging from the data [297]. All sub-themes were constantly compared to the definition of the broader code to ensure that they remained relevant to the coding framework.

b) Objective 3: Sub-Objective 2

Using data from the Post-test Counselling Evaluation (described in Table 3-3), we sought to describe the content and delivery of interpersonal health communication provided by lay counsellors during post-test counselling sessions in routine public sector health facilities. Specifically, we sought to assess whether the delivery of post-test counselling sessions was consistent with patient-centred approaches of counselling and if the health messages aligned with the goals of promoting the value of ART to increase coverage among all PLHIV with an HIV-positive diagnosis.

Study population: We analysed data collected from the Post-test Counselling Evaluation. Of the 160 post-test counselling sessions recorded across the ten health facilities, we analysed 40 (25%) sessions that were with clinic patients who had an HIV-positive test result (Figure 3-9). The sessions included in the analysis were evenly distributed across the ten health facilities.



Data analysis: All post-test counselling sessions selected for this analysis were transcribed and translated into English. We removed all participant identifying information or details of where participants received care from the transcripts. We saved files using a study identification number issued by study staff at enrolment. For quality assurance of the translation process, transcribers conducted peer reviews of each other's transcripts. This process was supervised by the team leader, who also randomly sampled transcripts to assess the quality of transcripts after peer review by transcribers. Query resolution was through discussions among the transcribers and team leaders either in-person, via email or telephonically.

A preliminary coding structure was generated *a priori* using the HIV Counselling and Testing Guidelines for South Africa in use at the time of the study [282], and the value-cost framework of engagement in HIV medical care [66]. Using the HIV Counselling and Testing guidelines, we developed broad codes on:

1. Counselling techniques: we explored the counsellors' use of health communication techniques to promote deliberative dialogue and motivational interviewing with the client (e.g. open questions, affirmations, reflections, summaries, supporting self-efficacy, or developing discrepancy) to provide health messages or education relevant to the client.
2. Counselling content: We also explored the inclusion of core post-test counselling information:
 - The medical meaning of an HIV-positive result
 - HIV as a chronic long-term condition
 - The therapeutic benefit of ART to maintain or restore health and allow living a normal life
 - The recommendation of ART for all HIV-positive people
 - The prevention benefits of ART in reducing sexual and mother-to-child (MTC) transmission of HIV
 - The importance of starting ART as soon as possible

- How disclosure to supportive family or friends can help with coping and treatment success.

Secondly, we applied the 'value versus cost' theoretical framework as the second coding structure. Using this framework, we explored how the counselling content and techniques may have influenced the patient's perception of values and costs of engaging in HIV medical care. After assigning definitions to each broad code to ensure consistency in coding, TM and CJH applied the broad codes to a few transcripts, and where indicated, revised the codebook to ensure that the broad codes captured relevant patterns from the participant narratives with minimal overlap [297]. Next, using an inductive approach to qualitative data analysis, TM and CJH collaboratively developed 'fine' codes by reviewing all coded excerpts to create a list of sub-themes emerging from the data [297]. All sub-themes were constantly compared to the definition of the broader code to ensure that they remained relevant to the coding framework.

CHAPTER 4 : RESULTS

4.1 Introduction

In this chapter, I highlight key study findings, grouping them according to the two main thesis themes outlined below:

1. Factors which influence engagement in care

This thesis theme speaks to the first two constructs of the thesis conceptual framework. Firstly, each person diagnosed with HIV is unique; there is a dynamic interaction between the person diagnosed with HIV, their environment, and the behaviour they seek to perform. In this results section, I start by presenting results from quantitative analyses on factors associated with linkage-to-care among ART-eligible adults diagnosed through mobile HTS. After that, I present qualitative study findings on the considerations made by ART-eligible adults in appraising the significance of the HIV diagnosis and the value of engaging in HIV medical care. In the last part of this section, I present findings on how participant perceptions of clinic-level costs influence engagement in HIV medical care following HIV diagnosis.

2. The role of interpersonal health communication and patient-provider relationships on linkage-to-care

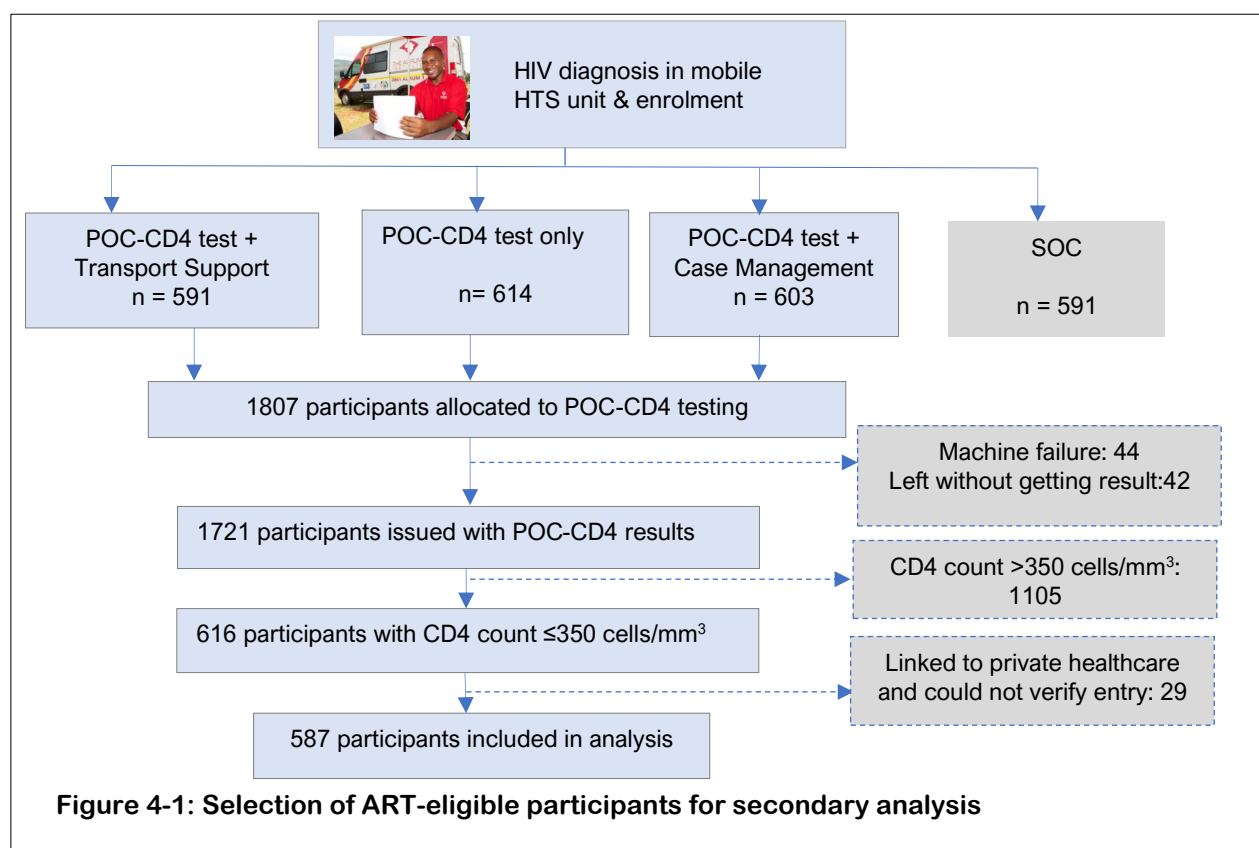
This thesis theme speaks to the third construct of the thesis conceptual framework - care that places the patient at the centre through mutual patient-provider collaboration leads to better outcomes. In this results section, I present results on the challenges and opportunities for patient-centred interpersonal health communication to improve timely linkage-to-care. These findings include the content and delivery of structured longitudinal case management sessions implemented within a research context, and routine post-test counselling sessions offered immediately after HIV diagnosis in public health facilities.

4.2 Factors associated with linkage-to-care among ART-eligible adults

4.2.1 Study participants

From March 2013 to October 2014, a total of 2558 participants were enrolled in the Thol'impilo Intervention Study (Figure 4-1). After enrolment, 1,807 (71%) were randomised to an intervention arm that offered POC-CD4 testing, of which all participants agreed to perform the test. Eighty-six participants (5%) were not issued with their CD4 results on the day of diagnosis, the primary reasons being: machine failure at the time of testing (44, 2.4%) or participants leaving before the machine produced the result (42, 2.3%). Of the 1721

participants issued with a CD4 result, 616 (36%) had a CD4 count ≤ 350 cells/mm³, and were eligible, per guidelines in place at the time, to start ART. Of those issued with a result and eligible to start ART, we could not access medical records to ascertain linkage-to-care for 29 (5%) participants referred to private healthcare facilities or self-reported receiving care at private healthcare facilities. For the remaining 587 (95%) participants, the study team went to the clinics that participants self-reported receiving care, or to the clinic that participants had been referred to at enrolment if they could not be contacted during follow-up.



A total of 587 participants were eligible for analysis (Table 4-1). Overall, 295 (50.2%) were women, the median age was 35 years (Interquartile range (IQR): 28 – 42 years), the median CD4 count was 242 cells/mm³ (164 – 300), and the majority were enrolled from urban study sites (385, 65.6%). Concerning HIV testing: 254 (43.2%) were first time testers, and about a third were testing because of suspected exposure to HIV infection (203, 34.6%). Data on disclosure were collected for 491 (84%) participants; 327 (66.6%) participants voluntarily disclosed their HIV status to another person within the first 180 days of follow-up, and a further 164 (33.4%) disclosed after 180 days of follow-up. Information on the distance to the referral clinic was missing for 30 (5%) of participants, for whom information on the home address was not accurate to establish GPS coordinates which were required to calculate the distance.

Table 4-1: Participant baseline characteristics by linkage-to-care status at 180 days

		Total N=587		No verified linkage N = 264		Verified linkage N = 323	
		n	%	n	*%	n	*%
Study arm	POC-CD4 + Transport	185	31.5	86	46.5	99	53.5
	POC-CD4 + Care facilitation	199	33.9	76	38.2	123	61.8
	POC-CD4 only	203	34.6	102	50.3	101	49.7
Age, years	Median (IQR)	35 (28 -42)	-	34(28-41)	-	36(29-43)	-
	18-30	196	33.4	95	48.5	101	51.5
	31-40	218	37.1	99	45.4	119	54.6
	>40	173	29.5	70	40.5	103	59.5
Sex	Male	292	49.8	142	48.6	150	51.4
	Female	295	50.2	122	41.4	173	58.6
Country of origin	South Africa	493	84.0	219	44.4	274	55.6
	Other	94	16.0	45	47.9	49	52.1
District of enrolment	Urban/peri-urban	385	65.6	179	46.5	206	53.5
	Rural	202	34.4	85	42.1	117	57.9
Employment status	Employed	288	49.1	117	39.1	182	60.9
	Unemployed	299	50.9	147	51.0	141	49.0
Number of workdays per week	0	299	51.0	117	39.1	182	60.9
	1-5 days	188	32.0	93	49.5	95	50.5
	6-7 days	100	17.0	54	54.0	46	46.0
Highest level of education	None/primary	163	27.8	72	44.2	91	55.8
	Secondary/higher	424	72.2	192	45.3	232	54.7
Dwelling	Formal	381	65.0	165	43.3	216	56.7
	Informal	206	35.0	99	48.1	107	51.9
**Distance to referral clinic, km (n=557)	≤5	336	60.3	150	44.6	189	55.4
	5-10	84	24.6	42	46.7	73	53.3
	>10	137	15.1	37	44.1	47	55.9

		Total N=587		No verified linkage N = 264		Verified linkage N = 323	
		n	%	n	*%	n	*%
Planned mode of travel to referral facility	Taxi/other	356	60.6	159	44.7	197	55.3
	Walk	231	39.4	105	45.5	126	54.5
CD4, cells/mm ³ at diagnosis	Median (IQR)	242 (164 – 300)	-	247(169-306)	-	237 (157 – 288)	-
	≤ 100	53	9.0	19	35.9	34	64.1
	101-200	153	26.1	72	47.1	81	52.9
	201-300	235	40.0	97	41.3	138	58.7
	> 300	146	24.9	76	52.1	70	47.9
Relationship status	No relationship	84	14.3	26	31.0	58	69.0
	In a relationship	503	85.7	238	47.3	265	52.7
Reason for HIV testing	Suspected exposure	203	34.6	80	39.4	123	60.6
	Routine test	384	65.4	184	48.0	200	52.0
Place where HTS was done	Community	516	87.9	229	44.4	287	55.6
	Workplace	71	12.1	35	49.3	36	50.7
Previous HIV test and result	No test	254	43.2	123	48.4	131	51.6
	Negative	277	47.2	125	45.1	152	54.9
	Positive	56	9.6	16	28.6	40	71.4
Knows partner's status (n=503)	Yes	64	12.7	29	45.3	35	54.7
	No	439	87.3	209	47.6	230	52.3
Willing to disclose status at enrolment	No	277	47.2	160	57.8	117	42.2
	Yes	310	52.8	104	33.6	206	66.4
***Disclosed HIV status (n=491)	No	164	33.4	105	64.0	59	36.0
	Yes	327	66.6	95	29.1	232	70.9

*row percentages

**Distance from a participant's residence and the referral clinic was calculated using the Haversine Formula by inputting GPS coordinates of the place of residence and referral clinic.

***Data on disclosure were used to generate an updated explanatory variable for disclosure of HIV prior to engagement in care.

POC-CD4: Point-of-care CD4 count at diagnosis; IQR: Interquartile Range

4.2.2 Linkage-to-care outcomes

Participants were followed up for 57,107 person-days or 156 person-years. At 180 days, 323 (55%) participants had verified linkage-to-care (Figure 4-2). The median time to verified entry into care among those who achieved the primary outcomes was 12 days (IQR: 3, 39). 264 (45%) of the participants had no verified linkage-to-care, of these 140 (53%) were still in follow up; 137 (52%) were lost to follow up despite multiple attempts to contact them telephonically or via home visits, and searching both national electronic laboratory records and national registries for death records. An additional 3 (2%) died before entering care.

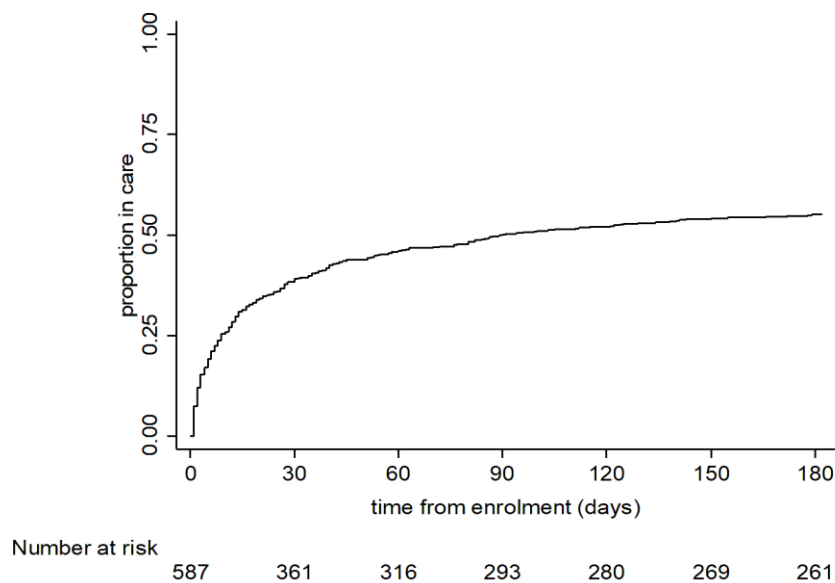


Figure 4-2: Kaplan-Meier estimates of time to verified linkage-to-care within 180 days of enrolment

4.2.3 Factors associated with linkage-to-care

In univariable analysis (Table 4-2), being male ($p=0.05$), being employed ($p=0.003$), a higher number of workdays in a week (test for linear trend $p = 0.01$), routine HIV testing without reported concerns of exposure to HIV or presence of illness symptoms ($p = 0.06$), being in a relationship ($p=0.005$), and a higher CD4 count (test for linear trend $p = 0.07$) were associated with a reduced hazard of linkage-to-care. Further, participants who reported previously testing HIV-positive were substantially more likely to enter care compared with first-time testers ($p=0.003$). Having ever disclosed HIV status to another person within 180 days of follow-up was associated with increased linkage overall with a stronger effect size for men than women (p -value for interaction $p = 0.006$). Testing in the more urban area, participant's age, country of origin, the highest level of education, the reason for testing, knowing partner's HIV status at the time of diagnosis, and distance to referral clinic, were not associated with time to linkage-to-care (all $p>0.1$).

We considered the following variables for inclusion in multivariable analysis: participant's sex, employment status, the number of workdays in a week, CD4 count, relationship status, and reason for HIV testing, HIV testing history. Collinearity diagnostics using Pearson's correlation coefficients revealed a strong collinear relationship between employment status and the number of days worked in a week (correlation coefficient = 0.90, $p < 0.0001$). For multivariable analysis, we retained the number of days worked in a week and dropped employment status because the latter provided more detailed information on the potential association between the levels of time constraints and the time to linkage-to-care. We did not identify any additional collinear variables.

In the multivariable model ($n=491$), being in a relationship (adjusted hazard ratio (AHR) 0.69, (95% CI 0.51 – 0.94) compared to no relationship was associated with lower linkage-to-care (Table 4-2). Participants with a previous HIV-positive diagnosis, but who had not previously engaged in care were more likely to link-to-care compared with first-time testers (AHR 1.52, 95% CI 1.04 – 2.21). However, there was no difference between first-time testers compared with those who had previously tested negative (AHR 1.05, 95% CI 0.81 – 1.35). The interaction between disclosure and the participant's sex remained significant (p -value for interaction = 0.002). The effect of disclosure on the hazard of linkage-to-care was stronger among men (AHR 4.56, 95% CI 2.79 – 7.43) compared with women (AHR 1.84, 95% CI 1.27 – 2.67). Results for multivariable analyses are presented in Table 4-2 and represented for each significant variable in Figure 4-3. In adjusted analyses, there was no evidence of non-proportional hazards for all the variables using Schoenfeld residuals.

Table 4-2: Analysis of factors associated with verified linkage-to-care at 180 days

		Unadjusted Hazard Ratio (95% CI)	*Adjusted Hazard Ratio (95% CI)
Sex	Female	1.00; $P = 0.05$	1.00; $P = 0.74$
	Male	0.81 (0.65 – 1.00)	0.95 (0.72-1.27)
Age	18-30	1.00; $P^T = 0.19$	-
	31-40	0.29 (0.89 – 1.51)	
	>40	1.29 (0.98 – 1.69)	
Country of origin	South Africa	1.00; $P = 0.50$	-
	Other	0.90 (0.66 – 1.22)	
Region	Urban	1.00; $P = 0.20$	-
	Rural	1.16 (0.92 – 1.45)	
**Employment	Unemployed	1.00; $P = 0.01$	-
	Employed	0.74 (0.60 – 0.93)	
Number of workdays per week 0		1.00; $P^T = 0.01$	1.00; $P^T = 0.21$

		Unadjusted Hazard Ratio (95% CI)	*Adjusted Hazard Ratio (95% CI)
	5 days	0.74 (0.58 – 0.95)	0.80 (0.61 – 1.07)
	6-7 days	0.66 (0.47 – 0.91)	0.77 (0.53 – 1.12)
Highest level of education	None/primary	1.00; P=0.60	-
	Secondary/higher	0.94 (0.73 – 1.19)	
Dwelling	Formal	1.00; P=0.32	-
	Informal	0.89 (0.70 – 1.12)	
Distance to referral clinic, km	≤5	1.00; P ^T = 0.85	-
	5-10	0.95 (0.72 – 1.25)	
	>10	1.05 (0.77 – 1.45)	
CD4 count, cells/mm ³	≤ 100	1.00; P^T = 0.07	1.00; P ^T = 0.30
	101-200	0.75 (0.50 – 1.12)	0.96 (0.61 – 1.49)
	201-300	0.85 (0.58 – 1.24)	0.99 (0.66 – 1.50)
	> 300	0.62 (0.41 – 0.93)	0.74 (0.48 – 1.18)
Relationship status	No relationship	1.00; P=0.01	1.00; P=0.02
	In a relationship	0.66 (0.50 – 0.89)	0.69 (0.51 – 0.94)
Reason for test	Suspected exposure	1.00; P=0.06	1.00; P =0.35
	Routine test	0.80 (0.64 – 1.01)	0.89 (0.70-1.13)
Place where HTS was done	Community	1.00; P=0.41	-
	Workplace	0.86 (0.61 – 1.22)	
Previous HIV test and result	No test	1.00; P=0.01	1.00; P=0.72
	Negative	1.05 (0.83 – 1.33)	1.05 (0.81 – 1.35)
	Positive	1.70 (1.19 – 2.42)	1.52 (1.04 – 2.21)
Knows partner's status	No	1.00; P=0.80	-
	Yes	1.04 (0.73 – 1.49)	
Disclosed HIV status - male	No	1.00; P<0.001	1.00; P<0.001
	Yes	4.48 (2.77 – 7.24)	4.56 (2.79 – 7.43)
Disclosed HIV status - female	No	1.00; P<0.001	1.00; P=0.001
	Yes	1.86 (1.29 – 2.66)	1.84 (1.27 – 2.67)

*Adjusted for intervention arm, sex, workdays per week, relationship status, previous testing history, and CD4 category adjusted for each other in complete case analysis

**employment not added to multivariable model due to collinearity with number of working days

P: p-value for main effects of previous HIV test as a whole variable

KM: Kaplan-Meier; HR: Hazard Ratio; CI: confidence interval, P^T: p value for linear trend

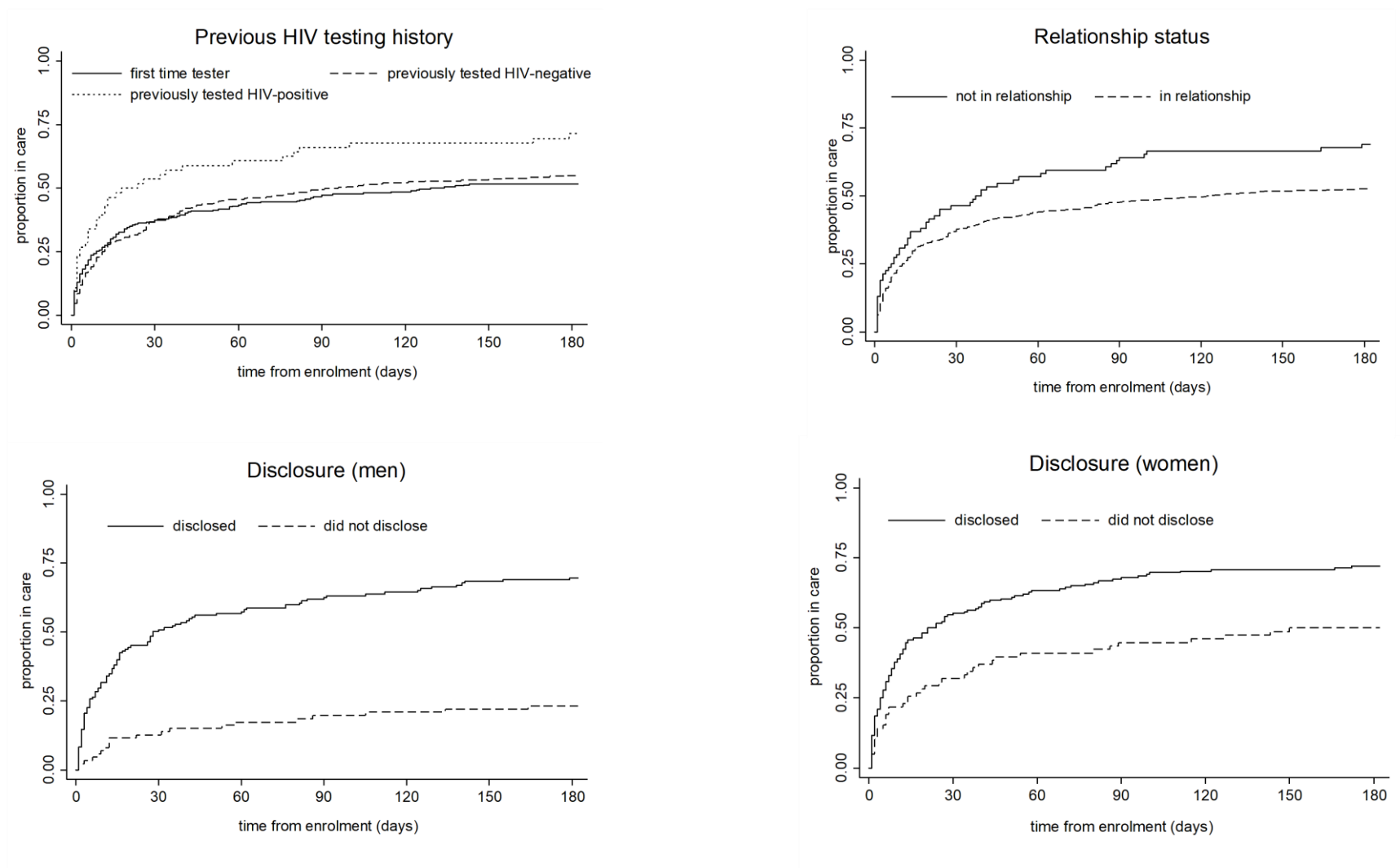


Figure 4-3: Kaplan Meier estimates of linkage-to-care by 180-day, by risk factor in the final multivariable model

4.3 Strengths and limitations

For this component, we had the benefit of POC-CD4 results for a large number of participants at the time of HIV diagnosis. At the time of the study, POC-CD4 testing and immediate availability of results (i.e. within 20 minutes) were not standard of care [282]. Also, among the few research studies that had used POC-CD4 testing at the time of diagnosis, none had large numbers of participants aware of their ART eligibility at the time of HIV diagnosis comparable with the Thol'impilo parent study [192,194,196]. Therefore, our study was able to show the magnitude of the delays in linkage-to-care among ART-eligible PLHIV and forecast the potential pitfalls of UTT programmes in the absence of interventions to improve linkage-to-care. Further, our outcomes were based on verified linkage-to-care. Verifying linkage-to-care involved rigorous paper and electronic record searches at over 200 referral clinics. Verification of linkage-to-care is important, given that some studies have shown that participant self-report may overestimate linkage-to-care by 20% to 30% compared to verified linkage-to-care outcomes [298].

However, there are limitations of the quantitative study component. About 24% of all participants included in the quantitative analysis, were lost to follow up despite multiple attempts to contact them telephonically or via home visits and searching both national electronic laboratory records and national registries for death records. In addition, linkage-to-care may have been underestimated due to inadequate record-keeping or backlogs in updating of patient records at the district clinics. Although the use of three distinct sources of verifying linkage-to-care may have minimised this limitation, it is unlikely to have eliminated the problem. Also, our search for participant health records was mainly based on participant names and dates of birth, as a key variable for probabilistic matching. This method may have also resulted in missing some participant clinic records. The lack of unique patient identifiers in South Africa poses a substantial challenge to documenting the journey through the care continuum for a single individual. Other weaknesses of the quantitative study component include missing data for some variables such as GPS coordinates required for calculating the distance to the clinic, and the non-collection of data to quantify the extent to which migration and mobility of participants, may have influenced care engagement outcomes.

4.4 Appraisal of the HIV diagnosis and the value of HIV medical care among ART-eligible individuals

4.4.1 Study participants

We included 50 ART-eligible participants in this analysis, of which 28 (56%) successfully engaged in care within the first three months of study enrolment. The sample was relatively balanced by the participant's sex, employment status, and previous HIV testing history. Table 4-3 summarises selected participant characteristics stratified by care engagement status at three months of study follow-up.

Table 4-3: Baseline characteristics of ART-eligible in-depth interview participants

		Total (N=50)	Engaged in care within three months (N=28)	Not engaged in care within three months (N= 22)
Residence	Rural	16	11	5
	Urban	34	17	17
Age (years)	Median (IQR)	36 (28-48)	40 (29-49)	32 (27-48)
Gender	Male	25	12	13
	Female	25	16	9
Study arm	POC CD4 only	22	12	10
	*POC CD4 + additional support	28	16	12
Employment status	Employed	23	11	11
	Unemployed	17	17	11
In a relationship	No	9	6	3
	Yes	41	22	19
Previous HIV testing	First-time tester	23	14	9
	Previous tester	27	14	13
CD4 count cells/mm ³	Median (IQR)	220(143-306)	214 (137-258)	248 (150-321)

POC-CD4: Point-of-care CD4 count at diagnosis; IQR: Interquartile Range

* additional support = care facilitation and transport support

4.4.2 Themes

We identified two principal themes that influenced participants' behavioural intentions in seeking HIV medical care. Firstly, we identified factors which influence acceptance of the HIV test result by ART-eligible individuals, before they contemplate performing any action to engage in HIV medical care. Secondly, we identified the factors that ART-eligible individuals consider when they appraise the value of HIV medical care. We did not identify any differences in themes by participant's sex, age or site of enrolment (i.e. rural or urban). Also, we did not find value in separating the themes by 90-day entry-into-care status, since there were similarities in the appraisal processes and the influence of contextual factors among

participants in both groups. Therefore, all results are combined for all participants and reported under the two main themes.

A. FACTORS WHICH INFLUENCE ACCEPTANCE OF THE HIV DIAGNOSIS

1. The need to re-test and confirm the HIV diagnosis

Two participants immediately challenged the accuracy of their HIV test results, including the CD4 count results, which showed that they had advanced HIV disease. They delayed seeking HIV medical care by prioritising repeat HIV testing and placing a high value on a hoped-for negative result. One participant doubted the reliability of rapid HIV test devices once he tested positive. The other participant explained how she did not believe the HIV positive result because she perceived herself to be at low risk of being infected with HIV:

“It has been 3 or 4 years ever since I broke up with my boyfriend. So, after that, I did not have a boyfriend. That is why I was shocked, and like I said before - I had tested before, and the results were negative. This was after I had broken up with him. I went to the doctor to prove whether I am really positive.” - Female (F), 31years (y), CD4-337cell/mm³, not in care at three months

Both participants also related scepticism regarding the accuracy of HIV tests that was re-enforced by their social networks. They both explained:

“I told my cousin and my sister. They were also shocked because they knew me as a person who holds proper conduct. So, I went to the doctor to prove whether I am positive” - F, 31y, CD4 -337cell/mm³, not in care at three months

“My friends told me to go back and get tested again...Aah! Even them, they are not sure about this thing. They said, No! Go get tested again so that you can be sure about it.” - Male (M), 31y, CD4 - 253cell/mm³, not in care at three months

Although both participants talked about the urgency of re-testing; it was only the female participant perceiving herself to be at low risk of HIV infection, who repeated the HIV test. After an HIV-positive repeat test, she made a transition from denial to acceptance and engaged in clinical care. She said: *“I just accepted it because I was ready for anything”*. Conversely, the other participant, supported by the scepticism of his social network, did not seek any re-testing services and had not engaged in care three months from the time of diagnosis.

2. Searching for causal attributions

Some participants did not explicitly challenge the HIV diagnosis but searched for causal attributions by questioning how they could have become infected with HIV. This often

resulted in prolonged periods of assessing whether the diagnosis was plausible, leading to delays in care engagement for some participants. One participant talked about how she delayed the decision to fully accepting her HIV diagnosis when her partner told her that he was HIV negative. At the same time, she believed that she had been loyal to this one partner. The HIV status discordancy in the partnership and the scepticism from her partner on the questionable quality of free mobile HIV testing services prolonged the time to initial engagement in HIV medical care. She explained:

“I spent the whole month, not believing. I did not believe it because I was not running around, and I was sleeping with one partner. He said those things (HIV testing kit) make mistakes, but I said no, they do not make mistakes. He says things from the street do make mistakes... But I tell myself that the results cannot tell me lies, but these are confusing me. I was asking myself - is it possible for them (results) to be in this way.” - F, 29y, CD4 -234cell/mm³, 44 days to care

Another participant, who sought causal attribution for the HIV diagnosis, talked about how he eventually gave up on this search and started making progressive moves to accept and address the diagnosis. He said – *“Finding out how I got infected, was no longer important. The priority was to go on with my life.”*

In cases where participants suspected exposure to HIV infection, contemplations over causal attributions were less protracted, leading to earlier acceptance of the HIV diagnosis. This was the case for two participants; one knew that her sexual partner was living with HIV, and the other had strong suspicions that his sexual partner was living with HIV. Both participants talked about how they easily accepted the HIV diagnosis, with both seeking HIV medical care within a month of diagnosis. In the quotes below, the two participants talked about how they were prepared for an HIV positive diagnosis:

“I already knew (that I would test HIV positive) because my husband died due to this disease. They found that it is there you see, but I was not scared because like I said, my husband was sick... He died this month.” - F, 48y, CD4 -211cell/mm³, 26 days to care

“It’s something I had prepared myself for when it happens because it is what made me go and test in the first place. It’s because I do not trust the person that I am dating - I don’t trust her in a lot of things.” - M, 33y, CD4 -205cell/mm³, 8 days to care

3. Influence of POC-CD4 results

Receiving CD4 count results immediately after HIV diagnosis, showing an impaired immune system, also helped promote acceptance of the HIV diagnosis among some participants.

Three participants who had been diagnosed with HIV before (but not in care) explained how seeing their low CD4 count results prompted them to question their decisions of not believing their previous HIV diagnosis. One participant described this transition:

Denial of previous diagnoses: “When they told me that I have it (HIV), I said to myself - No they are joking, I have nothing, I only have a womb problem. You see what I am saying. So, I relaxed.”

Shift after POC-CD4 count test - “When they checked me, they said it is there (HIV) indeed, and they said to me my CD4 count is very low... I did not even waste any time. I went to the clinic. I got a letter which I took it to the clinic.” - F, 42y, CD4 -220 cell/mm³, one day to care

4. Voluntary disclosure of HIV status by sexual partners

In some cases, the voluntary disclosure of an HIV-positive status by sexual partners of study participants also helped to overcome non-acceptance of the HIV diagnosis. One participant mentioned how he only accepted his HIV diagnosis when his wife disclosed that she had also received an HIV diagnosis:

“The thing is at the mines there is this tendency of saying that we are sick so that they can cut down on production. I just thought they were talking about something that does not exist, but when it kept repeating itself, that is when I saw that this thing is serious. I recognised that something is very wrong; I need to start taking it seriously. I only realised now that this thing is serious because my wife is now telling me that she has also been told the same thing (HIV positive diagnosis) ... It is starting to worry me now. All this time I just took it as a joke.” - M, 34y, CD4 -333cell/mm³, not in care at three months

B. FACTORS WHICH INFLUENCE THE VALUE PLACED ON HIV MEDICAL CARE

1. Life goals and valued states of being

When participants talked about the value of engaging in HIV medical care, they often referred to important life goals. Several participants spoke in general terms about how they wanted to continue with their ‘normal’ lives. Many participants also talked about not wanting to be sick, weak or bedridden. These were highly disvalued states that were often associated with increased chances of death, loss of functional independence, loss of economic productivity or loss of social identities.

Parental responsibilities were among the key commitments that increased the value of ART from the increased longevity it could offer. Five participants talked about the importance of starting treatment to continue with their parental responsibilities. These participants mentioned how concerns over their children were among the first thoughts that came to mind when they made the initial appraisals of the threats posed by being HIV positive and the actions that they needed to make. Two participants quoted below, provided different perspectives on how HIV treatment aligned to their parental responsibilities, although this did not always translate to early engagement.

“The thing that made me take the treatment is that I still want to live, I still have a future. I still want to raise these girls that I have. I don’t want the mistakes that I have made to make me die in a short time without seeing where my children will end up.” - M, 37y, CD4 -206cell/mm³, 11 days to care

“I don’t want him (son) to grow up without a dad as well. We should give him all the support that he needs in life so that he can become what he wants to be. Not like us who had to force everything in life, you understand.” - M, 25y, CD4-315cell/mm³, not in care at three months

One participant talked about the importance of treatment with regards to increasing the chances of starting a family, which promoted the value placed on seeking HIV medical care.

“With regards to children, my wife is still negative; she is still testing negative. They told her that she needs to come and test; she tests negative. As it stands, my CD4 count is too low. I think it was 295. So, they advised me to wait until it gets to 450 or above. And then I can bring my wife. They will give us pills; I forgot the name of the pills we will use them then we can have the child.” - M, 37y, CD4 -206cell/mm³, 11 days to care

2. Modelling behaviour and avoiding regret

Several participants modelled health-seeking behaviours from individuals in their social networks, who were living with HIV and had achieved favourable health outcomes. On the other hand, participants also spoke about avoiding following the path of other people they knew who had delayed engaging in HIV medical care. They associated these delays with highly disvalued states of disease and premature death.

Six participants talked about close people who died from AIDS-related illnesses, and how these deaths were preventable if the people had accepted their HIV diagnosis, accessed medical treatment earlier, or avoided reliance on non-medical care. Participants recounted the losses of their spouses, children, siblings, and friends. The fear of anticipated regret from delayed engagement in HIV clinical care appeared to promote urgency of clinic visits, with all

six participants successfully entering care within two months of receiving their HIV diagnosis (range: 0- 54 days).

One participant who had experienced the loss of her husband explained:

"I just told myself that "my partner, has passed on", that means if I don't take treatment, I will also die like him. I looked after him, and I could see how sick he was. He could wake up, doing nothing. When I told him to eat, he did not want to eat. He did not want to do anything. I saw that with my own eyes... I could see that "Mmm, here, I must take treatment". And indeed, I took it; I don't have any illness or anything." - F, 53y, CD4 - 153cell/mm³, 39 days to care

Another participant who re-tested at the study site to confirm a previous HIV-positive diagnosis, explained how witnessing HIV-related deaths in her extended family motivated her to place a high value on seeking HIV medical care:

"My brother and his wife said the clinic was telling them lies (that they were HIV positive). They were afraid to go to the clinic up until they died in the house. The whole family passed on, and there was no one left - even the children passed on. I told myself that I could not just delay. To know it is not the same as not knowing, because if you know your status, you can start with the pills. Had I delayed, maybe I would also be dead." - F, 42y, CD4 -220 cell/mm³, one day to care

3. Health education and counselling

One participant who identified herself as a traditional healer highlighted the potential of how health education can promote the value of HIV medical care and alter belief systems rooted in non-allopathic care. The traditional healer talked about the knowledge that she had gained from a series of HIV workshops. She also mentioned how her understanding of the limitations in traditional medicine increased the value she placed on HIV medical care:

"I am not like other traditional doctors that might say that it is witchcraft or something else. I understand that I have a virus, and I must deal with it with western medication because our traditional remedies don't have a cure for it. I attend workshops. The fact that I am a traditional doctor seeking western medication for the illness that I have should be an indication that I am clued up and informed about HIV and AIDS. You understand!" - F, 37y, CD4 -60 cell/mm³, 47 days to care

Ongoing longitudinal follow-up provided by case managers in the parent study, assisted some participants in shifting their perceptions towards seeing the value in seeking HIV medical care. One participant talked about how interactions with study staff and the study

interviewer, helped him address issues of temporal discounting that had resulted in delaying HIV care engagement.

"If no one was following up on me (case manager) it would have turned out differently. When I saw people outside, I used to tell myself that I will not have this thing (HIV), it is things like that. I didn't expect it. I asked, "Why me?" I had to reach a point of accepting, but what helped me most was talking to you to help me realize that there are things such as these. After meeting with you (interviewer), I felt that I have to go to the clinic because I was still waiting to have pains, and that did not happen. I followed your advice that I should go to the clinic regardless of how I feel so that I can get the pills, and also get myself checked." - M, 68y, CD4 -117 cell/mm³, not in care at three months

4. Social support and pressure

After voluntary disclosure of their HIV-positive diagnosis, participants also mentioned the influences from people within their social networks in promoting the value of HIV medical care. The influence of social networks ranged from subtle persuasion to more heavy-handed pressure to engage in medical care. Most participants talked about influence from other people living with HIV, spouses or partners, family and religious leaders.

One participant explained how a friend's disclosure of their HIV status, eventually prompted him to shift from utilising traditional medicine to HIV medical treatment:

"I was sick, and then I thought it is better if I go to a black person, I can say that it is an African doctor (traditional doctor) ...He treated me; he made me steam. I was able to cook and eat, and I did not run to the toilet (no diarrhoea) you see. Then there was this friend of mine who said that I should go to the clinic, and I should stop going to African doctors. I refused at first, until he told me that he had been in the same situation before (disclosed his HIV status). On that day, I hurried up to the clinic. I almost died for nothing, but I am alright now, you see." - M, 53y, CD4 -87 cell/mm³, not in care at three months

Several participants mentioned voluntarily disclosing their HIV-positive status to their spouses or partners, and how they received reinforcement for their decisions to access medical care.

When asked what led to initial care engagement, one participant explained:

"It's because my woman told me to go and check because if I don't do that, she is afraid I die, they will suffer from hunger. She said, If I refuse to take my treatment, will God take me early and our children will die of hunger, but if I take the necessary treatment, I might live longer. I will see my children grow, and by the time I pass on,

they will be old enough to do things on their own. It put me under pressure to go to the clinic.” - M, 34y, CD4 -333cell/mm³, not in care at three months

In other examples, the pressure from social networks was less subtle compared with the example above. One participant talked about her brothers, who knew that her late husband had died from AIDS-related illnesses because he had not gone to the clinic. When the brothers found out that she was taking traditional medicine – they pressured her to go to the clinic:

“They (brothers) told me to go to the clinic because they knew my husband was sick (living with HIV). I was taking traditional medicine, and then they told me to stop and go to the clinic. I then stopped taking traditional medicine” - F, 48y, CD4 -211cell/mm³, 26 days to care

Some participants also talked about an internalised burden that they had placed on themselves to engage in HIV medical care, in response to what they believed were the expectations of people who were taking care of them. These subjective norms were more significant among participants who were receiving support from their family or friends. Two examples are quoted below:

“I felt happy, and I said I am getting support at least there are people who encourage me, so I must not just sit, I must go!” - M, 48y, CD4 -297cell/mm³, 14 days to care

5. Alternative sources of HIV care

HIV medical care was not the only available source of care that participants sought or the care that they sought first. Some participants decided to maintain their traditional or religious belief systems in response to the HIV diagnosis. While this eventually shifted for most participants through social influence or health education; one participant remained resolute in her religious beliefs as the only source of interpretation and relief for her diagnosis:

“I found that my CD4 count has dropped. After that, I realised that I don’t have a solution - ARV’s are not for me. I started to go to church. I realised that it is time for me to concentrate on God; he is needed. When I started to go to church, I told myself that I am not ill, even from the start I told myself that I am not ill... Since I have tested positive, I haven’t done anything. I am just saying time will come maybe God is still busy working on me, he is healing me. I am not in a hurry. I will go and test. Now I can see that under God, people are being cured. People can believe what they want to believe, but I believe that God is there, Satan came with this disease, and it will be cured.” - F, 30y, CD4 -243cell/mm³, not in care at three months

In another example of alternatives to medical care, one participant narrated how he had delayed starting HIV treatment after complying with the counsel from his mother to place more weight on divine religious healing over seeking medical treatment. However, further discussions with his church leader prompted him to re-evaluate this decision and align his healthcare-seeking behaviour to his own healthcare beliefs – seeking medical treatment.

“The reason that I took a long time to go to the clinic is that I was living with my mom, and we go to the same church. Her faith is stronger than mine. After telling her that I have this condition, she told me not to take the treatment because God would help me. I listened to her. I then moved from home to live at church, that is when the pastor and his wife told me to not to do things according to her, as this is my life.” - M, 20y, CD4 -336cell/mm³, 82 days to care

6. Competing life priorities

In some instances, competing life priorities superseded the immediacy of seeking medical care. One participant pointed out how the value of seeking employment outweighed the urgency of seeking medical treatment. The participant acknowledged the need for medical care, but in his appraisal had concluded that he first needed to seek employment so that he could also be able to buy food which he considered necessary for taking HIV treatment. Inadvertently, the challenges of getting a job, led to delays in care engagement until the participant developed TB, which prompted him to seek care. By that time, his CD4 count had dropped from 330 cells/mm³ at the time of diagnosis to 160 cells/mm³ at the time of care engagement:

“I already knew that I am HIV positive as I used to test but seeing my CD4 count so low it was for the first time. I didn't expect it to be that low, but I accepted and told myself that I have to take treatment so that I can be okay...I understood that it (CD4 count) was very low, so I tried hard to take care of myself to increase my cd4 count – but I was having a lot of stress from seeking employment at that time” - M, 36y, CD4-160cell/mm³, not in care at three months

7. Temporal discounting

The lack of disruptive illness symptoms at the time of diagnosis also resulted in prolonged periods of contemplating the value of HIV medical care, before taking any action. One participant narrated how a lengthy period of searching for causal attributions, coupled with the absence of disruptive symptoms, led to delays in placing value on HIV medical care and subsequent delays in making a clinic visit:

"I thought a lot. I just wanted to be alone. I kept on asking myself how I got this thing – how did it happen? How will I live? - I don't know. I thought to myself, let me just wait and see. I just told myself that I want to see first what will happen, if any changes would happen to me. There haven't been any changes happening to me. That is why, even now, I haven't been to the clinic. That is true; I want to see what will happen. I want to see if there will be any changes. I haven't seen them since I have tested, and I haven't been to the clinic." - M, 68y, CD4 -117 cell/mm³, not in care at three months

8. Fatalism

In one case, a participant exhibited a fatalistic view in response to the HIV diagnosis. He referred to a predetermined fate of death, and that living with HIV had no bearing on when he was fated to die. As such, he did not place any value on HIV medical care:

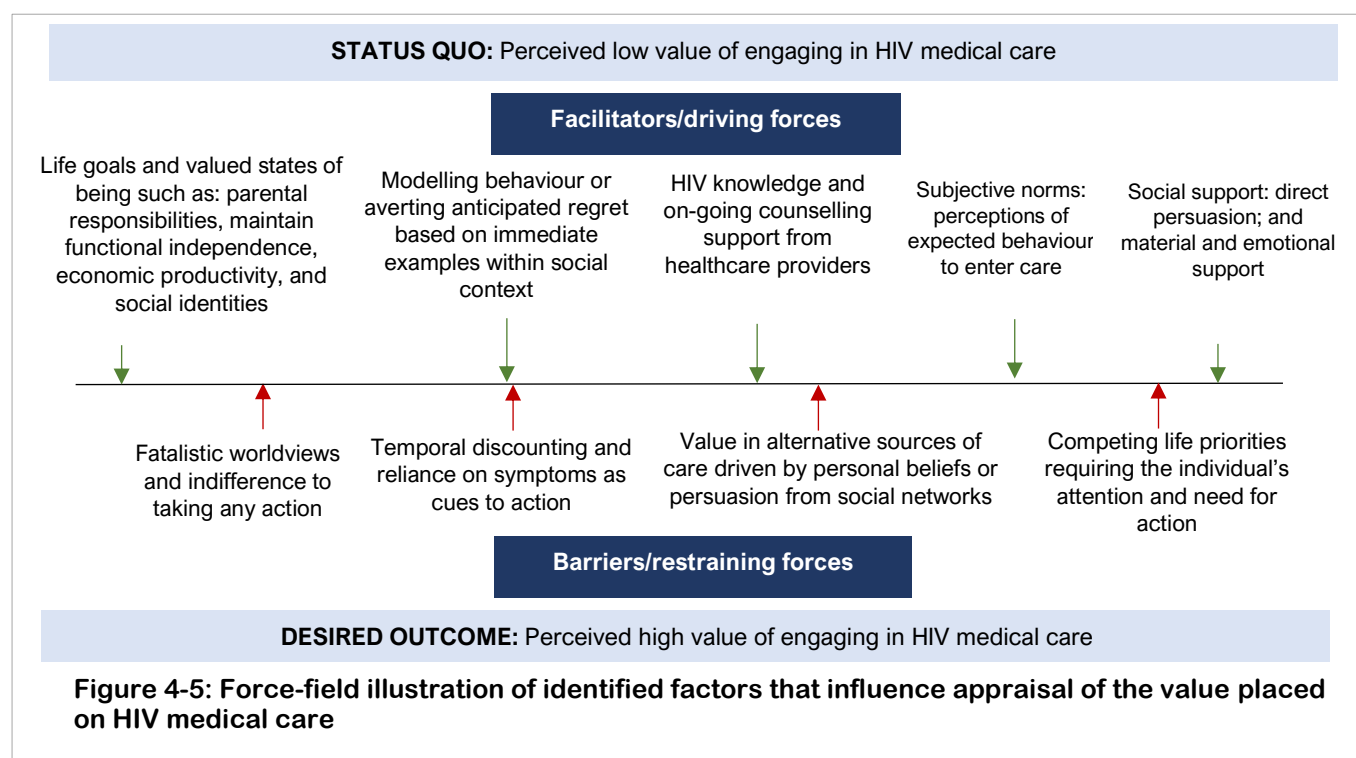
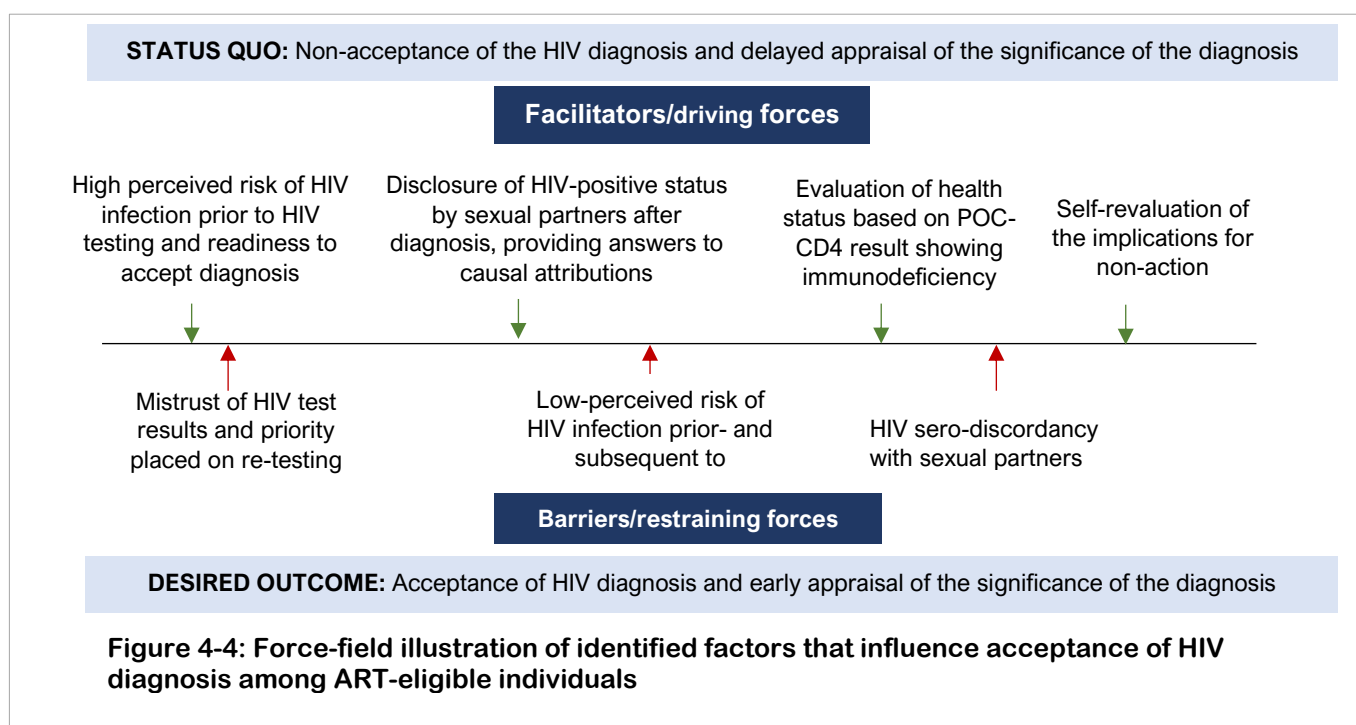
"No, no, no. I'm saying, since if found out that I am HIV positive I have always maintained that HIV is just a disease I mean it's just a virus...I am not taking anything, but life is in me, and death is in me. I carry them daily. Do you get me? I am going to choose between the two. Do I want to die, or I want to live? By just accepting my status, I'm fine. I am HIV positive, so what? Do you know that I sometimes forget that I'm HIV positive? I only remember when you phone. It is fear that is killing us!" - M, 51y, CD4 - 216 cell/mm³, not in care at three months

4.5 Strengths and limitations

This analysis provides balanced perspectives from both groups of participants with timely or delayed linkage-to-care. Our findings focus on the trajectory of healthcare-seeking decisions among a group of adults aware of their ART-eligibility at the time of diagnosis. This strength allows us to signal some of the barriers and facilitators that programme implementers are likely to encounter as HIV programmes continue to optimise UTT policies. A limitation of this analysis and qualitative research in general, is that our findings are primarily representative of the value and costs identified or expressed by participants. The findings presented may not be inclusive of what operates subconsciously, what they cannot put into words, what doesn't seem reasonable to explain to someone, or what is too sensitive to say.

4.6 Summary of findings

Figures 4-4 and 4-5 below are force field illustrations [299] of the factors identified to influence acceptance of the HIV diagnosis and appraisals of the value placed on HIV among ART-eligible individuals.

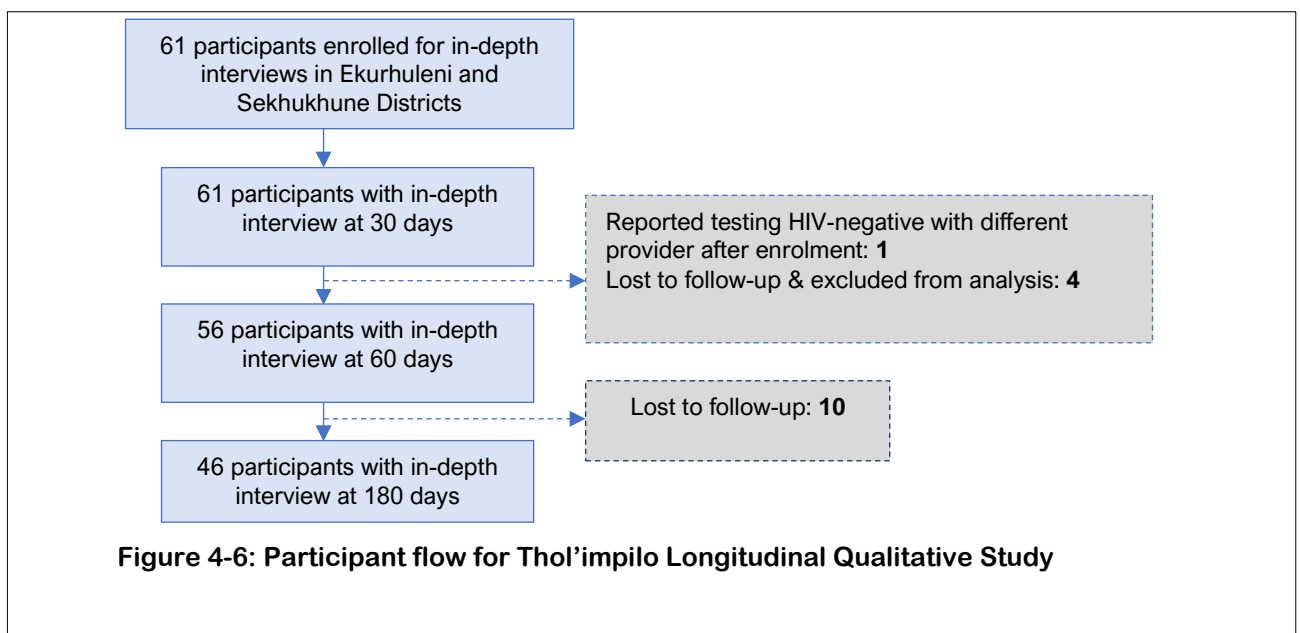


4.7 Clinic-level factors and engagement in HIV medical care

4.7.1 Study participants

From January 2012 to February 2013, 61 participants were enrolled and followed-up for in-depth longitudinal interviews. All 61 participants attended the 30-day interview. Four participants were lost to follow-up after the first interview and were excluded from the final analysis since we sought to explore how participant decisions to enter care changed over time. Also, at the 60-day interview, one participant reported subsequently receiving an HIV-negative test result after a repeat HIV test with a different HTS provider. This participant was excluded from the final analysis. Ten participants were lost to follow-up after the 60-day interview. At the end of the study follow up period, 46 (75%) of all enrolled participants had attended all three interviews (Figure 4-6). Our final analysis included 56 participants who had a 30-day interview, and at least one additional interview at 60 or 90 days.

We identified three main patterns of HIV medical care engagement among the 56 participants included in the final analysis (Figure 4-7). Eighteen participants failed to enrol in care within three months of diagnosis, 7 participants disengaged from care after initial enrolment, and 31 participants entered HIV medical care early and remained in care. Selected participant baseline characteristics are presented in Table 4-4, stratified by care engagement outcomes.



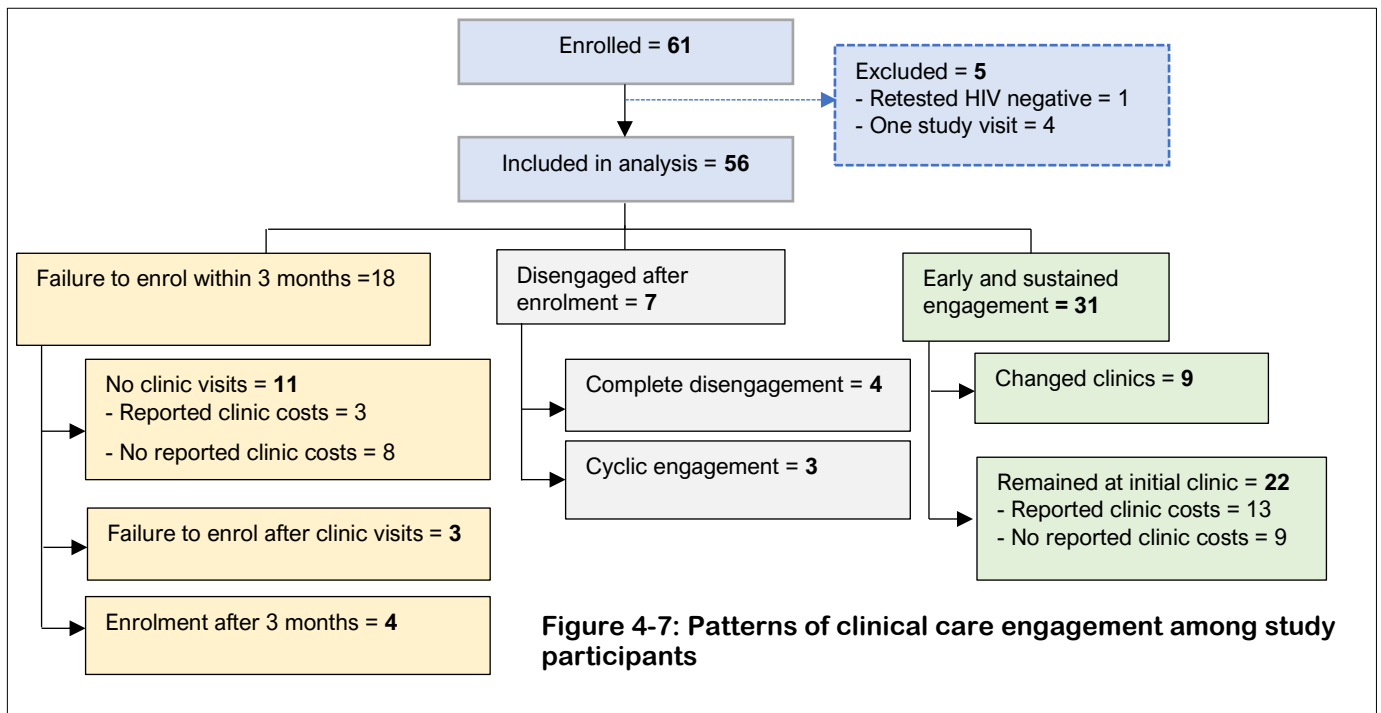


Table 4-4: Participant baseline characteristics by 90-day care engagement status

	Total (N=56)	Failed to enrol within three months (N= 18)	Disengaged after initial enrolment (N=7)	Early & sustained engagement (N=31)
Residence				
Rural	25	11	2	12
Urban	31	7	5	19
Age (years)				
Median (IQR)	31 (25 – 40)	30 (23 – 37)	22 (20 – 28)	34 (27 - 45)
Sex				
Male	23	7	2	14
Female	33	11	5	17
Employment status				
Employed	32	12	1	19
Student	4	2	2	0
Unemployed	20	4	4	12
Previous HIV testing				
First-time tester	18	8	2	8
Previous tester	38	10	5	23

4.7.2 Themes

We did not find major differences in our findings by participant characteristics, except that rural participants (Sekhukhune District) voiced more mistrust of community healthcare workers than did urban participants (Ekurhuleni District). We describe participant perceptions

of clinic-level costs for each pattern of HIV medical care engagement. We include some participant quotes in the main body of this section. In addition, we also refer to additional quotes in Table 4-5.

A. FAILURE TO ENROL IN HIV MEDICAL CARE WITHIN FIRST THREE MONTHS OF DIAGNOSIS

Participants who failed to enrol in care within three months either had no clinic visit attempts went to the clinic but did not enrol in HIV medical care, or first went to the clinic more than three months after diagnosis.

1. No attempt to make clinic visits

Eleven participants failed to make any attempts to visit the clinic for HIV medical care; of these, three participants specifically discussed clinic-related costs as part of their health-seeking decisions (Quote 1.1 – 1.3). Two of the participants anticipated negative clinic experiences based on what they knew of other community members' clinic experiences. In particular, they anticipated community-wide disclosure of their HIV status either from community health workers disclosing information about others HIV status, or neighbours seeing clinic affiliated community health workers arriving for home visits. The feared costs of social isolation, discrimination, and distress for their family members appeared to be higher than the limited value they had placed on HIV medical care. For example, one participant believed that religious care was superior in offering a cure for HIV, and the other remained in denial of her HIV diagnosis (Quotes 1.4 – 1.5). As a result of the low perceived value of clinical care, the anticipated costs shifted the value-cost balance towards non-enrolment in care. The participant who embraced religious care explained:

“I don't have any stress at all, that is why I am saying sometimes I forget that I am HIV positive. I only remember that I am HIV positive when you call me. I am not going to the clinic and I am not planning to go either.” Month 3, Female (F), 27years (y)

The third participant who specifically discussed clinic-related costs for not making any clinic visit attempts, also placed a low value on seeking clinical care. However, in the first two interviews, she cited the long clinic queues and the need to take time off from work as unacceptable costs. However, in the third interview, the participant's explanation for not seeking care shifted to that of actually perceiving low value in seeking HIV medical care as the main reason she had not engaged in care.

“When I am at home, you find that I am just sitting and socializing. After resting, I find out later that there is no more time (to go to the clinic). My reasons for not going to the

clinic are not that major, because I sit and later realize that the time has gone. I just feel like my body is tired and I lack the interest of going anywhere” - Month 6, F, 33y

2. Failed enrolment after clinic visits

For three participants, their visits to the clinic did not translate into successful enrolment in HIV medical care. Instead, they encountered clinic-related costs that led to a discontinuation of any further attempts to seek HIV medical care. Two of these participants were turned away by clinic staff because the clinic was about to close. The third participant reported experiencing long and slow-moving queues (Quotes 1.6 – 1.8). All three participants who were full-time employees talked about how their time away from work increased the costs of entering care. However, after the failed clinic visits, there was a noticeable decrease in the initially high value that participants had initially expressed regarding HIV medical care (Quotes 1.9 – 1.10). Two of them switched to the use of herbal and traditional medicine, while the third remained ambivalent on seeking any care. In the two consecutive interviews after being turned away, one participant stated:

“I never went there (clinic) again and I haven’t gone to any clinic, since I told you at the beginning that I haven’t noticed anything wrong with my body, and I am still healthy.” - Month 3, Male (M), 47y

“I will go to the clinic once I start experiencing illness that will be incurable; only then I will start thinking about going to the clinic. I also think that I will go to the clinic once I start losing weight or when something happens in my body.” - Month 6, M, 47y

3. Clinic visits and enrolment after three months of diagnosis

Four participants who had accepted their HIV diagnoses did not place immediate value on seeking HIV medical care and only sought care after three months of receiving their HIV diagnosis. One participant went through the first five months without considering the HIV diagnosis as a threat or disruption to her everyday life. The other three participants had other higher priorities that preceded accessing HIV medical care. For example, two participants focused on seeking employment around the same period when they were diagnosed with HIV (Quote 1.11 – 1.12), while the other was in the process of mourning the deaths of two close family members. The latter participant explained:

“I have just buried my mother who passed away on Good Friday and even if you can check the day, I got tested you will see what I went through. Following that, I have just buried my younger sister again this month. Do you see that there is no way I can concentrate on the idea that I am sick? Honestly speaking currently, I don’t feel

anything, and I am not implying anything. But I know that I am HIV positive, do you understand?" - Month 1, M, 37y

All four participants eventually made clinic visits, when they had addressed competing priorities or when they started experiencing illness symptoms. For example, when the grieving 37-year-old rural participant quoted above eventually entered care after five months, he explained:

"One day I got severely ill and I decided to go the clinic...I was told that I should start taking HIV treatment and I agreed. I am currently on ARVs and I have been taking them for a month now...My legs were so painful because I am a security officer. You find that I stand at one place for a long time and my legs swell. So, I decided I had to go to the clinic." - Month 6, male, 37y

B. DISENGAGEMENT FROM CARE AFTER INITIAL ENROLMENT

Participants who enrolled in HIV and became disengaged had either decided to stop care or described ambivalence leading to cycling in and out of care.

1. Complete disengagement from care

The burden of multiple unproductive clinic visits after enrolling in HIV medical care was the predominant theme among participants who altogether discontinued clinic visits. Withdrawal from care was most notable in the pre-ART assessment period in place when this study was conducted. Pre-treatment assessment included laboratory testing and additional counselling before ART initiation (Quotes 2.1. – 2.3). These multiple clinic visits resulted in either financial costs (travel costs to the clinic, lost income for daily wage earners, having to use numerous leave days) or affective costs (increased uncertainty and distress from the additional time waiting to start treatment). Eventually, the cumulative burden of each of these unproductive clinic visits began to outweigh the initial value that participants had expressed regarding clinical care. One participant explained:

"I understand that it is my life, and I must use every chance I get. However, even when I go to the clinic on the day that suits them, I still don't get help again... To be honest with you, I will never go back to that clinic." - Month 3, M, 28y

In addition to the costs of multiple clinic visits, one participant also talked about how the demeaning engagement by clinic staff, loss of confidentiality, and experiences of clinic-enacted stigma led to disengagement from care. Before the clinic visit, this 19-year-old female participant had anticipated these costs, based on other community members'

experiences. When she experienced these costs, she discontinued her clinic visits. She narrated:

“As young people, we are also scared to go to the clinic because we know that the nurses are going to shout at us. We end up not going (to the clinic) there even if we are not feeling well. They don’t know how to treat the youth well, whereas the clinic is the place which is supposed to make us feel free to talk about our lives” - Month 3, F, 19y

After discontinuing care, all four participants appeared to reduce the value they had initially placed on clinical care. Moreover, the decline in the perceived value of care was reinforced by the absence of symptoms (Quotes 2.4. – 2.5). For example, participant narratives started to centre around wait-and-see fatalistic statements such as: “...when the time comes for me to die, let it be...” or “we will see what will happen as the time goes on.”

2. Cyclic engagement in and out of care

Three participants returned to clinical care after initial disengagement due to clinic-related costs. Following diagnosis, all three had expressed high value in HIV medical care, with self-reported linkage-to-care within the first month. Before discontinuing care, they experienced unwanted costs including, demeaning attitudes by clinic staff, or the anticipated involuntary disclosure by community health workers from the local clinic or the separation of queues for people receiving HIV medical care at the clinic (Quotes 2.6 – 2.8). Notably, the value they placed on clinical care began to diminish after discontinuing care, although none of these participants resorted to the use of non-allopathic treatment. Eventually, when all three participants experienced illness or weight loss, there was a shift in the value-cost balance leading to re-engagement in care (Quotes 2.9 -2.10). This surge in the value placed on HIV medical care exceeded the initially identified costs that had resulted in discontinuation from care. The participant who had disengaged from care because of demeaning attitudes by clinic staff explained:

“I have currently changed my thoughts, and I don’t worry about anything with regards to going to the local clinic. I don’t want my life to be ruined because of somebody else. It is better I go to the clinic. Even if people talk, it is all the same because there is nothing that they can do!” -Month 6, F, 20y

3. EARLY ENROLMENT AND SUSTAINED ENGAGEMENT IN CARE

Most participants who entered care within the first three months of being diagnosed were retained in care, although some experienced costs like those that led others to discontinue care. The consistently high value they placed on HIV clinical care appeared to be the main

driver in promoting retention in care. Among this group, some remained at the clinic they had first been registered for care, while others transferred to others clinic to reduce the encountered costs at the clinics from which they were receiving care.

1. Sustained engagement in care with a change of clinics

To avoid discontinuing care due to clinic costs from where they were receiving care, some participants switched to more efficient clinics or private medical care (Quotes 3.1– 3.4). However, in doing so, participants had to make trade-offs between their current costs of remaining at the same facility and the new costs associated with switching clinics. For example, two participants without any medical insurance switched from free public sector HIV medical care to private medical care after several unsuccessful attempts to receive their laboratory results required to check for ART eligibility. Although the switch to private medical care added consultation fees and laboratory test costs, it reduced the costs associated with repeat visits and the distress from not making progressive steps to start ART if indicated. However, the cumulative financial burden of using private medical care began to take its toll on both participants, who began contemplating transferring back to free public HIV medical care, as one participant explained:

“The doctor told me that if I am supposed to take treatment, I will have to pay around R600 every month. I then told him that I wouldn’t be able to afford them, and if I had to start them, I would have to go to the local clinic. This means I will have to tell them at work about my situation and ask for day offs so that I can be able to go to the local clinic.” -Month 6, M, 34y

To remain in care, some participants who had initially entered care at more distant public clinics to avoid inadvertent disclosure of status in their local community, eventually switched to closer local clinics to reduce the costs of care engagement. Following numerous fruitless visits at the distant clinics, participants were willing to trade-off the high travel costs and distress from not receiving services with the possibility of involuntary disclosure of their HIV status, by being seen receiving HIV services at the local clinic. One participant explained:

“I take the last bit of money that I have and go to the (distant) clinic, but when I get there, they tell me lots of stories, and I go back to the clinic over and over again. Now I don’t have a problem with what people will say (at the local clinic) because I can see that a lot of people are living with HIV.” – Month 6, F, 45y

2. Sustained engagement at the initial enrolment clinic

Twenty-two participants remained in care at the clinic where they initially engaged in care after diagnosis throughout the length of follow up: of these, thirteen described clinic-related

costs. Among the thirteen, the weight assigned to identified clinic costs was variable and notably lower in comparison to other participants who had discontinued care. In contrast to those who stopped care, the significance of anticipated or experienced costs declined over time for those who continued receiving care from one clinic. One participant explained:

“I am no longer afraid of people. I queue where other people queue, but before I couldn’t do that. I would wait for all the people to leave before I go into the clinic alone. But currently, I am not afraid of anyone, and I can even discuss my HIV status with other people... I am also able to guide those who are still afraid to go to the clinic for HIV treatment.” – Month 3, F, 23y

Moreover, the overall care experience appeared to modulate the clinic costs as participants gained more clinic experience (Quote 3.5). Other recurrent costs of clinic care engagement, such as long waiting times to receive clinic services, eventually became of lower significance when participants resigned to them as part of the routine costs of receiving public sector clinic services (Quotes 3.6 – 3.7). Some participants made personal adjustments by waking up early to join clinic queues a couple of hours before the clinic opening times. Also, other participants told their employers about their need to access HIV medical care services, so that they could reduce the opportunity costs associated with the extended clinic visits (Quote 3.8). In an insightful remark, one participant talked about the importance of patience as an essential virtue to ensure sustained engagement in public sector HIV medical care facilities:

“We are now used to that (long waiting times). You find that after the nurses have helped very few people, they start going up and down in the clinic. If you are not patient, you will leave the clinic.” -Month 6, M, 37y

In some instances, supportive patient-provider relationships reduced costs of remaining in care. For example, in situations of drug shortages, some clinic staff delivered ART refills to patient homes, used cell phones to keep patients informed, and provided positive reinforcement to encourage patients to continue returning to the clinic (Quote 3.9 – 3.10). When drugs became available after periods of shortages, some clinics provided patients with more than the standard medication supply to compensate for the additional clinic visits that patients had to make during the disruptive periods.

Participants who remained in care (whether or they switched clinics) placed a high value on HIV medical care, with all of them entering care within the first three months of diagnosis. At times the importance they placed on HIV medical care increased beyond what they had initially anticipated before enrolling in care. For example, participants often spoke about the additional value derived through interpersonal relationships with clinic staff or other patients (Quotes 3.11 – 3.12). These relationships appeared to reduce anxiety related to navigating

medical care services and helped to lessen internalised HIV stigma. Also, the value placed on HIV medical care increased as participants observed significant improvements in their health following ART initiation (Quotes 3.13 – 3.14). Unlike other participants for whom perceptions of better health resulted in discontinuation of care, participants who remained in care expressed high value on continuing care to avert deterioration in health.

4.7.3 Strengths and limitations

The prospective study design, starting from the point of HIV diagnosis, provided a longitudinal understanding of how value-cost mechanisms influenced engagement in HIV medical care over time. In addition, because we sampled clients at the time of diagnosis, our study sample included a mix of participants who were subsequently either engaged or did not engaged in clinical care. This allowed for a balanced view of the different value-cost outcomes across the participants. Lastly, the study included both rural and urban participants, giving multiple perspectives on the role played by clinic factors on the continuum of care in both settings.

However, the study is not without limitations. First, we relied on participant self-report with regards to their HIV medical care engagement status. This may have caused participants to over-report entry-into-care as has been seen in some quantitative studies, with self-reported entry being 20% to 30% higher than verified entry [298] . To minimize this, our interview guide had multiple questions at different points in the interview to ascertain clinic details and the type of care received. An additional limitation is that our findings are primarily representative of the value and costs identified or expressed by participants which may not be inclusive of what operates subconsciously, what they cannot put into words, what doesn't seem reasonable to explain to someone, or what is too sensitive to say.

Table 4-5: Selected participant quotes by main clinical care engagement pattern

1. FAILURE TO ENROL IN CARE WITHIN THE FIRST THREE MONTHS OF DIAGNOSIS	
No clinic visits	Costs of making initial clinic visits
	1.1 "I don't want to go to the clinic because at the clinic they talk a lot and they like coming to our homes, and I don't want that. No, I don't want to be visited. I will go to the clinic by myself... I cannot explain what they (community health workers) do because I just see them visiting the HIV positive people, and I don't know what exactly goes on." - Month 3, F, 29y
	1.2 "My uncle's wife is a home-based care worker at the clinic, and the sisters (nurses) know me. And she speaks a lot. There is a certain lady who tested HIV positive, and we have all since known that she is (HIV) positive." - Month 3, F, 27y

	1.3 "I clock-in in the morning and knock-off at 5 pm, even on Fridays and Sundays. I only take a day off on the 15th of every month. When I am at home, I have some other commitments that I need to take care of, and as a result, I fail to go to the clinic." - Month 3, F, 33y
	Moderators to the value placed on clinical care
	1.4 "One day, when I do HIV tests, I know I will test HIV negative. That is why I am saying I don't want to go to the clinic for treatment... The thing is our church doesn't want people to mix medications. I can't take pills (at the clinic) while I am also drinking tea (church medication). When I am drinking tea, I am drinking tea; it ends there!" - Month 3, F, 27y
	1.5 "I think that it is possible that they can tell me that I am HIV positive whereas I am not...I think that I don't have HIV and I need to go to the clinic for HIV retest. At the clinic, most of the people tested HIV positive, but when they went to other HIV testing facilities, they tested HIV negative."-Month 3, F, 29y
Failure to enrol in care after clinic visits	Costs of enrolling into clinical care
	1.6 "When I got there, they told me to come back the following morning, and I didn't get time to go back again since I am working...I never went there again, and I haven't gone to any clinic since, but I told you at the beginning that I haven't noticed anything wrong with my body and I am still healthy. I don't see a need for me to go there." - Month 1, M, 47y
	1.7 "The thing is that from Monday to Friday, I am busy studying. I only get time during the weekends...I went to the clinic, and they told me that it was late, and they had to cut the queue. They then told us to come back the following day. I didn't go back again..." - Month 3, F, 25y
	1.8 "At the clinic, there are always a lot of people, and I am not satisfied with crowded areas. I always hate waiting for a long time on the queues while in need of help. Two hours to three hours is just too much for me. I think that 1 hour at the clinic is fine because I can still go and do some other things." - Month 3, M, 28y
	Diminution of value placed on clinical care following failed enrolment
	1.9 "...I am using some traditional medicine which will boost my immune system and keep me strong...I just buy it and use it especially if I am getting weak because it helps boost my immune system so that I can always be strong..." - Month 3, M, 47y
	1.10 "I am taking an immune booster since I was told it strengthens my immune system. I went to the Pharmacy to buy it, and it is the only thing that I am taking since it gives me energy and also increases the CD4 Count"- Month 3, M, 36y
Care enrolment after 3 months of diagnosis	Competing priorities in the first three months of diagnosis
	1.11 "My employment contract ended yesterday. I want to go to another farm because I have another contract there. After I secure my contract, I will go to the clinic for my treatment." - Month 3, F, 39y

	1.12 "I don't meet my needs, and at home, there is no one who is working.... I will go to the clinic at some point, but I am currently still looking for a job. I want to have money first so that I will be able to go to the clinic." - Month 3, F, 25y
2. DISENGAGEMENT FROM CARE AFTER INITIAL ENROLMENT	
Complete disengagement from care	Costs leading to disengagement after initial enrolment in clinical care
	2.1 "...I tried to go to the clinic because I wanted to know my CD4 count. I then asked them to test me, but they kept on telling me to come back the following day up until I gave up going there... That is why I am saying, me and the clinic, is a NO!" - Month 3, M, 28y
	2.2 "I used to go there (clinic) every week on Tuesday (to check laboratory results), and when I arrived there, they used to tell me that the person who is taking blood was not available and I had to come back the following week... I have also given up going there, and I told myself that I would see what will happen to me as the time goes on..." - Month 6, M, 43y
	2.3 "I do not like their treatment, and they take time, and I am busy at school. They will then tell me to come on a certain date, and I will go there and don't get help, and I become demotivated." - Month 6, F, 22y
	A decline in the perceived value of clinical care after disengagement
	2.4 "...I am still healthy, and I am not getting the help that I deserve...I will try by all means to live positive, but when the time comes for me to die, let it be." - Month 3, M, 28y
	2.5 "I am not receiving any other care, and I just told myself that I wouldn't use anything because I saw that it was just a waste. I haven't noticed any difference in my body since I didn't get any help from the clinic and I went to check for my weight, and it was 85kg" - Month 6, M, 43y
Cyclic engagement in and out of care	Costs leading to initial disengagement from clinical care
	2.6 "I don't want to go back anymore. Yes, because people at the clinic know the queue for people who are taking HIV treatment and all that. So, I don't want to go there anymore."-Month 1, F, 21y
	2.7 "I didn't go back to the clinic, and I should go there to do other blood tests, but I fear that I will find home-based care workers because they are working at the clinic as well. I fear because I don't want them to know my HIV status. I have stopped going to the clinic since then." - Month 3, M, 40y
	2.8 "...There was a certain nurse at the clinic, and she liked shouting when she spoke. After that, I left the clinic without going in for HIV care."- Month 1, F, 20y
	Increase in value of clinical care leading to re-engagement
	2.9 "I am currently thinking of going to the clinic because I am even losing weight. If I don't go to the clinic, I don't think that there is anything that will help me." - Month 6, F, 20y

	2.10 "I took five months without going to the clinic. Then I developed flu and had it for quite a long time... I was coughing, and I thought that perhaps it was TB." - Month 1, F, 21y
3. EARLY AND SUSTAINED ENGAGEMENT IN CARE	
Changed clinics	Costs leading to change of clinics
	3.1 "I went to the local clinic over the weekend, and they were closed. I then decided to go to a private doctor, and I paid a lot of money ... My problem is that I am always at work and I can't go to the clinic over the weekend. I am also scared of how I am going to tell employer because there was another guy who was working, and his employer suspected that he was HIV positive and he was fired from work." - Month 1, M, 34y, changed to private care
	3.2 "When I went back for my results, they told me that those people who were responsible for taking blood were on strike and they used to come around 11, and they knock off early, and they had a lot of stories...I have to repeat the tests at another clinic."- Month 3, M, 47y, changed to another public clinic
	3.3 "Sometimes you end up waiting for nurses while they are busy chatting and you won't even understand if they all went for lunch and you won't know how possible that is that, and you end up waiting for them. That day I was on my way to work, and I had to wait because I wanted to know my CD4 Count results and I wanted to start there before I went to work and I ended up being stressed and got scared as if it was my first time to get tested" - Month 1, M, 24y, changed to another public clinic
	3.4 "They told me to wait for the people who take blood, and they didn't come. I then went there several times, and I then decided to change that clinic since time waits for no man. I then went to a private doctor, and I explained everything to him, and I also told him about my clinic visit." - Month 1, M, 36y, changed to private care
Remained at initial enrolment clinic	Adjusting to clinic costs for sustained engagement in care
	3.5 "I was demotivated (after a demeaning encounter with the nurse) of going to the clinic, but I quickly got over it because it only happened once and now things go well."- Month 6, F, 41y
	3.6 "It's only the long queues. When I go there, I need to prepare myself that I will stay for the whole day there." - Month 1, M, 55y
	3.7 "I don't care about what they say (demeaning attitudes by clinic staff) because when I am in the clinic, it is my time and I am going to use it for the betterment of my health."- Month 3, M, 37y
	3.8 "One Monday morning, I asked to have a conversation with him (employer). He took me to his office, and I told him that I am living on (HIV) treatment. I told him that I love my job because even if I stay home that won't help. I told him that I am taking my HIV treatment in town. I asked him to give me time to go home whenever my appointment date for treatment collection arrives. He kept quiet and looked at me. Then he said that there is no problem." - Month 3, F, 45y

	3.9 "...I didn't receive the complete course of treatment when I went to the clinic, but I just forgot their names. But the nurse brought them to me later because she doesn't stay far away from where I am staying. It is not the first time we ran short of the pills at the clinic because they were out of the stock, but when the stock comes in, she delivers the pills to me because she knows that I didn't get chance to go back." - Month 6, M, 37y
	3.10 "I haven't experienced many challenges besides that I sometimes do not get all the treatment. However, the Clinic Manager then came to address us and told us about people at the clinic who were stealing our treatment and selling it. He said that they were going to change some of the Doctors and one of them is gone already" – Month 6, M, 54
	Promotion of value placed on clinical care
	3.11 "A lot of people (at the clinic) made me accept my HIV status...I sometimes just go to them, even though I don't know them. I tell them that I know that people who are this side are here for HIV treatment, and I ask them if they are also HIV positive. They respond by saying that they are indeed HIV positive and, they encourage me to take treatment."- Month 3, F, 45y
	3.12 "There is a nurse that I go to when I have issues. She only allows me to speak with her when there are not busy at the clinic. If she is busy, she will tell me to come during lunchtime. When I meet her, we talk, and she will tell me a lot of things."- Month 6, M, 29y
	3.13 The treatment they gave me at the clinic is helping me a lot since I am now able to walk faster than before when I used to stroll... I also think that my sugar diabetes is now getting better since I started ARVs because when I went to the clinic, it used to be 20, 17 or even 11 and now is around 5, 7 or even 6 and they told me that it was normal." Month 3, F, 49y
	3.14 "I have realized that a lot has changed since I started going to the clinic. I can do chores at home the whole day, and I am also able to eat well now, unlike before. Before I started treatment, I was unable to eat... I have also gained weight because I was weighing 71 kg when I started going to the clinic, and I am currently weighing 80 kg. I am happy because I am regaining my normal body weight." Month 6, F, 41

4.8 Case management support and linkage to HIV medical care

4.8.1 Study participants

Of the 28 participants, we included in the analysis of case management session transcripts; most were female (18/28), and participant ages ranged from 18 to 66 years. We achieved a reasonable balance in terms of rural/urban residence, and ART eligibility at the time of diagnosis (CD4 count ≤ 350 and >350 cells/mm³) (Table 4-6). Among the 28 participants included in the analysis, seven had entered care prior to attending the first case management

session. Sixteen participants began care within 90 days after attending the first case management session. Five participants who had participated in at least one case management session failed to enter care within 90 days of diagnosis - one client had reached the maximum number of sessions, while the remaining four did not attend all five sessions.

Table 4-6: Baseline characteristics of participants included in the analysis of case management sessions

Baseline characteristic		N=28
Site	Urban	13
	Rural	15
Gender	Female	18
Age (in years)	Median, range	34 (18-66)
	18 – 30	10
	31 – 40	5
	41 – 50	3
	>50	10
Education	No school/preschool education	3
	Primary school education	7
	Secondary or tertiary school education	18
Employment status	Employed	9
	Unemployed	19
Previous HIV test	No	15
	Yes	13
CD4 count value cells/mm ³	≤ 350 cells/mm ³	15
	> 350 cells/mm ³	13

4.8.2 Delivery of sessions

Face-to-face sessions were longer (median = 45 minutes; Interquartile range (IQR): 30 – 50 minutes) compared to telephonic sessions (29 minutes; IQR: 25 – 46 minutes). Telephonic sessions were often interrupted by poor network connections, and participants expressed frustrations in repeating themselves, especially when they wanted to be discrete, or they had limited time to talk to the case manager. When this happened, sessions were typically rushed with fewer opportunities for effective client engagement. Language barriers were also another challenge with communication, which compromised the ability of case managers to achieve a shared meaning of participant goals and weakened the process of building trust and rapport with the client. One client appointed a translator, while in other cases the case managers conversed using basic knowledge of the dominant language in the area – which all case managers were well versant. Some clients had a low tolerance for language barriers. The example below is of a client who in her severe frustration, terminated the telephonic session and never picked up any calls after that.

Client: “No. I have answered you already... I told you that my problems come from people who did this (witchcraft). You asked, and I answered.”

Case manager: “Sometimes, I don’t get it clearly, mama.”

Client: “You don’t understand Sepedi (a local language with different dialects) well do you? Where do you come from?” - F, 49y, rural

4.8.3 Structure of the case management sessions

1. Building the foundation for health communication

Case managers started the sessions with open-ended questions to explore the personal significance of the HIV diagnosis, including their self-perception based on the knowledge that they are living with HIV. By eliciting the client’s appraisal of the meaning of the diagnosis and their response for coping with the consequences of the diagnosis, case managers built a foundation for further discussion. Although simple in concept, bringing a client to express their values or goals in adapting to the HIV diagnosis was challenging for case managers. To encourage client participation, case managers relied heavily on techniques for reflective discussion and questioning. The transcripts below illustrate the range of initial confusion and distress often described by clients, on which case managers modelled discourse around.

Client: “I have accepted, but it is stressing me (HIV diagnosis). I am beginning to think that my life might end any day from now. I might die any day. I will die and leave my children behind. I want to know what I need to do when things are like this. I want to know if I will get any treatment ... I am stressed now because I was not sleeping around. I don’t understand how I got this virus!” - F, 22y, urban

Client: “It is tough my brother. I have not yet disclosed to my partner about my status. I am scared; I don’t know how I am going to break the news to her. This is the challenge I am faced with. I am worried I might end up infecting her with HIV since we are not used to condoms. That is a big challenge” - M, 40y, rural

Client: “I don’t believe the results (HIV test results) ... I am very confused, and I want to test again to prove that it is true.” - F, 31y, urban

To unearth underlying client concerns that may not have been verbalised, case managers also triggered discussions on commonly reported issues that had emerged from other client sessions. Examples include topics on the value placed on illness symptoms, risk of infecting loved ones, and the desire to have children. In one case of a 22-year-old female client who was in a steady relationship and had no children, the case manager opened a discussion on safe pregnancy among PLHIV. During the discussion, she disclosed that she was two months pregnant and had been harbouring anxiety on future steps. At the time of the counselling, all pregnant women were eligible for immediate ART initiation; therefore, communication changed from a discussion around pre-ART care to the urgency and availability of ART.

Understanding the stage at which the client was in adapting to their diagnosis, assisted case managers in setting in pacing the sessions to allow clients to lead in their care engagement processes. The level at which participants engaged with case managers during the sessions appeared to be mediated by the extent to which participants had accepted the diagnosis and thought through the personal significance of living with HIV. Also, it took time for some participants to open up to the case managers. In this regard, a 51-year-old female client remarked, “I am generally not an open person, but I started to open up to you with time and told you my worries. So, I feel very much relieved.”

2. Exploring and promoting the value of HIV medical care

Entry into HIV medical care was the primary goal of this case management intervention. The tailoring of health communication around client narratives provided an opportunity for case managers to identify the potential value of HIV medical care for their client, and to develop health messages around that. Case managers mostly linked the importance of HIV clinical care to client concerns over death, relief of symptoms, their ability to remain functionally independent, or the ability to conceive. Promoting the value of HIV medical care was equally crucial for clients who had not entered care and those who had already entered care. For the latter, case managers compensated for health communication gaps between clients and healthcare providers from where they were accessing care by providing additional health education and encouraging clients to engage with their healthcare providers during routine health consultations. The extracts below are examples of such health communication gaps.

Case manager: “So, when you went back to the clinic for the second time, did they show you your blood results? Did they explain your CD4 count results to you?”

Client: “They just talked amongst themselves (the nurses), and she said, “Here are the results... So, I don’t know what they mean.”- F, 57y, in care at urban, public healthcare facility

Case managers found it challenging when clients did not perceive value in HIV clinical care, especially among those who were not eligible for ART or those who had directly or vicariously experienced adverse outcomes from previous clinic visits. When clients displayed signs of resistance to HIV medical care issues (arguing, inattention, side-tracking, or cutting off), case managers were trained to “roll with resistance”, but often failed to shift focus and re-frame the discussion to offer a new meaning/perspective for the client’s consideration. As a result, some clients who were attending sessions disengaged from HIV medical care, reverted to states of in-action while waiting for illness symptoms to appear as a cue for the need to re-engage in care, or focused on other non-clinical care-related goals.

3. Collaborative identification of goal-oriented activities

Case managers worked with clients to develop detailed care plans, which included timelines for completing identified activities, practical preparation and execution steps that would lead to the successful completion of defined tasks (e.g. taking time off work or selecting clinics). In cases where case managers identified deficiencies in care plans, they used non-judgmental critical questioning or paradoxical scenarios to challenge the proposed plan. In some cases, this revealed underlying concerns that the client had not communicated.

Case manager: “So, you are saying that you will not disclose to him...? How do you plan to take treatment when he is around? “

Client: “I don’t know. It will not be easy because I want to take the treatment. I will also have a problem of having unprotected sex because I haven’t told him about my status... I don’t know where I’m coming from or going. I am confused... My partner and I have not been faithful to each other. I have someone else that I am dating, and he also has someone else.” - F, 51y, rural

Clients who had entered care and experienced paternalistic treatment from their HIV clinical care providers appreciated the participatory and collaborative interaction with the case managers. In the example below, the client chose to seek private medical care but felt that her doctor did not provide her with an opportunity to participate in the decision around starting ART. After evaluating her situation with the case manager, she resolved to change the care provider.

Client: “He (private doctor) dealt with me as if I have already said yes to one, two and three. He said, “You are ready to start”, things like that. At least you had already explained the process that would happen, but he didn’t tell me anything ... When I got there, he said: “Here is your medication, take and drink” ... I was not expecting that. I expected to be counselled and asked if I am ready to be initiated.” - F, 31y, urban.

4. Identification of barriers to goal-oriented activities

When case managers thought that clients might not have thoroughly considered the potential obstacles to implementing their care plans successfully, they tactfully used challenging questions to maintain mutual dialogue without appearing overbearing or judgmental. By talking about potential barriers and working to identify ways around those barriers, the focus of health communication was on the client, and this may have encouraged increased entry-into-care. In the example below, an elderly client had missed several opportunities of accessing HIV medical care from a mobile clinic that frequently serviced her village. In her sessions, she kept on talking about the lack of money to go to the hospital as a barrier to

accessing care, until the case manager helped her resolve this discrepancy (conversation quoted below).

Case manager: “I can see that money is a real issue for you in planning how you are going to reach the hospital... What do you think is the way forward?”

Client: “I’m waiting to find the money so that I can go to town. That is all I am waiting for. I don’t know when or how I will find it.”

Case manager: “I understand that your challenge is money. So, is it possible that you go mobile clinic when it comes (to this area) next week?”

Client: “Yes, it’s possible. I will go because you don’t pay you just walk.” - F, 56 years, rural

The approach of on-going case management sessions allowed for continued reflection by both case managers and clients on barriers to care engagement, which may have been initially dismissed or not even identified in earlier meetings.

Case manager: “Since you were not able to complete the task of going to the clinic, let us talk about last week’s conversation when you mentioned that you had no hindrances (going to the clinic). Today, do you have any concerns or obstacles that may prevent you from going to the clinic?”

Client: “No, the only challenge I have is time.”

Case manager: “So, the main challenge you have is time?”

Client: “Yes, that is the only problem. I only have time over the weekends.” - M, 40y, urban

After identifying barriers to care engagement, case managers steered their clients to constructively reframe their perspective on how they could potentially overcome the identified challenges.

Case manager: “How do you think you can overcome this issue of the long queues and your thoughts of poor services at the clinic?”

Client: “I can go back, but not when I’m going to school because I don’t want to disturb my studies.”

Case manager: “Oh, ok. So, you feel that you can overcome this by going to the clinic when you are not going to the school because you will be able to handle the long queues?”

Client: “Yes, even if I find the queues, I will not be rushing anywhere.” - F, 20y, urban

Some clients presented themselves as being highly motivated and confident to navigate their barriers but failed to complete their care plan activities. For example, one client continuously talked about the challenges faced by other people in accessing care, until the case manager applied 'focusing' techniques to direct the conversation back to issues that personally pertained to the client. In shifting the discussion, the case manager said: "Earlier you said that it is important that everything should start with 'I' (me) because this is about you ...". After the discussions shifted back to the client, it surfaced that behind the displayed levels of self-efficacy, the client had underlying challenges with accepting his status, and had resorted to emotional coping, by dissociating himself from the reality of living with HIV.

5. Drawing upon client strengths

Case managers also assisted clients in being self-aware of their capacities and strengths to manage their own lives. These strengths were primarily identified by asking clients to talk about past difficult life experiences and their coping mechanisms to these challenges. This allowed case managers to highlight client strengths and resiliency, ignite a sense of self-worth for the client, and discuss how the observed strengths and resilience could be applied to their current situation. The identification of strengths helped address issues of negative self-evaluation, low self-esteem and a lack of self-efficacy to engage in HIV medical care. In the example below, the case manager amplified the client's strengths to increase their motivation towards care engagement.

Case manager: "My brother, as you were busy talking, I was listening to you. I saw a determined person. I can see a person who doesn't lose hope in life. I also see a courageous person, because when you were met with life situations, you never turned back ...?"

Client: "I don't know where it comes from myself." - M, 30y, urban

6. Transitioning out and discontinuation of sessions

Towards the end of the allocated number of sessions, case managers summarised and reflected upon the content of earlier meetings, with primary emphasis on the client's resources required to achieve or maintain HIV medical care engagement. In turn, case managers also asked clients to summarise any learning or experiential growth that had occurred during the sessions. Clients identified value in terms of redefining their self-worth, accessing social support, educational messaging and entering care.

Client: "If I had not talked to you, maybe things have turned out differently. I never thought I would ever get HIV. After having lived a good life, I asked myself "Why me?" Obviously, I had to reach this point and accept, but what helped me the most was you

talking to me, and helping me realize issues about the disease and myself... I am thankful for the things you have done.” - F, 31y, urban

Client: “I have seen that these sessions have helped me a lot because the heavy burden I used to carry has gone... I have realised that when I do something, it comes from my efforts. I am only moving forward. I no longer have any backward thinking. I am only moving forward.” - F, 20y, rural

While case managers appreciated client gratitude to the provided services, there was a tendency to miss subtleties around mild forms of dependency, which were a possible threat to sustainable HIV medical care engagement.

Client: “Even though my sessions are over, we will need you (case manager) now and again to keep on talking to you. You should not stop talking to me.”

Case manager: “Ok mama”

Client: “Because you are the third person who knows about this, I have not told anybody else.”

Case manager: “OK mama, if there is some information that you need, I will give it to you.” - F, 51y, urban

4.8.4 Strengths and limitations

This study has the strength of assessing real-world case management sessions as part of a health communication arm of a trial to accelerate entry into care after testing HIV-positive. However, our study is not without limitations. We did not assess the proportion of client-counsellor communication that led to tailored or precision communication compared to more general information provision. Furthermore, we did not assess whether specific communication sessions appeared more or less likely to lead to entry-into-care. The principle reason we did not try to associate specific messages with entry-into-care is that the ease that a case manager had in reflective interviewing with a specific client may have correlated with the client’s interest in entry-into-care and not been causal.

4.9 Alignment of post-test counselling sessions to universal test and treat goals

4.9.1 Participant characteristics

A total of 45 counsellors across the ten facilities (range 4 – 6 counsellors per facility) participated in the study; most were female (41/45, 91%), all were employees of the Department of Health, and had worked as HIV counsellors for a median of 12 months (Interquartile range (IQR) 6 months - 2 years). None of the counsellors had prior clinical training. However, all counsellors had gone through a standardised 3-day curriculum

required for practising as a lay counsellor; some had received refresher training. Of the 45 counsellors, 34 (76%) conducted at least one post-test counselling session in which a client who received an HIV positive result. To maintain participant confidentiality, we only collected information on the participant's sex. Of the 40 patients included in our analysis, 13 (33%) were male, and 27 (67%) were female.

4.9.2 Content and delivery of sessions

We identified five general themes related to counselling messages listed below. We purposefully framed and organized the themes to provide a pragmatic lens to identify opportunities for developing strategies to improve the content and delivery of post-test counselling sessions.

1. Behaviour changes necessary to maintain or improve health when living with HIV
2. Scripted information on the potential biomedical benefits of ART
3. Misinformation supplanting the potential value of ART
4. Behaviour changes are needed for ART to be effective
5. Overemphasis of the inevitable side effects of ART requiring vigilance from the client

The discourse of the post-test counselling sessions was predominantly didactic, characterised by lists of instructions. Notably, we did not observe any interactions fitting within strengths-based counselling or motivational interviewing techniques nor any generally patient-centred dialogue. In turn, this limited the opportunities for patients to participate in the counselling sessions. Overall, there weren't any notable differences in counselling content or technique by counsellor's sex, patient's sex, nor by the clinic. Therefore, we combined results for all counsellors. Table 4-7 contains additional participant quotes referenced in the text.

A. BEHAVIOUR CHANGE “NECESSARY” TO MAINTAIN OR IMPROVE HEALTH FOR PEOPLE WITH HIV

In most sessions, counsellors explicitly communicated the need for behaviour change as an imperative and provided clients with lists of behaviours they had to maintain or improve health when living with HIV. These behaviours generally focused on avoiding some foods and eating other foods, drinking eight glasses of water daily, exercising regularly, and getting plenty of sleep. Such messages appeared to be generalised to all clients, without counsellors exploring their client's actual current behaviour concerning the desired actions. Messages

related to nutrition were uniformly directed at the need to increase vegetable consumption and to reduce or eliminate fatty foods and sometimes spicy foods (Quotes 1.1 – 1.5).

The stated benefits of the recommended foods and changes in diet were diverse: improving digestion, cleansing the gut, helping to fight infection, giving energy, and avoiding weight loss. One counsellor explained these food requirements to their patient as follows:

“The important thing is changing your lifestyle. On food, you need to take lots of fruits and fresh vegetables; they will help to fight other infections in your body. You must also take brown rice, brown bread, pap and samp; they will help to give you energy. And then you must eat beans, lettuce, chicken, fish and eggs, they will help to build your body, and they also will keep you strong. And then you must take butter, peanut butter, nuts, cooking oil and fresh milk, they will help you to stop losing weight, and they will also give you energy. You must also take yoghurt and milk they will help you with digestion. Again, you must take eight glasses of water.” - Counsellor

Importantly, the “required” changes to diet may have immediate potential financial implications. Some of the counsellors sought to address financial concerns by briefly explaining the food options that the patient could choose from:

Client: “As you speak about eating the right food. If I don’t have the right food, what must I do?”

Counsellor: “By the right foods, I don’t mean expensive food. Cabbage from street vendors is five rands you can eat that cabbage; beetroot is also five rands, carrots are also five rands. Try to have one vegetable in your plate every day and drink water, two litres a day which is about eight glasses of water.”

Some participants also perceived non-direct financial costs of making the required dietary changes. These costs included the potential for opportunity costs of being directed to give up pleasurable foods or activities, and the possible need for disclosure to make those changes.

One patient explained his challenges to the counsellor:

Client: “It will take some time for me to adjust from the food that I am eating to the food that I am only supposed to eat. It will take me some time.”

Counsellor: “Why is it that it will take you some time?”

Client: “I don’t know where to start with the woman that I live with. I don’t know how I will start the topic. I am stressed about where I will start, although I must tell her?”

B. SCRIPTED INFORMATION ON THE POTENTIAL BIOMEDICAL BENEFITS OF ART

Commonly, the discussions on the benefits of ART were not framed in terms of client's values, needs or preferences. This limitation was due to the lack of deliberative dialogue which reduced opportunities for clients to participate in decisions of their care. In most counselling sessions, the conversations on the value of ART were limited to general statements of benefit, mostly emphasising that living with HIV was no longer a 'death sentence' because of the availability of ART. In one typical example, the counsellor explained:

"There is no grave for an HIV positive person. It is only the person who wants to die who would be killed by HIV. Yes, before the introduction of treatment, people died of HIV but now that there is treatment. Life goes on." - Counsellor

In the main, counsellors emphasised the general biomedical benefits of ART in terms of preventing damage to the immune system and controlling the multiplication of the virus (Quotes 2.1 – 2.9). However, the benefits of ART in reducing the risk of transmission to sexual partners (i.e. treatment as prevention) were overlooked by counsellors in all the reviewed counselling sessions, even though test and treat policies were policy at the time.

The only contextualised information regarding the benefits for ART was provided to pregnant women presenting for HIV testing (Quotes 2.10 – 2.12). In one of the post-test counselling sessions with a pregnant patient, the counsellor explained:

"Look, the baby will not get infected; it's good that you knew about your status early because you'll drink your ARVs (antiretrovirals) early. ARVs suppress the virus and then by the time you get the baby, your viral load will be low, and then after you deliver, they will check the baby, and they will give the baby nevirapine drops. You will also be drinking nevirapine while you're pregnant and the baby will have treatment that he or she will take." - Counsellor

Although the information on PMTCT was contextualised for pregnant women, counsellors often gave information on PMTCT to women regardless of pregnancy status or intent. An example of a misplaced discussion of PMTCT to one patient is quoted below:

Counsellor: Alright, thank you, my dear. When you want a child, you will get one.

Client: I don't want a child. I've got two kids already.

C. MISINFORMATION SUPPLANTING THE HEALTH BENEFITS OF ANTIRETROVIRAL THERAPY

Misinformation on non-medical ways to maintain health and a normal CD4 count was highly prevalent in the counselling sessions. This misinformation often occurred ahead of or in place

of information on ART. The most commonly described method for maintaining health was to use condoms consistently. Condom use was presented in nearly all counselling sessions as essential to prevent HIV-related complications, CD4 decline, and HIV re-infection – supplanting the health benefits of ART. Counsellors often told clients that failure to use condoms would lead to a weak immune system (CD4 count decline) and could lead to non-suppression of the HIV viral load – essentially making ART ineffective (Quotes 3.1 – 3.6). For example, one counsellor explained:

“Sometimes, when you are taking pills, and you do not use a condom - it will be like doing nothing. The most important thing is that you must always use a condom and on the other hand you take the pills.” - Counsellor

The quote below is an example of instances where condoms were promoted ahead of the importance of ART (Quotes 3.7 – 3.9).

“Yes, life goes on. It doesn’t mean that just because you tested positive today, it is the end of the world. What you must do is take care of yourself, use condoms, and then move on with life.” - Counsellor

D. ESSENTIAL BEHAVIOUR CHANGES REQUIRED FOR ANTIRETROVIRAL THERAPY TO BE EFFECTIVE

Similar to communication on required behavioural changes for adapting to the HIV diagnosis, counsellors also either directly stated or strongly implied that specific behaviours were not compatible with ART. In the same way, the need for these lifestyle changes lacked context.

Specific required changes in behaviour included the cessation of smoking or drinking alcohol before initiating ART (Quotes 4.1 – 4.4). Notably, counsellors failed to engage patients on whether they drank alcohol or smoked tobacco, nor did they explore how the ‘stopping’ would be achieved. The need for these changes was generally incorrectly justified as incompatibility or making ART ineffective, rather than potential adherence considerations with alcohol or general health problems from smoking. The following quote is illustrative:

“The medication that you are going to take counteracts with other things. Alcohol is strong and neutralises the medication. So, stop drinking (alcohol), stop smoking drugs, any drug, you don’t use any drug.” - Counsellor

Counsellors also told clients how they should make changes to their daily routines to ensure that they took ART at the same time each day. While overall, a reasonable suggestion to help with ART adherence, the changes to routine and need for taking ART at the same time each

day, were at times, presented as necessary for ART to work. Some counsellors stressed the need for strict adherence to the timing of taking doses of ART (Quotes 4.5 – 4.7). On the other hand, some counsellors were less prescriptive and appreciative of the possibility of unforeseen events or changes in routine. They educated their clients that if they missed the scheduled time, they could still go ahead and take their medication (Quote 4.8 – 4.10).

“You choose the time you take your medication; maybe you will drink it at 8, make sure that if you have a clock, you set your alarm when it is 8 o’clock you will know that it is time for you to take your treatment. Someone might choose half-past seven. Someone might want to drink it in the afternoon when you know that you have done all your duties and you are relaxed because others get dizzy, you see. And the pill does not have Monday it does not have a weekend, it is not like Panado or Grandpa which you only take when you feel a headache. This pill is for a lifetime; this means if you agree that you will take treatment today, you are committing to this for the rest of your life.” - Counsellor

E. THE INEVITABLE AND SEVERE SIDE EFFECTS OF TAKING ANTIRETROVIRAL THERAPY

ART side effects were generally stated either as a substantial danger or as something requiring understanding and vigilance from the patient. Both actual side effects and the need for vigilance added cost to taking ART (Quotes 5.1 – 5.2). One counsellor explained:

“Sometimes, it (ART) will make you dizzy. Sometimes you will have a rash. Sometimes you will have nightmares. Sometimes it will make you vomit. You will have bad dreams you will end up thinking that you are bewitched only to find that it is the medication that is doing that. You might have diarrhoea but just because you are experiencing these things it doesn’t mean that you should stop taking your treatment and say that it is making you sick. No, you must continue, that thing (side effects) might happen for 2 or 3 months.” - Counsellor

In contrast, some of the counsellors presented information on side effects as minor and only as a possibility (Quotes 4.3 – 4.4).

“Our pills have side effects, some of the side effects are rash, but they don’t do anything to other people; nothing at all. Someone else prefers to isolate themselves, someone else has nightmares when they are sleeping, others hallucinate, but these do not happen to everyone. You know that when you are drinking some pills, you feel like sleeping...these ones are the same as well. Isn’t we are not the same as people and the side effects are only for a certain period? You will not have them forever; you only have them when they are still getting used to your system.” - Counsellor

Table 4-7: Selected participant quotes by themes

1. Behaviour change “necessary” to maintain or improve health for people with HIV	
Required diet changes for people living with HIV	1.1. “...And then you will have to eat healthily, don’t eat food with a lot of oil, do not eat deep-fried food, ensure that your food has vegetables when you prepare it, make sure that you eat at least one fruit a day.” (Counsellor)
	1.2. “You have to eat the right food. You eat vegetables and fruits and drink water every day. You are going to stop drinking alcohol.” (Counsellor)
	1.3. “...The only food that we don’t eat is that which cleanses the gut. Not that you shouldn’t eat, you can eat occasionally. There are some people when they eat spinach, it cleanses the gut, and you will find them regularly eating because they love it, and whenever they eat the spinach, it cleanses their gut. And there are people when they eat pap (staple food) and milk; they cleanse the gut. You don’t eat such food. You eat occasionally.” (Counsellor)
	1.4. “From today you need to watch what you eat. Eat vegetables, eat fruits. When I say you should eat vegetables, I am not saying you must get home and tell them that you must eat at vegetables, they said I should not eat meat or pap (staple food). What I am saying is that you need to eat vegetables at least two times a week. Vegetables are nutritious so you will be helping the pill to fight off the virus so that the body soldiers can come alive. The pill assists the body soldiers. You have to assist the pill by eating vegetables and fruits.” - Counsellor
	1.5. Patient (P): What is important is that I must drink two litres of water. I should drink it well so that the virus must not defeat the immune system. My immune system must suppress the virus immune increase and win the battle. I forgot the others. Counsellor (C): We boil the food most of the time, we don’t fry P: Yes, we do not fry C: Because when you fry your vegetables, you add cholesterol. You must boil your food.
2. The benefits of ART	
General framing of the benefits of ART towards longevity and maintaining a high quality of life	2.1. “If you are positive, know that the only thing that will keep you alive is the ARV’s only.” - Counsellor
	2.2. “Take a deep breath and say whatever you want to say (Silence). You know very well that there are people who are HIV positive and they are healthy. It is not a life sentence this thing. It is not a death sentence. It is not a death sentence; you can live well with ARVs.” - Counsellor
	2.3. “...If you take your treatment properly, you stay normal, but if you stop the treatment and default, you are going to get AIDS. When you have moved into AIDS, it is going to be difficult. Everyone will see that you are ill, but if you take your pill properly, no one is going to see that you are ill. You can work and do anything you want.” - Counsellor
	2.4. “HIV does not mean that you have to stop things that you used to do. Just live a healthy lifestyle, use condoms, take your treatment and continue with your life. HIV

	does not stop anything. Your life doesn't stop today because you are HIV positive. Ok?" - Counsellor
	2.5. "There is no grave for an HIV positive person. It is only the person who wants to die who will be killed by HIV. Before treatment was available, yes, people died of HIV, but now that there is treatment, life goes on." - Counsellor
	2.6. "I beg you, don't harm your body. You may end up feeling stigmatised and being afraid to look at other people. I would like to see you maintain the way that you are, even when you start with treatment. Seeing you not getting sick and being able to take your treatment well. Do you want it (HIV) to knock you out with shingles, give you scars?" - Counsellor
General framing of ART benefits concerning CD4 count and viral load	2.7. "ARVs help with your CD4 count and your viral load will go down." - Counsellor
	2.8. "ARVs will help with bringing your CD4 count up and bringing your viral load down. Isn't it?" - Counsellor
	2.9. "The ARVs will help your CD4 count to go up and your viral load to go down. Those are the benefits of ARVs, isn't it? And then it will also help with reinfection so that HIV does not multiply." - Counsellor
Benefits of ART in pregnancy	2.10. "Now that you are positive, today you are going to start with treatment so that you can protect the baby from HIV. Also, it is possible for a mother that is HIV positive to have a baby that is HIV negative." - Counsellor
	2.11. "When you start with treatment today, it will build up your immune system to position the virus in one place so that it doesn't multiply every day. As long you take your pills every day and at the same time and use a condom when you have sex the virus won't replicate. The immune system goes up. It becomes strong. The baby gets protected, and the baby will be alright. That means it is all in your hands to protect the baby to be alright?" - Counsellor
	2.12. "Now that you are positive, today you are going to start with treatment so that you can protect the baby from HIV, and it is possible for a mother that is HIV positive to have a baby that is HIV negative." - Counsellor
3. Misinformation supplanting the health benefits of ART	
Misinformation on condoms and replication of the virus	3.1. "Viral load is the amount of virus in your body. When you take ARVs, they suppress the virus, they bring it down, and your CD4 count goes up, but only when you drink them well, and you use condoms. Because I said if you do not use condoms, the virus multiplies." - Counsellor
	3.2. "Now that you have tested you have to accept that you have this virus, and when you have sex use a condom because the more that you don't use a condom, the more the virus multiply." - Counsellor
	3.3. Counsellor (C): For you to be protected, you need to use a condom as you also mentioned that you heard from the radio that when you are not using protection, what do you do? Patient (P): You multiply the... (patient trying to remember)

	C: You increase the viral load in your body. What happens if you don't use the protection? P: You increase the viral load
	3.4. "Use a condom always when you have sex because when you don't use a condom while taking the pills, they are not going to work for you those pills." - Counsellor
	3.5. "Viral load is the amount of virus in your body. When you take ARVs, they suppress the virus, they bring it down, and your CD4 count goes up, but only when you drink them well and you condomise. Because I said if you do not use condoms, the virus multiplies." - Counsellor
	3.6. "And as from now on you have to use condoms no matter what because the viral load will increase instead of going down although you are taking treatment if you don't use a condom every time you have sexual intercourse." - Counsellor
Condoms promoted ahead of ART	3.7. "When you do not use a condom, or maybe you do not do the right things, we will see it when we check your viral load. When you are taking your treatment, yet your viral load is not going down, that is when the nurses will see that there is something wrong here. It's either you are not drinking your pills on time, or you are not using condoms, or you are not eating fruits or veggies which are bodybuilders." - Counsellor
	3.8. "If you are going to use traditional medicine, it will give you diarrhoea, and then you will become dehydrated. You will start getting ill until the virus becomes AIDS. Then you will be bedridden, that is why I am saying leave all other remedies, use a condom." - Counsellor
	3.9. "You must use a condom and stop saying sometimes; it is going to be your everyday job to use condoms." - Counsellor
4. Essential behaviour changes required for ART to be effective	
Required lifestyle changes	4.1. "And when you take these pills, make sure that you don't take alcohol so that the pill helps you well. Make sure that you don't take alcohol." - Counsellor
	4.2. "And please, please, please, no smoking, no alcohol, no using syringes no drinking medicine from traditional healers, please I beg you. I am not commanding or imposing. We are advising each other." - Counsellor)
	4.3. "The medication that you are going to take is affected by other things. If you are drinking alcohol, it counteracts with it because alcohol is strong. It will neutralise the medication. Stop drinking (alcohol), stop smoking drugs, any drug, you don't use any drug." - Counsellor
	4.4. Counsellor (C): You bought a packet of 20 (cigarettes), and you have five left? Patient (P): Yes, from yesterday morning C: No bhuti (brother) you smoke too much; you need to reduce the levels of your smoking. Do you know that the virus target where there is more damage in your body?
Scheduling when to take ART	4.5. Patient (P): So how does it work? Counsellor (C): If you drink it at 8 (pm) it must be like that. You drink them only at night.

	P: Only at night? C: Yes, if you drink them at 7 pm it must be 7 pm. if it's 8 pm it must be 8 pm. Don't change the time, because if you change the times, the medication will not be able to work its work in your body. Because they help with your body soldiers to go up and your viral load to go down. Do you know viral load? P: No.
	4.6. "You are supposed to take them at the same time. You will choose your time. If you choose seven, it must be seven. If you choose eight, it must be eight and what you need to know is that the pills that you are going to start taking have side effects." - Counsellor
	4.7. Counsellor (C): As long as you take your tablets at the same time; every day isn't it. Like you have said that you don't miss days as you have said, isn't it? Every day you take the pills at the same time. When you miss your pills, what is going to happen? Patient (P): You are getting hurt. You are inviting illness because the virus will go up. C: Yes, the virus will go high, and the CD4 count goes where? P: Down.
	4.8. "And then again, if you take your treatment at 8 (pm), and you go somewhere telling yourself that you'll come back and drink your medication, but you end up getting home before or after 9 (pm). As soon as you get home, you must take your medication it is better to drink it late than not to drink it at all, alright, mama." - Counsellor
	4.9. "And then again when you are going out thinking that you will come back in time to get your treatment and it happens that you do not come back on time, you end up getting home before or after nine. It's better to drink it late than not to drink it at all." - Counsellor
	4.10. "When you take your medication at 8 (pm), and your sister calls you to come and visit, and maybe you return before or after 9 (pm) and your time to take your medication has passed, as soon as you get home you must still drink your medication. It is better to drink it late than not to drink it at all. Timing is critical because no one is perfect, isn't it?" - Counsellor
5. Essential behaviour changes required for ART to be effective	
Side effects of ART	5.1. "And then there are other (side effects) that when you see them you must come to the clinic. Side effects such as thrush, swollen feet, when your eyes turn yellow it means that you have a liver problem and then a headache that doesn't stop. You should come to the clinic and report that since I started taking treatment this is what I have been experiencing. And then if it is vomiting and feeling dizzy, these are things that will happen for a few days and they will pass because the treatment will be getting used to your body. And then let's say you drink your pills and then you vomit, when you are done vomiting, sit down, take a deep breath and then drink water after two to three minutes try to drink another pill again..." - Counsellor
	5.2. "ARVs have side effects. You may experience the side effects, or maybe you will not experience them. Also, there are those side-effects which when they appear, you

	need to come to the clinic immediately. For example, rash, eyes that turn yellow, which are an indication of a liver problem, when your feet get swollen or a severe headache you come to the clinic since you will be on ARVs. And when you feel dizzy, that will happen for a few days, and then it'll stop. And then vomiting, you will vomit and if you do, sit down, take a deep breath and then relax, drink water then after two to three minutes, try again. Think about the time you vomited and ask yourself if it was before or after your meals. What is causing the vomiting, then you take it from there. You will know that this pill treats me well when I have eaten or when I have not eaten.” - Counsellor
	5.3. “Someone will have side effects. I don't know how I can put it in isiZulu (local language), someone else might develop a rash after drinking them, someone else may vomit. Yet, another person might get diarrhoea after drinking the medication. It does not mean that you should stop taking medication when you see all these things happening to you. You should not say that “the pill is making me sick”. This pill works, and I am asking you to please stick to the pills.” - Counsellor
	5.4. Counsellor (C): But it (side effects) is not going to happen for the rest of your life. It will be for that small period where it made your dizzy and nauseous. Maybe feel like vomiting and feeling tired, but once your body gets used to the treatment, it becomes alright. Patient (P): I will feel like vomiting and dizzy. C: Yes, for the time being when you start, but some people don't experience like that as our bodies are not the same.

4.9.3 Strengths and limitations

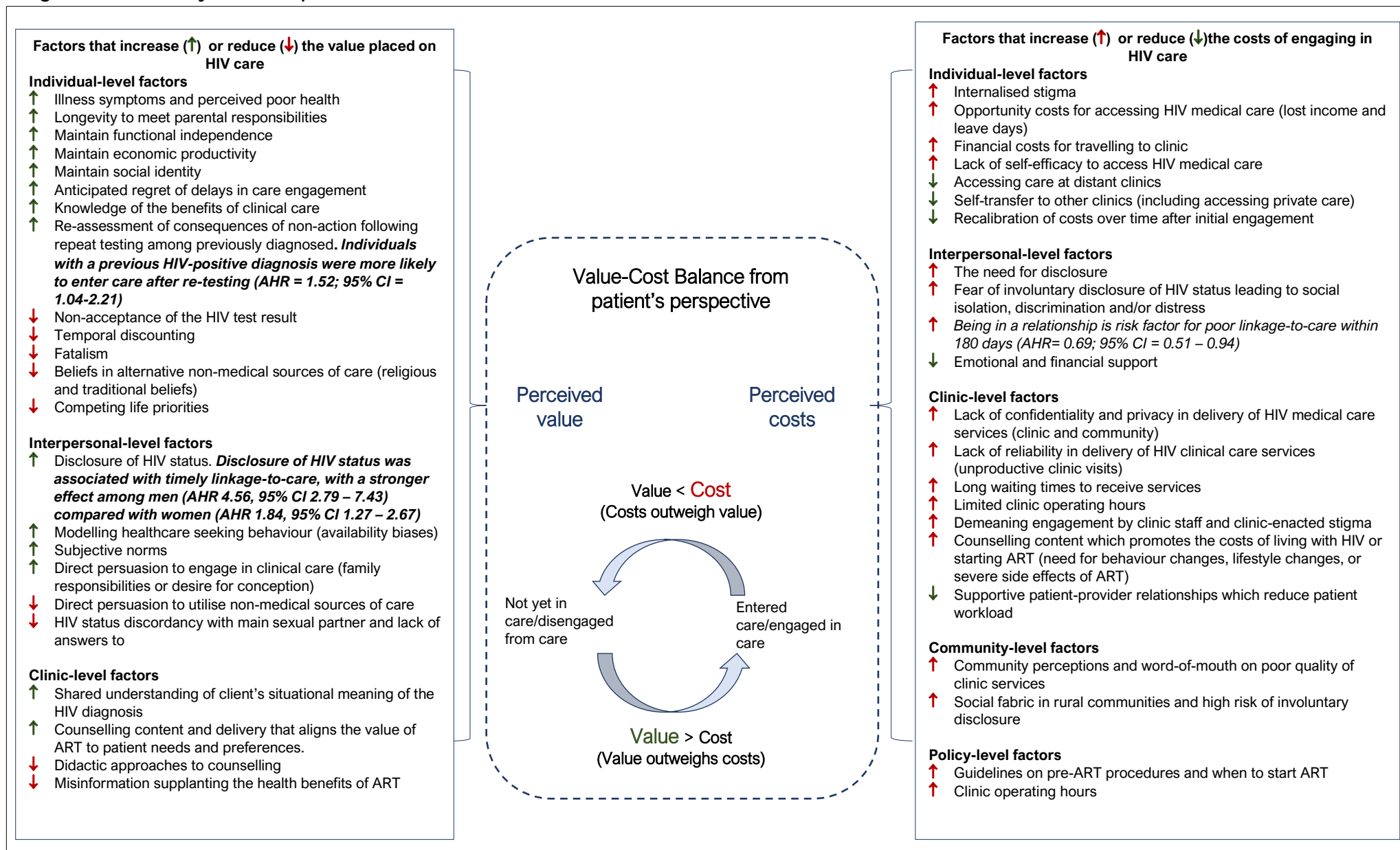
The strengths of this study include audio-recording of actual counselling sessions with the recording starting prior to obtaining test results, the inclusion of a substantial number of counsellors, and performing the study during routine care at public clinics. We do note potential limitations. One is that the counsellors or clients may have changed behaviour in the presence of the digital audio-recorder. It is possible that counsellors switched from a patient-centred approach to more of a didactic approach due to the presence of the audio-recorder in order to impress the research team with their comprehensiveness. We doubt that this occurred, partly because the counsellors received guidance on optimal counselling approach and content from the study team during the study period. However, the results of the training were not reflected in any of the recorded counselling sessions. In addition, audio-recording started much earlier during an HTS session, before pre-test counselling, and the recording device was placed to the side (on a cupboard) allowing for the counsellor and client to easily ignore the presence of the recording device by the time post-test counselling occurred.

4.10 Summary of patient perspectives on linkage-to-care: a value-cost approach

Figure 4-8 provides an overview of patients' views on the contextual factors that influence the conscious or unconscious appraisal of values and costs of engaging in HIV medical care following HIV diagnosis. These underscore the importance of the three core constructs upon which the conceptual framework of this thesis is based:

1. Each person diagnosed with HIV is unique (e.g. how each person appraises the value of HIV medical or how they weight the costs of engaging in medical care)
2. There is a dynamic interaction between the person diagnosed with HIV, their environment, and the behaviour they seek to perform (e.g., social support or how clinic services are delivered had an influence on care engagement outcomes).
3. Healthcare that places the patient at the centre through mutual patient-provider collaboration leads to better outcomes (e.g., the case management intervention showed that counselling content and delivery that aligns the value of ART to patient needs and preferences, promotes engagement in medical care).

Figure 4-8: Summary of results placed within the value-cost framework



CHAPTER 5 : DISCUSSION

5.1 Key study findings

Increasing engagement in HIV medical care and ART initiation, especially after diagnosis in non-clinic sites such as mobile HTS units, is essential to reach asymptomatic individuals, men, and youth to achieve targets for HIV treatment and prevention [29,30,124,300]. The availability of well-tolerated and simple ART regimens makes early initiation of lifelong ART practical and safe. However, attempts to identify pragmatic and effective strategies to overcome challenges to early and sustained engagement in HIV medical care in sub-Saharan Africa have yielded limited success [86-88]. Understanding HIV medical care-seeking behaviour has become an increasingly important area of research, as guidelines and national policies throughout the world are calling for universal access to ART with rapid initiation of therapy after diagnosis [55]. We sought to identify the contextual factors that influence patient-level decisions for engagement in HIV medical care among adults diagnosed with HIV and to explore how each of the identified factors plays a role in shaping healthcare-seeking decisions.

5.1.1 The gap between observed linkage-to-care outcomes and the goals for UTT

We studied 587 PLHIV diagnosed through mobile HTS who were informed that they were eligible to be started on ART and given a referral letter to a local health facility of their choice. Over a 6-month follow-up period, just over half of the participants had verified linkage-to-care. At the time of conducting this study from 2014 to 2015, the challenges of delayed linkage-to-care were attributed mainly to PLHIV aware of their status, but not eligible to start ART (i.e. pre-ART patients) [201,301,302]. Findings from several studies in the pre-UTT era suggest that pre-ART patients perceived low value in accessing medical care, mostly because they only went to the clinic for prophylactic measures and the routine monitoring of CD4 counts and viral loads [303,304]. However, our study findings reveal that even among ART-eligible clients, delays in linkage-to-care are a significant problem.

Our findings are among the first from community-based HTS programmes in the pre-UTT era, to signal potential pitfalls to the anticipated benefits of universal ART coverage, if similar levels of linkage-to-care observed among our ART-eligible participants, persist. Further, our qualitative study findings suggest that recurrent issues of non-acceptance of HIV diagnoses, temporal discounting (or feeling healthy), non-medical sources of HIV medical care, and clinic-level barriers (discussed later in this chapter) [65], still play a role in delaying linkage-to-care even among PLHIV who know they are eligible for ART at the time of diagnosis.

The disquieting picture of poor linkage-to-care among ART-eligible individuals is corroborated by evidence from recent community-based cluster randomised trials; though conducted in more controlled research settings compared to this study. The ANRS 1229 TaSP Trial is one of the first studies conducted in South Africa to evaluate the effectiveness of UTT approaches in reducing population-level HIV incidence [210]. In this research setting, only 47.6% of participants randomly assigned to receive immediate ART initiation had linked to care within six months of receiving the HIV diagnosis. This finding was not significantly different from the linkage-to-care outcomes of participants in the standard of care arm (47.4%) who were only initiated on ART if they met the CD4 eligibility criteria. In the POP-ART trial conducted in South Africa and Zambia, participants diagnosed with HIV in seven communities were assigned to receive immediate ART initiation regardless of the CD4 count [212]. In the three South African communities, 6-month linkage-to-care outcomes significantly fell short of the 90% UNAIDS targets, ranging from 45% - 56%, and 38% - 65% in the four Zambian communities.

The adoption of UTT approaches by high HIV-burden countries, such as South Africa, is progressive toward earlier ART initiation and maximizing the individual and public-health benefits of ART. However, our findings, combined with those from recent cluster-randomised trials [210-212], highlight that mere expansion of ART services towards universal coverage, is inadequate to be used by all those who require them. Coupling UTT with additional interventions that promote the value and reduce the costs of HIV medical care for PLHIV diagnosed through these approaches is necessary to translate the benefits of the broad reach of community-based HTS approaches into tangible programme benefits.

5.1.2 Linkage-to-care among repeat HIV testers aware of their HIV-positive status

Our findings suggest that repeat HIV testing facilitates linkage-to-care among ART-eligible PLHIV aware of their HIV status, who have never engaged in HIV medical care.

The practices of repeat HIV testing by people who know they are HIV-positive are anecdotally described for people seeking an avenue to return to HIV medical care after discontinuation of ART (unpublished routine programme data). However, our study identified the additional role of repeat HIV testing as a tool for facilitating initial engagement in care among PLHIV aware of their status, who had never engaged in care. In our study, participants with a previous HIV-positive diagnosis but who had not previously engaged in care were about 1.5 times more likely to link-to-care compared with first-time testers. To a large extent, this finding is counterintuitive to contemporary programmatic emphasis for HTS providers to avoid repeat testing and duplicate counting of PLHIV aware of their status [305,306]. Additional findings from our qualitative findings extend beyond the

widely reported benefits of repeat HIV testing in promoting acceptance of the HIV test result [307,308]. Using the value-cost model, we learnt that increases in the perceived value of HIV medical care, often motivated PLHIV previously aware of their HIV-positive status to re-test for HIV as an entry point for quick access to HIV medical care. This increase in the value placed on HIV medical care occurred mostly when participants experienced disruptive illness symptoms or when they reevaluated the potential harm from maintaining the status quo of inaction. We also found that among some repeat HIV testers aware of their HIV status; issuing POC-CD4 results raised their consciousness to the reality of depreciating immune systems. In turn, this promoted the value of HIV medical care and subsequent timely linkage-to-care.

Facilitating linkage-to-care for this sub-group of HTS clients requires tailored health communication messages which are non-judgmental to patient delays in seeking care. The value of CD4 counts for initiating ART has diminished with the advent of UTT. However, CD4 count results can still be useful to guide health communication which breaks the status quo, addresses temporal discounting, and promotes linkage-to-care among repeat testers aware of their HIV-positive status. Lastly, the temporal shifts in the value placed on HIV medical care observed among repeat testers aware of their HIV-positive status underscore the importance of on-going case management and counselling support. Such on-going support allows healthcare providers to develop patient-centred care plans which are concordant with their client's goals at different stages of their trajectory of dealing with the HIV diagnosis.

5.1.3 HIV status disclosure: the benefits and complexities for PLHIV in relationships

Our findings suggest that the benefits of voluntary HIV status disclosure in facilitating linkage-to-care are more significant for ART-eligible men than ART-eligible women. However, people in relationships appeared to encounter additional linkage-to-care barriers, possibly linked to anticipated costs of disclosure.

In our study of HIV-positive adults diagnosed through mobile HTS, men eligible for ART who disclosed their HIV status were almost five times more likely to enter care, compared with men who did not disclose their HIV status. Although disclosure also facilitated linkage-to-care among women, the effect was lower compared with observed effects among men. Our qualitative findings were only able to provide insights into the overall benefits of disclosure for both men and women combined, as we did not find any differences in themes by participant's sex in our analyses. Generally, participants who disclosed their HIV status talked about how people within their social networks persuaded them to go to the clinic. Participants also spoke about the social pressure they felt to enter care; and other forms of support which addressed emotional, financial or informational needs. We did not collect any

quantitative information on perceptions of stigma after HIV diagnosis. Still, it is highly plausible that the men who successfully disclosed their status, represent a sub-group of men with low internalized stigma – a commonly reported facilitator for early linkage-to-care [65,70]. Findings from other studies suggest that men are likely to face fewer and less negative consequences of disclosure, which may impede engagement in care compared with women [309,310]. On the other hand, women have been reported to be at increased risk of intimate partner violence after disclosure of HIV status [310,311]. Other studies postulate that men are likely to receive more support from their partners than women do when they disclose to their partners [312-314]. The finding on delayed linkage-to-care among people in relationships may reflect the flip-side when PLHIV lack the self-efficacy to disclose their status, or when the anticipated costs of disclosure are perceived to outweigh the benefits expected from disclosing. Our qualitative findings throw some light on this issue. Some participants in relationships had protracted periods of searching for causal attributions of the HIV diagnosis. If they had a low perceived risk of acquiring HIV or when their partners self-reported being HIV-negative. It is also highly plausible that communication provided through post-test counselling sessions may have escalated costs for people in relationships. Examples include messages by counsellors which often made it imperative for clients to disclose their HIV status to implement “required” dietary changes or to negotiate condom use. More deliberative dialogue is required between healthcare providers and their clients to unmask the potential costs to care engagement for people who are in relationships.

5.1.4 Clinic-level barriers to engagement in HIV medical care

The way HIV medical care services are delivered in public sector clinics escalates the costs of linkage-to-care which shift the balance further away from care engagement.

Our findings from a cohort of 56 newly diagnosed participants followed up for six months for in-depth longitudinal interviews, provide a balanced view of how patient perceptions on the value of HIV medical care and clinic-level costs influence linkage-to-care. In using the value-cost framework, our findings uniquely contextualise the influence of anticipated or experienced clinic-level barriers to engagement in HIV medical care, relative to the value that individuals assign to HIV medical care. In our study, clinic-level factors imposed high costs to care engagement, which often outweighed the value participants placed on HIV medical care. The functional quality of clinic services, which refers to the processes by which HIV medical care services are delivered [315], was the primary source on which participants perceived clinic-level costs for engaging in HIV medical care. These findings are consistent with the growing literature on patient satisfaction and the continued use of services [316-319]. These costs to care utilisation undermined engagement in HIV medical care even among some individuals who saw value in clinical care as a resource to cope with their diagnosis.

Most of the clinic-level costs identified in our study, are modifiable and can potentially be reduced. Organizing clinic systems around the patient rather than the provider, including minimizing clinic visits and reduce waiting times, could substantially reduce costs. The feasibility of prompt ART initiation in health facilities and its effectiveness in improving care engagement has been demonstrated in studies conducted in South Africa, Kenya and Uganda [206-208]. Similarly, the costs of linkage-to-care among PLHIV diagnosed through community-based HTS approaches, can be reduced through the availability of community-based ART initiation services. For persons diagnosed through community-based HTS, immediate ART initiation may reduce other costs associated with the risk of being seen accessing services at the clinics and may further lessen the opportunity costs for lengthy clinic visits. However, this needs to be balanced with potential costs of fear of involuntary disclosure identified among several participants in our study.

Models of community-based ART initiation have been successfully implemented and shown to improve linkage-to-care in studies conducted in Malawi, Lesotho and Nigeria [203,205,320]. Notwithstanding the benefits of community-based ART, current models described in the literature, still require patients to go to health facilities to continue with ART services after community-based initiation. Therefore, initially averted costs may yet be re-introduced when patients are required to go to the clinic for ART maintenance. This is corroborated by findings from the CASCADE trial conducted in Lesotho [203]. This study evaluated the effectiveness of same-day home-based ART initiation compared with immediate clinic referrals. In the same-day group, almost all participants (98.6%) indicated readiness to start ART on the day of diagnosis and were initiated on ART, with a month's supply of ART. However, about 31% failed to go to the clinic within three months to continue with ART. Based on our findings in shifts in the value-cost balance over time, participants in this study may have experienced increased perceptions of costs to sustained engagement in care or reductions in their perceived value of HIV medical care. Intrinsically, community-based ART initiation models should be coupled with on-going care facilitation support which continuously monitors patient appraisals of their value-cost balance over time, with the goals of promoting sustained care engagement.

Also, reorienting the behaviour of healthcare workers to patient-centred care will have a direct impact in reducing a significant portion of the clinic-level costs, which affect linkage-to-care. The failure to address healthcare worker professional behaviour in searching for effective linkage-to-care interventions may dilute or entirely undermine the positive effects of high-potential interventions. Our study, and other studies, shows that patients mostly evaluate the processes by which healthcare is delivered when they assess the costs to care engagement. Changing the professional behaviour

of healthcare workers towards patient-centred approaches to care delivery will be a complex and challenging task. Providing patient-centred care is not piecemeal intervention; it is a change in paradigm and culture by all healthcare workers [321]. Theoretical frameworks on the adoption of new health service delivery practices provide a good starting point in developing sustainable reforms in reorienting the behaviour of healthcare workers. To promote the chances of getting buy-in from healthcare workers, programme implementers will need to address multiple behavioural domains, including convincing healthcare workers how patient-centred care is congruent to the professional roles, and discussing how such approaches will impact their workload [63,238,322].

The Health Workers for Change Programme is one example of an intervention which was effective in improving health service delivery [323]. The intervention was a series of workshops designed to assist healthcare workers in introspecting on their internalized views about their work and developing approaches to overcome personal challenges which would enable them to focus on respect and support of their patients. Overall, in the 11 countries (including South Africa) where the programme was evaluated, there were reports of improved provider-client relations, the functioning of health facilities and staff interrelationships [324]. Other interventions, which are promising but require additional investigations to minimise the risk of undesirable consequences, involve the use of conditional financial or non-financial incentives as positive reinforcements to reward high service quality. For example, pay-for-performance programmes have been shown to be effective in increasing the quality of child health delivery programmes in Rwanda [325]. However, evidence of effectiveness from other settings is inconclusive [326]. To sustain the effects of such interventions, health facility managers also need to create an enabling clinic environment which provides the required resources and support to promote a culture for patient-centred care.

In our study, we identified how some people relied on the word-of-mouth from other people's negative clinic experiences and their levels of dissatisfaction when making their decisions of not engaging in care. However, as some participants would only find out when they eventually went to the clinic, some of the anticipated costs generated through word-of-mouth were non-existent or had been exaggerated. Essentially, the failure of programme implementers to identify and address threats to the demand for healthcare services in the catchment areas in which they operate will likely result in service utilisation which falls short of programme goals. Therefore, healthcare providers need to continuously market images of a health service which values: privacy, confidentiality, respect for clients, efficiency, and reliability. One inexpensive way of communicating improvements in healthcare service delivery to communities is through word-of-mouth marketing approaches [169]. During clinic consultations, clinic staff can tell patients about the positive reforms

in clinic operations and combine such messages with high-quality service delivery. As patients go back to the community and share messages on improvements and personal experiences, community perceptions on clinic-level costs will likely be altered. Other approaches to the rebranding of clinic services include community dialogue sessions, the use of clinic committees which act as the interface between health facilities and their communities, or traditional mass-media campaigns [327-329]. Finally, to maintain the trust of their consumers, healthcare facilities should deliver the services as promised, to even exceed patient expectations.

Indeed, healthcare providers have a significant role to play in reducing clinic-level costs of care engagement. However, we also observed that internalised stigma at the individual-level played a critical mediating role in how participants evaluated the costs of linking to care. In cases where participants talked about experiencing internalised stigma, the perceived costs of linkage-to-care were often high. In this regard, counsellors need to explore how being HIV positive affects the social identity or self-esteem and to talk about the reactions their clients anticipate from those who they disclose their HIV status to. Shifting the focus of dialogue to promoting the value of ART is also another approach to moderating the effect of internalised stigma on inflating the costs of linkage-to-care. Moreover, healthcare providers should be encouraged to respect patient decisions which they consider necessary to minimise the disvalued effects of internalised stigma. For example, healthcare workers could provide a consistent message regarding policies and providing care for all residents in South Africa, regardless of catchment areas. Such messages could allow PLHIV to access care at the most suitable clinic which lowers the effects of internalised stigma. In essence, one closer to the place of work, open on weekends, or one that affords greater anonymity by way of being further from a place of residence.

5.1.5 The inadequacy of post-test counselling sessions to support the goals for UTT

Our findings from reviewing transcripts of post-test counselling sessions for HIV-positive in the UTT era create a concerning picture of the content and delivery of post-test counselling in public sector clinics of South Africa. Post-test counselling sessions were highly didactic, with counsellors seeking to instruct clients on how to manage or improve their health and comply with the lifestyle changes required to start ART or to ensure the effectiveness of ART. These messages are not aligned with the goals of UTT [57,85]. To meet the targets of the '2nd 90', the offer of ART should remain free of additional conditions such as the need for disclosure or lifestyle changes which may increase the costs of linkage-to-care. In addition to often being false, many of these messages exceptionalised living with HIV and taking ART. This contrasts with contemporary views of presenting the possibility

of a normal life through adherence to ART. Instead, the counselling messages may inadvertently reinforce HIV stigma.

Little health communication was focused on the benefits of ART for individual health or to prevent transmission. Instead, counsellors emphasised the costs of ART. In some sessions, the use of ART was often presented as secondary to the use of condoms or “lifestyle” changes as an intervention to maintaining health. Similar to other studies; our findings show that medical treatment has limited or no intrinsic value to some individuals [65]. Instead, its value lies in the extent to which it is useful in helping the individual to manage the perceived threats or losses from living with HIV. These values of HIV medical care, among others, include longevity, the reassurance of health, economic productivity, and social interaction. However, these values are not always apparent to a patient when counsellors: fail to engage with client’s concerns or goals; deliver messages that contain misinformation, or supplant the value of ART. Therefore, health communication that reassures of the continued possibility to achieve life goals and non-infectivity with an undetectable viral load could be part of motivational interviewing to introduce more immediate value for asymptomatic individuals who are prone to temporal discounting.

The quality of counselling observed in our study is discouraging given that most counsellors had started their work as counsellors and received counselling training since the change of treatment guidelines toward treat-all approaches. While the impact of these messages on ART initiation and adherence was not assessed in this study, the counselling we observed did not promote the value of ART or encourage prompt ART initiation. At the worst, some of these counselling sessions may have led some clients to delay accepting ART. We acknowledge that beyond the individual-level competency of counsellors, contextual factors such as the rationalisation of limited counselling rooms, the large number of clinic attendees requiring HTS services, or the pressure of same-day ART, can predispose counsellors towards didactic and scripted approaches to accelerate the counselling process [270,330,331]. However, even in such scenarios, misinformation and failing to establish the personal meaning of the diagnosis are fundamental flaws that warrant urgent attention. Creating a continuum of counselling support that extends to clinicians when they initiate ART, and to case managers who can provide ongoing support, is important to ensure timely linkage-to-care and sustained engagement in care.

Overall, our findings point to the need for capacity building and a review of counselling protocols to guide counsellors on correct information, counteract prevalent misinformation internalized by counsellors, and equip them to effectively communicate the immediate value of HIV medical care along with the long-term benefits of ART. Counsellors also require training to understand that the way information is described and presented, significantly influences the decisions a person makes –

a phenomenon known as the ‘framing effect’ [332]. This issue relates to the way counsellors overemphasized the side-effects of ART and the severity of side-effects in their counselling sessions. Mainly, information can be presented in a manner that highlights either the negative or positive features of a decision, modifying how a person responds. For example, as South Africa moves to the roll-out of dolutegravir, there are concerns about its use in pregnancy and its effect on higher weight gain compared to other drugs [333]. However, counsellors can discuss these side effects together with the improved tolerability, an increased barrier to resistance, and the broader value of ART for the patient. In doing so, the fears of taking dolutegravir can be moderated than if only the potential adverse effects are described.

Counsellors can be provided with scripts to increase the validity of health information and assure that counsellors communicate priority messages. In the long-term, digital media-based counselling provided through an interactive media display or professionalization of HIV counsellors in South Africa and elsewhere can lead to normalisation of best-practice counselling practices that align to patient-centred care and the goals of universal test and treat.

5.1.6 Linkage-to-care through patient-centred health communication

Our study findings suggest that structured approaches to longitudinal case management support have the potential to improve linkage-to-care. Despite the existence of moderate to strong evidence in support of the effectiveness of short-term strengths-based case management for successful linkage-to-care; there is limited application of these approaches in routine HIV programme settings [84,269,334-337]. Our findings from reviewing case management transcripts show how interpersonal health communication can assist clients in talking about their goals, describing pathways to achieving those goals, and potential challenges along identified pathways.

In the early stages of case management, providers sought to reach a shared understanding of the client’s appraisal of the significance of the diagnosis and the resources they intended to mobilize to cope with the HIV diagnosis if any. A failure to lay this foundation, and minimisation of the need to understand patients within their psychosocial contexts, may result in health communication messages that are off-base and unable to achieve the desired healthcare-seeking behaviour. In some of the sessions, the use of interpersonal communication may have been the only communication strategy able to bridge the gap from testing to initial care engagement. As observed in our study, the tailoring of messages to the immediate needs and concerns of the client, can improve the patient’s receptiveness to health messages and increase the chances of affecting behaviour change. However, we also observed that case managers are likely to face challenges with bringing some clients to participate in the sessions, which may lead to case managers missing

communication opportunities and, at times, reverting to prescriptive general messaging which is not patient-centred. Therefore, once trained, on-going oversight and mentoring are essential for quality assurance.

The relational process between case managers and their clients was positively influenced by having multiple sessions and having adequate time to conduct sessions, without any competing priorities for the counsellor at the time of the sessions. Multiple meetings were essential to building trust and rapport in the patient-provider dyad and assisted both client and counsellor in reflecting on client's perceived value of HIV medical care which may have been initially dismissed or not even identified. The flexibility of case managers to provide face-to-face sessions, and at community venues when necessary, may have improved interpersonal communication and strengthened the working relationship between case managers and their participants. In another study conducted in South Africa, to evaluate the effectiveness of strengths-based counselling on improving linkage-to-care; case managers took a different approach which placed primary reliance on telephonic support [213]. The intervention did not improve linkage-to-care, findings which study investigators attributed in part to the limitations of telephonic counselling which may have compromised the quality of support and weakened the therapeutic alliance between case managers and their clients.

Separate economic analyses of the case management intervention implemented in the Thol'impilo parent study, suggest that reduction in implementation costs are required to promote translation of our findings into practice [193]. The chance of translating these findings can be achieved by reducing the number of expected sessions. We base this recommendation on findings from the Thol'impilo parent study which showed that only 4% of participants who had the first sessions attended all five sessions, and only 14% had four or more sessions [338]. Further reductions in implementation costs can be achieved by changing the cadre of case managers providing longitudinal patient support. The Thol'impilo study utilized social workers and auxiliary social workers. The cost of such staff is higher than experienced case managers who may be able to deliver the strategy with similar fidelity.

5.1 Strengths and weaknesses

A key strength of this doctoral research was the use of complementary quantitative and qualitative methods. The qualitative data provided additional insights into how the factors found to be associated with linkage-to-care, influenced care engagement outcomes. Further, qualitative data allowed us to thoroughly explore contextual factors to individual decision-making, which are difficult to measure quantitatively using close-ended questions. Essentially, without the use of qualitative

research methods, participant perceptions of the values and costs of engagement in HIV medical care would have been inadequately explored.

Our quantitative study component had the benefit of POC-CD4 at the time of diagnosis and is nested in the largest Southern Africa study that we are aware of, assessing factors associated with linkage-to-care from mobile HTS. With this unique position, our study was able to highlight the magnitude of the delays in linkage-to-care among ART-eligible PLHIV and forecast the potential pitfalls of UTT programmes in the absence of interventions to improve linkage-to-care. However, similar to experiences from other pragmatic studies on linkage-to-care [98,121,213,215,222,339], the difficulties reported by the parent study in contacting participants and the subsequent loss to follow-up, may have introduced selection bias. Overall, the inclusion of urban and rural districts, the large sample size, the long follow-up time, availability of POC-CD4 results, and verification of linkage-to-care, strengthen the evidence from our study compared with previous studies of linkage-to-care from mobile HTS.

The key strengths of our qualitative study component included the use of in-depth longitudinal interviews to explore temporal changes in participant perceptions on linkage-to-care, and the analysis of health communication transcripts between healthcare providers and PLHIV, based in routine programme settings. Overall, the value-cost model, coupled with the social-ecological perspective provided a strong foundation for most of our qualitative analyses. We applied double coding in our qualitative analyses to ensure that the application of codes was consistent across transcripts and to assess the robustness of code definitions. We relied on consensus among the various analysis teams, rather than assessing for inter-rater reliability [340]. Also, the use of both deductive and inductive methods to data analysis allowed us to extract more from the data, painting a complete picture of broader linkage-to-care issues [341]. A weakness across most of our qualitative sub-studies is that our findings are primarily representative of the value and costs identified or expressed by participants. These findings may not be inclusive of what operates subconsciously, what they cannot put into words, what doesn't seem reasonable to explain to someone, or what is too sensitive to say. We also based our qualitative sub-studies on convenience or purposive samples. While the generalizability outside of these studies is unknown, we designed our qualitative studies to illuminate explanations and mechanisms of linkage-to-care, rather than estimating population parameters.

5.2 Future research directions

By conducting additional research on key aspects of values and costs of linkage-to-care at each of the social-ecological levels, critical new findings may be achieved to guide further programmatic improvements.

At the individual-level, additional research is required to explore the prominent role played by internalised stigma in influencing perceptions of the costs of care engagement. We did not design our study to fully examine the temporal changes in internalised stigma and the resultant effects on linkage-to-care. Generally, the association between internalised stigma and care engagement outcomes is understudied in longitudinal studies and is an area for additional research [342,343]. Notwithstanding current efforts, more efforts are required to accelerate the development of standardised and validated stigma measures that can be readily used by healthcare workers to support patients in their HIV medical care journey [344].

At the interpersonal-level, our finding that people in relationships are less likely to enter care requires further investigation since there are identified benefits of disclosure in facilitating linkage-to-care. There is also a need for additional research into the process and consequences of disclosure among men. Such research will help guide the development of core messages to assist with disclosure among men and address issues of masculinity that have been reported to reduce the willingness of men to disclose their status and be seen taking medications. These messages may include individual health communication and mass health communication to reshape community norms.

At the clinic-level, our findings point to the need for the reengineering of healthcare service delivery towards patient-centred approaches of care. Additional implementation science research based on theoretical frameworks such as the Theoretical Domains Framework or Normalisation Process Theory is required to explore how patient-centred care can be embedded in routine healthcare services [63,322]. Also, behavioural economics interventions such as nudges which use peer comparisons across health facilities or incentives can be explored to promote the large-scale implementation of patient-centred care in public sector clinics [345]. Further, theoretical and conceptual clarity is required on how to monitor and evaluate successful delivery of patient-centred care. These research efforts should include validating and standardizing measurement instruments and examining links between patient-centred care and outcomes [346,347]. Also, in line with patient-centred care, additional research on low-cost approaches to longitudinal case management support may help guide the scale-up of such interventions into routine HIV programmes.

At the community-level, decreasing stigma and increasing ART and HIV treatment literacy may be part of a combination HIV continuum strategy. There is a need for more research on long-term strategies to reduce community-level stigma. Such research should be coupled with the development of standardised methods for quantifying important aspects of community-level factors, such as social and gender norms, that may moderate levels of community stigma. Moreover, future

research should guide HIV programmes on how to effectively diffuse information regarding lower side-effects of current ART regimens, and the benefits of early ART.

At the policy-level, future research directions should focus on investigating the policy-practice gaps as approaches to HIV medical care service delivery continue to evolve. We base this recommendation on our findings which show that the content and delivery of post-test counselling sessions were divergent from the goals of UTT despite the policy being in existence for at least two years at the time of the study. Research on policy-practice gaps should explore the extent to which policies are translated into practice and the factors which influence policy implementation, generally remain unanswered.

5.3 Conclusions

With the global goal to end HIV as a public health threat by the year 2030 [57], timely linkage-to-care for all PLHIV aware of their diagnosis is of high priority, especially for high HIV-burden countries in Eastern and Southern Africa. To design effective interventions which increase utilisation of ART from investments in UTT, policymakers and implementers need to understand the factors that influence healthcare-seeking decisions of PLHIV. In this doctoral research, we sought to identify the individual- and contextual level factors that influence decisions for individuals diagnosed with HIV to engage in medical care following HIV diagnosis. Further, we sought to explore how the identified factors play the role they do in influencing healthcare-seeking decisions.

Our findings point to the potential pitfalls to realizing the full potential of UTT if observed low rates of linkage-to-care persist, even among PLHIV who are severely immunocompromised and likely to be symptomatic. As South Africa, and other high HIV-burden countries optimise UTT, and increase the reach of HIV diagnosis through community-based HTS, there is even more pressing need to identify ways of linking asymptomatic individuals to HIV medical care.

There is an urgent need to reengineer medical care delivery towards patient-centred approaches which promote the value PLHIV place of medical care while identifying pragmatic approaches to reduce the costs of engaging in medical care. We cannot understate the importance of aligning health communication messages during post-test counselling or on-going case management support to individual needs, goals or preferences, for each client. Several of our participants eventually made clinic visits when their perceived value of HIV medical care increased, even though clinic costs previously reported to be inhibitive, remained unchanged. Without addressing costs and assuring perceptions of the value of clinical care, the number of people engaging in HIV medical care is likely to fall short of the 90-90-90 goals.

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APPENDICES

1. Ethics approval for Doctoral Research
2. Faculty approval for change of title
3. Published and Unpublished Manuscripts
4. Turn It in Report



R14/49 Mr Tonderai Mabuto et al

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)**CLEARANCE CERTIFICATE NO. M160863****NAME:** Mr Tonderai Mabuto et al**(Principal Investigator)****DEPARTMENT:** School of Public Health
Aurum Institute**PROJECT TITLE:** Toward a Patient-Centred Understanding of
Entry-Into-Care Following HIV Diagnosis in Rural
and Urban South Africa: A Mixed Methods Study**DATE CONSIDERED:** 26/08/2016**DECISION:** Approved unconditionally**CONDITIONS:****SUPERVISOR:** Dr Salome Charalambous**APPROVED BY:**

A handwritten signature in black ink, appearing to read 'P Cleaton-Jones'.

Professor P Cleaton-Jones, Chairperson, HREC (Medical)**DATE OF APPROVAL:** 07/10/2016**This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.****DECLARATION OF INVESTIGATORS**

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 301, Third floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.** The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in August and will therefore be due in the month of August each year.

A handwritten signature in black ink, appearing to read 'Mabuto'.

Principal Investigator Signature

12 October 2016

Date**PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES**



Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

13 August 2019
Person No: 376101
TAA

Mr T Mabuto
27 Eton Close Villas
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Dear Mr Tonderai Mabuto

Doctor of Philosophy: Change of title of research

I am pleased to inform you that the following change in the title of your Thesis for the degree of **Doctor of Philosophy** has been approved:

From:

To: **Toward a patient-centred understanding of engagement in medical care among adults diagnosed with HIV in South Africa.**

Yours sincerely

A handwritten signature in black ink, appearing to read 'S. Benn'.

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

OPEN

Effective Interpersonal Health Communication for Linkage to Care After HIV Diagnosis in South Africa

Tonderai Mabuto, MPH,*† Salome Charalambous, PhD, MBBCh,*† and
Christopher J. Hoffmann, MD, MPH*‡§

Background: Early in the global response to HIV, health communication was focused toward HIV prevention. More recently, the role of health communication along the entire HIV care continuum has been highlighted. We sought to describe how a strategy of interpersonal communication allows for precision health communication to influence behavior regarding care engagement.

Methods: We analyzed 1 to 5 transcripts from clients participating in longitudinal counseling sessions from a communication strategy arm of a randomized trial to accelerate entry into care in South Africa. The counseling arm was selected because it increased verified entry into care by 40% compared with the standard of care. We used thematic analysis to identify key aspects of communication directed specifically toward a client's goals or concerns.

Results: Of the participants, 18 of 28 were female and 21 entered HIV care within 90 days of diagnosis. Initiating a communication around client-perceived consequences of HIV was at times effective. However, counselors also probed around general topics of life disruption—such as potential for child bearing—as a technique to direct the conversation toward the participant's needs. Once individual concerns and needs were identified, counselors tried to introduce clinical care seeking and collaboratively discuss potential barriers and approaches to overcome to accessing that care.

Conclusions: Through the use of interpersonal communication messages were focused on immediate needs and concerns of the client. When effectively delivered, it may be an important communication approach to improve care engagement.

Key Words: linkage to care, HIV, health communication, Africa, interpersonal

(*J Acquir Immune Defic Syndr* 2017;74:S23–S28)

INTRODUCTION

Achieving the promise of antiretroviral therapy (ART) to reduce HIV-associated mortality and transmission in sub-Saharan Africa relies on increasing behavioral change toward earlier engagement and sustained retention in HIV care after HIV diagnosis.^{1–3} Health communication may be an important component of increasing care seeking during the period between testing HIV positive and entry into care.^{4–7} Such communication may take several forms, including interpersonal health communication (IPC). IPC can bring constructs of client autonomy and shared decision making to health communication. By being as relevant as possible using a “precision health communication” approach, the chance of behavior change may be maximized. Such precision communication may bring the client to move more rapidly from testing positive to accessing care and initiating ART.

Although the value of IPC is appreciated in HIV care,^{8–11} there has been a limited application of structured approaches of IPC for the step of the care continuum from testing positive to entry into care. Furthermore, much of the published literature describes the effect of communication strategies on specific outcomes without description or analysis of the communication itself. We explored how IPC using a structured, strength-based, and motivational counseling approach can assist clients in enunciating their goals, describe pathways to achieving those goals, and identify potential challenges to consider along those pathways. This may enable clients to consider specific barriers and embrace a specific care-seeking plan. Using data collected from a randomized entry-into-care study (Thol'impilo study), we analyzed the content of longitudinal counseling sessions to describe how structured IPC can provide precision health communication to encourage care seeking.

METHODS

Population

Thol'impilo was a randomized pragmatic trial of strategies to accelerate entry into care after testing HIV positive at mobile HIV counseling and testing (HCT) units in South Africa. Three strategies were compared with the

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The authors have no conflicts of interest to disclose.

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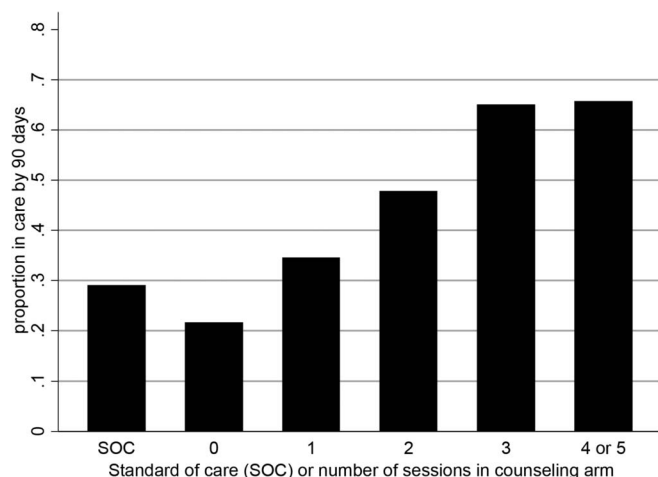


FIGURE 1. Proportion in care within 90 days from testing HIV positive and number of counseling sessions completed (χ^2 P for difference between arms, 0.002).

standard of care of a referral letter: (1) point-of-care CD4 count testing and health staging, (2) point-of-care CD4 count testing and longitudinal counseling, and (3) point-of-care CD4 count testing and reimbursement for the cost of travel to clinics. Entry into care was 40% higher for clinic-verified entry into care in the counseling arm when compared with the standard of care¹²; in the counseling arm, entry into care appeared correlated with the number of sessions attended (Fig. 1).

Longitudinal Counseling Sessions

Counseling sessions were provided using a structured, strength-based, and motivational counseling approach.⁷ Participants received up to 5 counseling sessions up to 90 days from enrollment. Each session was designed to follow a structured curriculum progressing from identifying client goals to determining strengths and finally entry into care.

Through the use of IPC between the client and the counselor, we aimed to empower clients and influence their decisions by allowing them to critically assess their preferences and needed resources for managing their HIV diagnosis. As a starting point, counselors applied inquiry and reflective feedback techniques to identify a client's immediate concerns. Specific well-characterized barriers that counselors could use to initiate discussion were internalized stigma, lack of HIV and/or treatment-related knowledge, use of non-allopathic HIV care services, perceived value of seeking HIV clinical care, and context-specific costs associated with seeking HIV clinical care.¹³ The ultimate goal was to engage the participant in self-identifying barriers or facilitators. Counseling sessions were provided telephonically or in-person at a mutually convenient and safe location. Counselors had formal training as either a social worker or auxiliary social worker, and they received additional training on the South African guidelines for the management of HIV in adults, adherence counseling, disclosure counseling, strength-based approaches, and motivational interviewing.

Study participants tested HIV positive at a mobile HCT unit were ≥ 18 years old, capable of providing informed consent, reported not receiving HIV-related care at the time of diagnosis, and had been randomized to the longitudinal counseling arm.

For this substudy, 28 participants were randomly selected from the 384 participants in the longitudinal counseling strategy arm who had attended at least 1 counseling session. We replaced randomly selected participants until we included participants from each of the following categories: male/female, rural/urban residence, and ART eligibility at the time of diagnosis (CD4 count ≤ 350 and >350 cells/mm³). Audio-recorded sessions were transcribed and translated into English. A total of 50 sessions were reviewed, 30 in-person session transcripts and 20 telephonic transcripts.

This trial is registered with ClinicalTrials.gov (NCT02271074) and the South African National Research Ethics Council DOH-27-0713-4480. Ethics approvals were provided by the University of the Witwatersrand Human Research Ethics Committee and the Johns Hopkins University Institutional Review Board. All participants provided written informed consent.

Analysis

Inductive thematic analysis was used to identify, analyze, and report on themes from the interaction between the counselor and client.¹⁴ Potential themes were collaboratively developed by 2 of the researchers (T.M. and C.J.H.), examining and reviewing the codes to identify patterned communication content and relational processes. NVivo 10 (version 10, 2012; QSR International Pty Ltd, Melbourne, Australia) software was used for data management and coding.

RESULTS

Participant Characteristics

Of the participants, most were female (18/28) and age ranged from 18 to 66 years (Table 1). Seven participants had entered care before attending the first session, whereas 16 of the remaining 21 clients entered care during the course of the intervention period (90 days post diagnosis). Among those who failed to enter care, 1 client had reached the maximum number of sessions, whereas the remaining 4 did not attend all 5 sessions.

Delivery of Sessions

Face-to-face sessions had longer median duration (45 minutes; interquartile range, 30–50 minutes) compared with telephonic sessions (29 minutes; interquartile range, 25–46 minutes). Telephonic sessions were often affected by poor network connections. Participants exhibited frustrations in repeating themselves, especially when they were uncomfortable in their environment and wanted to be discrete. Another challenge with communication was the existence of language barriers. One client appointed a translator, whereas in other

TABLE 1. Characteristics of 28 Participants Selected for Counselling Session Analysis

Site	
Urban	13
Rural	15
Gender	
Female	18
Age, yrs	
Median, range	34 (18–66)
18–30	10
30–40	5
40–50	3
>50	10
Education	
No school/preschool education	3
Primary school education	7
Secondary or tertiary school education	18
Employment status	
Employed	9
Unemployed	19
Previous HIV test	
No	15
Yes	13
CD4 count value, cells/mm ³	
≤350	15
>350	13

cases, attempts were made to converse using basic knowledge of the dominant language in the area—which all counselors were versant in. Some clients had minimal tolerance for these complexities. The example below is of a client who in her frustration, terminated the telephonic session and never answered any calls thereafter.

P: No. I have answered you already ... I told you that my problems come from people who did this [witchcraft]. You asked and I answered.

CF: Sometimes, I don't get it clearly mama.

P: You don't understand Sepedi [local language with different dialects] well do you? Where do you come from? [female, 49 years, rural].

Content of the Sessions

Building the Foundation for Precision Health Communication

The counseling sessions started with questions to explore the practical consequences of the HIV diagnosis to the client's everyday life. This guided a mutual understanding of the client's primary goals and served as a foundation for further discussion. Although simple in concept, in practice,

bringing a client to identify primary goals was often a challenge as illustrated by the following transcripts.

Client: I am beginning to think that my life might end any day from now. I might die any day. I will die and leave my children behind. I want to know what I need to do when things are like this. I want to know if I will get any treatment I am stressed now because I was not sleeping around. I don't understand how I got this virus! [female, 22 years, urban].

Client: It is very difficult my brother. I have not yet disclosed to my partner about my status. I am scared; I don't know how I am going to break the news to her. This is the challenge I am faced with. I am worried I might end up infecting her with HIV [male, 40 years, rural].

Client: I don't believe the results [HIV test results] ... I am very confused, and I want to test again in order to prove that it is true. [female, 31 years, urban].

Counselors also turned to themes common among recently HIV-positive individuals to unearth underlying concerns. This included topics on the progression of disease, interpretation of disease symptoms, risk of transmission to loved ones, and conception of persons living with HIV. In one example, a 22-year-old female client was in a steady relationship and had no children. The counselor opened a discussion on safe pregnancy among persons living with HIV. The client then disclosed that she was 2 months pregnant and had been harboring anxiety on future steps. This was particularly salient regarding communication around ART, shifting the discussion from pre-ART care to the urgency and availability of ART.

The clients' active participation and articulation of their subjective values and goals during the foundation building phase appeared to be mediated by (1) the extent to which the client had internalized the meaning of the diagnosis and (2) the extent to which the client had progressed in planning or taking action to meet the desired goals. Acknowledging these dynamics facilitated pacing of sessions to allow clients to lead in their own care engagement processes.

Exploring and Promoting the Value of HIV Clinical Care

The tailoring of communication to client narratives provided an opportunity to (1) engage the client in reflection on the congruency of HIV treatment with their stated goals and (2) promote accessing HIV clinical care as a health-related value in relation to their illness and potential treatment. Additional educational messaging was also often important to cement HIV care as an important goal. Counselors mostly linked the value of HIV clinical care to client concerns over death, relief of symptoms, ability to

remain functionally independent, or the ability to conceive. The promotion of value for clinical care was equally important for both clients who had not entered care or recently entered care within the first 90 days of diagnosis. For the latter, counselors compensated for health communication gaps between clients and health care providers such as those illustrated below.

Counselor: So when you got back to the clinic for the second time, did they show you your blood results? ...

Client: They just talked amongst themselves [the nurses] and she said, "Here are the results"... So I don't know what they mean [female, 57 years, urban, public health care facility].

Counselor: He gave me the medication and he didn't want to give me the pamphlet that shows the side effects. He said people like complicating things by reading these things [pamphlets] ... [female, 31 years, urban, private health care facility].

On the other hand, counselors faced difficulties when clients did not perceive value in HIV clinical care, especially among those who were not eligible for ART or those who had negative experiences from previous clinic visits. In sessions where clients exhibited signs of resistance to HIV clinical care (arguing, inattention, side-tracking, or cutting off), counselors were trained to "roll with resistance" but often failed to shift focus and reframe the discussion to offer a new meaning or perspective for the client's consideration.

Collaborative Identification of Goal-Oriented Activities

Through open-ended questioning, counselors probed for specific plans to go to a clinic. Where clients failed to identify deficiencies in their plans, counselors used non-judgmental critical questioning or paradoxical scenarios to challenge the proposed plan. In some cases, this exposed the underlying concerns that had not been communicated by the client.

Counselor: So, you are saying that you will not disclose to him...? How do you plan to take treatment when he is around?

Client: I don't know. It will not be easy because I want to take the treatment. I will also have a problem of having unprotected sex because I haven't told him about my status... I don't know where I'm coming from or going. I am confused.... My partner and I have not been faithful to each other. I have someone else that I am

dating and he also has someone else [female, 51 years, rural].

Clients who experienced paternalistic treatment from their HIV clinical care providers appreciated the participatory and collaborative nature of the support provided by the counselors. In the example below, the client chose to seek private over public health care but felt that she was not afforded the opportunity to participate in the decision around starting ART. The counselor provided additional support, with a subsequent resolution to change the care provider.

Client: ... He [private doctor] dealt with me as if I have already said yes to one, 2 and 3. He said "You are ready to start", things like that. At least you had already explained the process which was to be conducted but he didn't tell me anything ... When I got there he said "here is your medication, take and drink"... I was not expecting that, I expected to be counseled and be asked if I am ready to be initiated [female, 31 years, urban].

Identification of Barriers to Goal-Oriented Activities

The process of identifying barriers to the successful completion of activities also required the tactful use of questions to maintain mutual dialogue. Through highlighting potential barriers and working to identify approaches around those barriers, messaging was focused toward the client's needs and may have encouraged increased entry into care. In the example below, the elderly client had lived in a rural village that was serviced by a mobile clinic. However, the client had not accessed care from the mobile clinic.

Counselor: I can see that money is real issue for you in planning how you are going to reach the hospital.... What do you think is the way forward?

Client: I'm waiting to find money so that I can go to town. That is all I am waiting for...I don't know when or how I will find it.

Counselor: I understand that your challenge is money. So, is it possible that you go to the mobile clinic when it comes [to this area] next week?

Client: Yes it's possible. I will go because you don't pay you just walk [female, 56 years, rural].

The multiple session approach allowed for continued reflection on barriers, which may have been initially dismissed or not identified by both client and counselor.

Counselor: Since you were not able to complete the task of going to the clinic, let us talk about last week's conversation when you mentioned that you had no hindrances [going to the clinic]. Today do you have any concerns of hindrances that may prevent you going to the clinic?

Client: No, the only challenge I have is time.

Counselor: So, the main challenge you have is time?

Client: Yes that is the only problem. I only have time over the weekends [male, 40 years, urban].

Once barriers had been identified, counselors steered their clients to constructively reframe their perspective on the identified barriers, in terms of how they planned to overcome them.

Counselor: How do you think you can overcome this issue of the long queues and your thoughts of poor services at the clinic?

Client: I can go back, but not when I'm going to school because I don't want to disturb my studies.

Counselor: Oh ok. So you feel that you can overcome this by going to the clinic when you are not going to the school because you will be able to handle the long queues?

Client: Yes, even if I find the queues, I will not be rushing anywhere [female, 20 years, urban].

Some clients who presented themselves as possessing high levels of self-efficacy noted barriers faced by some people but insisted that they did not apply to them. Counselors applied "focusing" techniques to direct conversational flow back to the client. For a 51-year-old male client, the client refocused the session by noting, "*Earlier you said that it is important that everything should start with 'I' [me] because this is about you*" After this, it surfaced that behind the displayed levels of self-efficacy, the client had underlying challenges with accepting his status and had resorted to dissociation from the diagnosis as a form of coping.

Drawing Upon Client Strengths

Identification of strengths was conducted to provide clients with a self-awareness of their capacities and strengths to manage their own lives and illness. These internal resources

were primarily identified by asking clients to provide narratives about past difficult life experiences and their coping mechanisms to these challenges. This also addressed issues of negative self-evaluation, low self-esteem, and a lack of self-efficacy to engage in HIV care. In the example below, the counselor amplified the client's strengths to increase their motivation toward care engagement.

Counselor: My brother as you were busy talking as I was listening to you. I saw a determined person. I see a person who doesn't lose hope in life. I also see a courageous person, because when you were met with life situations, you never turned back ...?

Client: I don't know where it comes from myself [male, 30 years, urban].

Transitioning Out and Discontinuation of Sessions

At this stage, counselors summarized and reflected upon the content of previous sessions, with primary emphasis on the client's resources required to achieve or maintain HIV care engagement. Referrals were also made for 3 clients that required additional counseling, access to food parcels, and assistance with social grant applications.

In turn, clients were also asked to summarize any learning or experiential growth that had occurred during the sessions. Clients identified value in terms of redefining their self-worth, accessing social support, educational messaging, and entering care.

Client: ... If I had not talked to you, maybe things have turned out differently. I never thought I would ever get HIV. After having lived a good life, I asked myself "Why me?" Obviously I had to reach this point and accept, but what helped me the most was you talking to me, and helping me realize issues about the disease and myself... I am thankful for *things you have done* ... [female, 31 years, urban].

DISCUSSION

Through exploring specific themes from counseling sessions, we have demonstrated specific ways that IPC enabled a dialogue that could fit the immediate needs, concerns, or challenges of a client. In doing so, the precision health communication was able to provide communication that may have better met the needs of the client and better achieved behavior change. Through IPC, some clients enunciated goals and described challenges that they may not have previously been fully conscious of. In turn, this allowed the counselor to challenge the client to think through specific barriers and articulate solutions. In some of the sessions, the use of IPC may have been the only communication strategy able to bridge the gap from testing to planning on going to a clinic. A failure to lay this foundation may result in irrelevant messages or messages that are highly

relevant but may not have penetrated through the client's more immediate concerns. Such off-target messaging—either via mass media or one-on-one—may lead the person living with HIV to tune out and fail to achieve behavior change.^{15–17}

We also note challenges in providing precision health communication. Standard messaging as part of HCT, adherence counseling, and HIV care in South Africa is generally provided as informational outside of specific client context (eg, descriptions of HIV, warnings about the perils of missing doses of ART, instructions to use condoms, etc).¹⁸ Delivering precision health communication was not always easy for the counselors who both missed communication opportunities and, at times, reverted to proscriptive general messaging. Although not a common occurrence in this study, other studies have reported major challenges with counselors primarily relying on directing, moralizing, and health advising techniques.^{15,18} The consequences of such approaches can be client resistance or superficial therapeutic alliances that do not yield results.¹⁹ However, other researchers argue that some sub-Saharan African societies and cultures perceive value and favorably defer to paternalistic approaches with resulting positive HIV care engagement outcomes.^{20–22} Success with implementing precision health communication requires it being embraced by counselors and having ongoing oversight and mentoring to maintain and improve the quality of the counseling.¹⁶

This study has the strength of assessing real-world counseling sessions as part of a health communication arm of a trial to accelerate entry into care after testing HIV positive. Limitations include the small number of transcripts analyzed. In addition, we did not assess the proportion of client–counselor communication that led to tailored or precision communication compared with more general information provision. Furthermore, we did not assess whether specific communication sessions appeared more or less likely to lead to entry into care. HIV care seeking, continued engagement in care, and adherence to the treatment are all health behaviors. Health communication has an important role in positively influencing this behavior.²³ This communication may take many forms—from mass media, peer support, health care workers providing education and reinforcement, and messages developed through discussion with a client—as we have illustrated here. We believe that such precision health communication has an important role and may contribute to improving the care continuum.

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Perceptions of Value and Cost of HIV Care Engagement Following Diagnosis in South Africa

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Abstract

Understanding the role of contextual factors beyond individual behavioural determinants is critical to identify strategies to achieve engagement in HIV clinical care. We sought to examine how subjective and objective evaluations of clinic-level costs and value placed on allopathic care influenced HIV care engagement. We used repeat in-depth interviews over 6 months among newly HIV diagnosed adults in South Africa. Data were analysed using thematic analyses and framework matrices to explore individual trajectories over time. Three main patterns of care engagement emerged: failure to enrol in care within 3 months, disengagement after enrolment, and early enrolment with sustained engagement. Findings show that burdensome health systems coupled with low perceptions of the future value of HIV care, compromise HIV care engagement. Without addressing these costs and enhancing perceptions of value on clinical care, the number of people engaging in HIV care is likely to fall short of goals.

Keywords HIV · Linkage-to-care · Care continuum · Africa

Introduction

Simple, well tolerated antiretroviral therapy (ART) regimens make early initiation of lifelong HIV treatment practical and safe [1, 2]. Furthermore, guidelines and national policies throughout the world are calling for universal access to ART with rapid initiation of therapy after diagnosis [3, 4]. However, attempts to identify pragmatic and effective strategies to overcome challenges to early and sustained engagement in HIV care in sub-Saharan Africa have yielded limited success [5–7], even in clinical trial settings of test and treat programs [8, 9]. It is increasingly recognised that optimal design of effective approaches is hampered by limited understanding of factors beyond individual behavioural determinants (e.g.

knowledge, self-efficacy, income) that mediate engagement in care [10, 11].

Several studies have identified the clinic context as an important influence on successful care engagement [12–16]. Importantly, the mere availability of clinic services is inadequate to achieve use by all those who require them [17–19]. In a recently proposed explanatory framework for HIV care seeking behaviour, clinic-level barriers to HIV care engagement can be further conceptualized as clinic processes or structures that levy financial and/or non-financial costs to the HIV care engagement process [20]. The ultimate behaviour regarding going to the clinic is determined by the subjective (or objective) evaluations influenced by psychologically conscious or unconscious priorities regarding the balance between the *value* and *cost* of engaging in care [21–23]. Within this balance, (1) when value exceeds costs, engagement in care is likely; (2) when costs exceed value, entry into care may not occur or disengagement from care is more likely; and (3) when value and costs are nearly equal, an individual may be ambivalent leading to cycling in and out of care [20].

We sought to examine the value placed in HIV clinical care and perceptions of clinic costs affecting decisions regarding engagement in HIV care through a qualitative analysis of clinic-level experiences and perceptions among

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a cohort of newly HIV diagnosed adults in South Africa. Specifically, we conducted in-depth interviews at three time points after individuals tested HIV positive to explore behavioural processes and experiences with HIV care engagement. Themes were organised along the value-cost framework [20].

Methods

We conducted repeat in-depth interviews at 30, 90, and 180 days after HIV testing to address the study objectives. Clients testing HIV-positive at mobile HIV Testing Service (HTS) units were recruited immediately following post-test counselling. The mobile HTS units were deployed in two districts in South Africa: a rural district in Limpopo Province and an urban/peri-urban district in Gauteng Province. Mobile HTS units were deployed in communities, workplaces, commercial shopping areas, and at special events as part of routine service delivery. Clients were eligible to participate in this study if they were diagnosed HIV positive from one of the mobile HTS units, ≥ 18 years old, capable of providing informed consent, and not reporting current engagement in HIV-related care (receiving ART or other regular ongoing HIV-related care). Trained interviewers used a semi-structured guide which covered topics including the meaning of HIV to the individual, barriers to engagement in care, experiences with the health care system, beliefs and knowledge about HIV, and individual health perceptions. Interviews were audio-recorded and conducted in four local languages (Sesotho, Sepedi, isiZulu or Xhosa), in-person in a private room or telephonically. Interviews lasted about 1 h, and participants were issued USD6 in cash to cover costs for travel and time, in keeping with local practice. Immediately after every interview, study staff compiled field notes documenting personal reflections of each interview to describe the interview context and methodological issues. The study was approved by the institutional review board of the University of the Witwatersrand, South Africa (M110722).

All in-depth interviews were transcribed and translated into English. After completion of data collection, two researchers (TM and CJH) read and summarised all interview transcripts to familiarise themselves with the data, and to capture the context of participant narratives. A preliminary coding structure was generated a priori from the ‘value versus cost’ theoretical framework [20] and inductively from the available data. The coding structure was tested on a selection of transcripts, and revised to ensure that it captured relevant patterns from the narratives with minimal overlap. Coding was performed by TM and CJH using NVivo 10™ (QSR International Pty Ltd., Melbourne, Australia, Version 10, 2012). Thematic analysis of qualitative data was used to identify, analyze, and report on themes [24] related to

the interaction between study participants and the health care system or their perceptions of value or costs associated with accessing health care. Themes were developed from the coded text, taking into account code frequency, connections between codes, and consistency with the text. In addition, framework matrices [25] were developed for each participant to identify individual trajectories over the three interviews and to explore the shift in the value-cost balance regarding accessing health care over time.

Results

From January 2012 to February 2013, repeat in-depth interviews were conducted with 61 participants at 30, 90, and 180 days after testing, for a total of 155 interviews. Five participants were excluded from analyses; four who had a single interview and one who reported a subsequent HIV negative diagnosis at a different testing site soon after study enrolment.

During analyses, three main patterns of clinical care engagement emerged: failure to enrol in care within 3 months of diagnosis ($n = 18$), disengagement from care after initial enrolment ($n = 7$), and early enrolment with sustained engagement in care ($n = 31$). Table 1 presents a breakdown of study participants by residence (rural/urban), age, gender, employment status, and whether they had previously tested for HIV. We found no major differences in our findings by participant characteristics, with the one exception that rural participants voiced more mistrust of community healthcare workers than did urban participants. The outcomes of the participants’ conscious or unconscious subjective evaluations regarding the balance between the value and costs of engaging in care are described for each pattern of clinical care engagement (Fig. 1).

Failure to Enrol in Care Within First 3 Months of Diagnosis

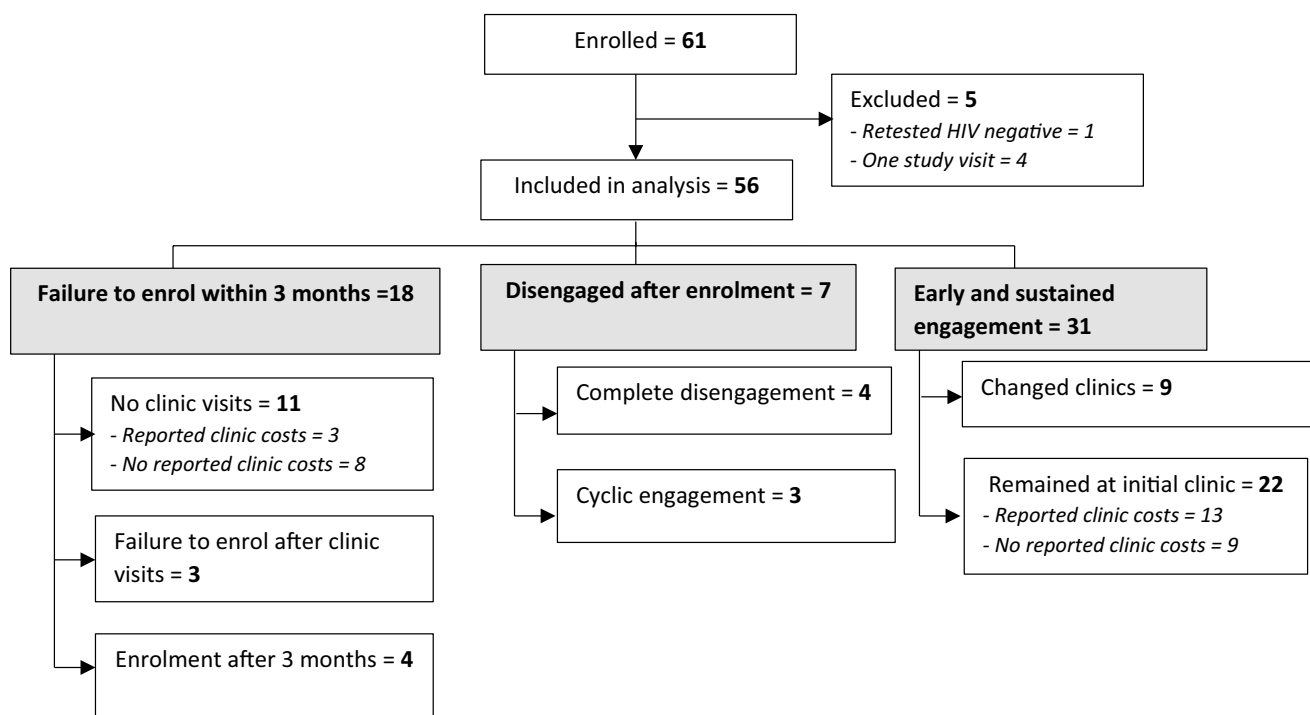
Participants who failed to enrol in care within 3 months either had no clinic visit attempts, went to the clinic but did not enrol in HIV care, or first went to the clinic more than 3 months after diagnosis.

No Clinic Visit Attempts

Descriptions of high clinic costs coupled with a low perceived value of HIV clinical care were predominant themes among the eleven participants who failed to make any HIV clinical care visit attempts during the follow up period. Three participants specifically discussed clinic-related costs as part of their health-seeking decisions (Quote 1.1–1.3). Based on what they knew of other community members’

Table 1 Study participants by main clinical care engagement patterns

		Total (N = 56)	Failed to enrol within 3 months (N = 18)	Disengaged after initial enrolment (N = 7)	Early and sus- tained engage- ment (N = 31)
Residence	Rural	25	11	2	12
	Urban	31	7	5	19
Age (years)	Median (IQR)	31 (25–40)	30 (23–37)	22 (20–28)	34 (27–45)
Gender	Male	23	7	2	14
	Female	33	11	5	17
Employment status	Employed	32	12	1	19
	Student	4	2	2	0
	Unemployed	20	4	4	12
Previous HIV testing	First-time tester	18	8	2	8
	Previous tester	38	10	5	23

**Fig. 1** Patterns of clinical care engagement among study participants

clinic experiences, there was a common perception that they would have negative experiences if they did go to the clinic. For example, two participants anticipated community-wide disclosure of their HIV status either from neighbours seeing clinic affiliated community health workers arriving for home visits or from community health workers disclosing information about others HIV status. They feared that this would lead to social isolation, discrimination, and distress for their family members. This perceived cost appeared to be greater than the limited value participants expressed regarding HIV care. One participant embraced religious care as superior in offering a cure for HIV, and the other remained in denial of

her HIV diagnosis (Quotes 1.4–1.5). As a result of the low perceived value of clinical care, the anticipated costs swayed the value-cost balance towards non-enrolment in care. The participant who embraced religious care explained:

I don't have any stress at all, that is why I am saying sometimes I forget that I am HIV positive. I only remember that I am HIV positive when you call me. I am not going to the clinic and I am not planning to go either. - Month 3, F, 27y

The third participant who specifically discussed clinic-related costs for not making any clinic visit attempts, also

placed low value on seeking clinical care. However, in the first two interviews she maintained that it was the high clinic-related costs that kept her away from making any clinic visits despite a desire to go to the clinic. Specifically, she described long queues and required time off from work as unacceptable costs. By the third interview, the participant's explanation for not seeking care shifted to seeing low value in care as the main reason she had not engaged in care.

When I am at home you find that I am just sitting and socializing. After resting I find out later that there is no more time [to go to the clinic]...My reasons for not going to the clinic are not that major, because I sit and later realize that the time has gone. I just feel like my body is tired and I lack interest of going anywhere - Month 6, F, 33y

Failed Enrolment After Clinic Visits

Clinic visit attempts did not consistently translate into HIV care enrolment. Three participants made their first clinic visit, and encountered clinic-related costs that led to a discontinuation of any further attempts to seek clinical care. On the first clinic visit, two of these participants were turned away by clinic staff because the clinic was about to close, while a third experienced long and slow moving queues (Quotes 1.6–1.8). For all three participants, each employed full-time, the frustration and time away from work increased the perceived costs of enrolment in HIV care. However, subsequent to the failed clinic visits, there was a noticeable diminution of the initially high value that participants had initially expressed regarding clinical care. Two of these participants switched to the use of herbal and traditional medicine (Quotes 1.9–1.10), and placed more weight on their current feeling of good health which further diminished the perceived value of clinical care. In the two consecutive interviews after being turned away, one participant stated:

I never went there [clinic] again and I haven't gone to any clinic, since I told you at the beginning that I haven't noticed anything wrong with my body, and I am still healthy. - Month 3, M, 47y
... I will go to the clinic once I start experiencing illness that will be incurable, only then will I start thinking about going to the clinic. I also think that I will go to the clinic once I start losing weight or when something happens in my body. - Month 6, M, 47y

After being unable to efficiently access care, one of the three participants switched to a state of denial of his HIV diagnosis and exhibited ambivalence in seeking clinical care. He explained:

...At times I would think of going to the clinic. I would actually get out of the gate, however I would end up

just deciding to turn back and not go to the clinic... - Month 6, M, 28y

Clinic Visits and Enrolment After 3 Months of Diagnosis

Despite having accepted their HIV diagnoses, seeking clinical care was not of immediate importance for four participants who made their first clinic visit and enrolled in care more than 3 months after diagnosis. One participant did not consider the HIV diagnosis as a threat or disruption to her everyday life for the first 5 months. For the other three participants, accessing clinical care was preceded by other higher priorities. For example, two participants were focused on seeking employment at the time of diagnosis (Quote 1.11–1.12), while another was in the process of bereavement from the deaths of two close family members. The latter participant explained:

I have just buried my mother who passed away on Good Friday and even if you can check the day I got tested you will see what I went through. Following that, I have just buried my younger sister again this month. Do you see that there is no way I can concentrate on the idea that I am sick. Honestly speaking currently I don't feel anything and I am not implying anything. But I know that I am HIV positive, do you understand? - Month 1, M, 37y

When all four participants eventually made clinic visits, this appeared to be prompted by increased value placed on clinical care. In some instances clinical care remained important when competing priorities had been addressed or when participants began to experience illness symptoms which were a threat to functional independence, job security, or social status. For example, when the grieving 37 year old rural participant quoted above eventually entered care after 5 months, he explained:

One day I got severely ill and I decided to go to the clinic...I was told that I should start taking HIV treatment and I agreed. I am currently on ARVs and I have been taking them for a month now...My legs were so painful because I am a security officer. You find that I stand at one place for a long time and my legs swell. So I decided I had to go to the clinic. - Month 6, M, 37y

Disengagement from Care After Initial Enrolment

Participants who enrolled in HIV and became disengaged had either made a decision to stop care or described more ambivalence which led to cycling in and out of care.

Complete Disengagement from Care

The predominant theme among participants who completely disengaged from care was the cost of multiple unproductive clinic visits after enrolling in HIV care—particularly in the pre-treatment assessment period (laboratory testing and pre-treatment counselling) (Quotes 2.1.–2.3). These multiple clinic visits translated to either economic costs (cost of travel to the clinic, lost income for daily wage earners, having to use multiple leave days) and/or affective costs (increased uncertainty and distress from the additional time waiting to start treatment). Eventually, the additive weight of each of these clinic visits that appeared to provide little to no tangible value began to outweigh the initial value that participants had expressed regarding clinical care. One participant explained:

I understand that it is my life and I must use every chance I get. However, even when I go to the clinic on the day that suits them, I still don't get help again... To be honest with you, I will never go back to that clinic.
- Month 3, M, 28y

In addition to multiple clinic visits, one participant also reported demeaning interaction by clinic staff, loss of confidentiality, and clinic-enacted stigma as the costs leading to disengagement from care. Prior to the clinic visit, this 19 year old female participant had anticipated these costs, based on word-of-mouth from other community members. When this information was confirmed through personal experience, she discontinued her clinic visits. She narrated:

As young people, we are also scared to go to the clinic because we know that the nurses are going to shout at us. We end up not going [to the clinic] there even if we are not feeling well. They don't know how to treat the youth well, whereas the clinic is the place which is supposed to make us feel free to talk about our lives
- Month 3, F, 19y

Following disengagement from care, all four participants appeared to experience a waning of the value they placed on clinical care. The decline in perceived value of care was reinforced by the absence of symptoms (Quotes 2.4–2.5). The perceptions of the limited future value of clinical care were expressed in several wait-and-see statements such as: "...when the time comes for me to die, let it be..." or "we will see what will happen as the time goes on."

Cyclic Engagement In and Out of Care

Three participants returned to clinical care after having discontinued clinic visits due to clinic-related costs. All three had expressed high value in clinical care soon after diagnosis, with self-reported entry-into-care within the first month.

Prior to disengaging from care they experienced unwanted costs including the lack of privacy at the clinic due to separate queues for people coming for HIV care, anticipated involuntary disclosure by community health workers linked to the clinic, and demeaning attitudes by clinic staff (Quotes 2.6–2.8). Although none of these participants resorted to the use of non-allopathic treatment, the value they placed on clinical care began to diminish after disengagement from care. The eventual shift in the value-cost balance leading to re-engagement in care came from an increase in the perceived instrumental value of clinical care when all three participants began to experience illness and/or weight loss (Quotes 2.9–2.10). This increase in value of clinical care exceeded the costs that they had experienced. One participant who had disengaged from care because of demeaning attitudes by clinic staff explained:

I have currently changed my thoughts and I don't worry about anything with regards to go to the local clinic. I don't want my life to be ruined because of somebody else. It is better I go to the clinic. Even if people talk, it is all the same because there is nothing that they can do! -Month 6, F, 20y

Early Enrolment and Sustained Engagement in Care

The majority of participants who enrolled within the first 3 months were retained in care, albeit facing costs similar to those that led others to disengage from care. What differentiated these participants who remained engaged in care was the consistently high value they placed on HIV clinical care. These participants either remained engaged at the original clinic or transferred to another clinic to reduce perceived costs.

Sustained Engagement in Care with Change of Clinics

In order to remain in clinical care, some participants sought to reduce clinic costs by switching to more efficient clinics or to private medical care (Quotes 3.1–3.4). However, participants had to make trade-offs by comparing the weight of current costs to that of the new costs from switching clinics. For example, two participants without any medical insurance moved from free public HIV care to private medical practitioners after multiple visits at the local government clinic without receiving their laboratory results. Although the switch added consultation fees and laboratory test costs, it reduced the costs associated with repeat visits and lack of confidence in the quality of services being provided. However, in subsequent interviews, participants began contemplating transferring back to free public HIV care as the cumulative financial burden of private care grew. One participant explained:

The doctor told me that if I am supposed to take treatment, I will have to pay around R600 every month. I then told him that I won't be able to afford them and if I had to start them, I will have to go to the local clinic. This means I will have to tell them at work about my situation and ask for day offs so that I can be able to go to the local clinic. -Month 6, M, 34y

Trade-offs were also reported when participants switched to local clinics after initial enrolment at more distant public clinics which had been selected to avoid inadvertent disclosure of status in their local community. Following multiple unfruitful visits at the distant clinics, participants were willing to trade-off the high transport costs and distress from not receiving services with the potential loss of privacy and loss of confidentiality from receiving care at the closest local clinic. One participant explained:

I take the last bit of money that I have and go to the [distant] clinic, but when I get there, they tell me lots of stories and I go back to the clinic over and over again. Now I don't have a problem with what people will say [at the local clinic] because I can see that a lot of people are living with HIV. – Month 6, F, 45y

Sustained Engagement at Initial Enrolment Clinic

Twenty-two participants were retained in care at the same clinic of initial enrolment throughout the length of the study; of these, thirteen described clinic-related costs. Among the thirteen, the weight assigned to various clinic costs varied, although it was notably lower in comparison to other participants who disengaged from care or changed clinics. Importantly, and in contrast to those who disengaged from care, the magnitude of anticipated or experienced costs declined over time. One participant explained:

I am no longer afraid of people. I queue where other people queue, but before I couldn't do that. I would wait for all the people to leave before I go into the clinic alone. But currently I am not afraid of anyone and I can even discuss my HIV status with other people... I am also able to guide those who are still afraid to go to the clinic for HIV treatment. – Month 3, F, 23y

Moreover, as participants gained more clinic experience, clinic costs appeared to be modulated by the overall care experience (Quote 3.5). Other constant costs of clinic care engagement, particularly long waiting times during clinic visits, were eventually assigned lower weight when participants resigned to them as an inherent characteristic of free public health care (Quotes 3.6–3.7). To accommodate these waiting time costs, these participants made personal adjustments by waking up early to join clinic queues a couple of hours before the clinic opening times, while a few disclosed

their HIV status to their employers to reduce the opportunity costs associated with the lengthy clinic visits (Quote 3.8). In an insightful remark, one participant highlighted the importance of patience in receiving public healthcare services as a means to ensuring sustained engagement in care:

We are now used to that [long waiting times]. You find that after the nurses have helped very few people they start going up and down in the clinic. If you are not patient, you will leave the clinic. -Month 6, M, 37y

At times, supportive interpersonal relationships with clinic staff led to reduced costs of care. For example, in situations of drug stock-outs or shortages, some clinic staff reduced costs of additional clinic visits by delivering medication to patient homes, using cell phones to keep patients informed, and providing positive reinforcement to encourage patients to continue returning to the clinic (Quote 3.9–3.10). When drugs were available, some clinics compensated for the return costs by providing patients with more than the standard medication supply.

Beyond the weight assigned to clinic costs in this group, participants who were retained in care placed a high value on clinical care, with all of them entering care within the first 3 months of diagnosis. At times the magnitude of value placed on clinic care increased beyond what was initially anticipated prior to clinic enrolment. Noteworthy, additional value was often derived from supportive interpersonal relationships with clinic staff and/or other patients (Quotes 3.11–3.12). These relationships appeared to reduce anxiety related to navigating clinical care and helped to mitigate internalised HIV stigma. The value placed on clinical care also increased as participants observed significant health improvements from HIV treatment (Quotes 3.13–3.14). In contrast to other participants for whom improved health led to present bias and disengagement from care, participants in the sustained engagement in care category expressed high future value as a means to averting deterioration in health.

Discussion

In this longitudinal qualitative cohort of 56 newly diagnosed adults living with HIV in South Africa, we described the balance of perceived values and costs leading to outcomes of failure to enrol in care, disengagement from care after initial engagement, or sustained engagement in care. Our findings show that burdensome health system requiring long queue times and repeat visits for services, along with low perceptions of the future value of HIV care, compromise the full potential individual and public health impact of HIV care and treatment programmes.

Participants facing the same situations made different assessments of the value or cost of accessing care. As a

result, some participants achieved sustained engagement in care. While other participants failed to attend a single clinic visit. To increase linkage to and engagement in care, the value-cost balance will need to be shifted toward value for an increased number of people with HIV. The minimization of the future value of HIV care by several study participants who felt they were in good health is important for the scale up of HIV care and treatment programmes. Identifying approaches to communicate the immediate value of care along with the long term benefits may help to overcome the effects of present bias on linkage to care among healthier patients [26]. To underscore the importance of this, a recent South African clinical trial did not demonstrate an effect on HIV incidence of offering immediate ART (test and treat) compared to standard ART initiation [27]. In our study, present bias also led to prolonged periods of disengagement after initial enrolment in care. These participants appeared to rationalize that care provided little value because they were free of obvious symptoms.

Promoting the value of HIV care to increase uptake of available services requires a shift from health promotion messaging that is primarily hinged on the efficacious biomedical properties of HIV treatment [28, 29]. Our findings show that HIV treatment has limited or no intrinsic value to some individuals; rather, in so much as it can restore health it may help in the pursuit of life goals. Previous work by our team [30] and others [31–34] suggests the potential benefit of collaborative inter-personal communication between healthcare providers and patients in promoting value of HIV care. Longitudinal counselling support for HIV patients coupled with deliberative dialogue has been shown to promote a shared understanding of the ‘meaning’ of the client’s HIV diagnosis and the contextual role of clinical care [30, 31]. Additional counselling skills may also be required to explore and resolve ambivalence in health seeking behaviour, particularly among patients whom we observed to mask low perceptions of value of HIV care by attributing non-action to external factors. Skills in motivational interviewing may allow counsellors to identify these discrepancies, and to apply approaches in defusing resistance where participants exhibit desire for the status quo [35]. Concepts such as being non-infectious and able to have safe procreation with an undetectable viral load [36] could be part of motivational interviewing to introduce more immediate value for asymptomatic individuals (Table 2).

The functional quality of clinic services, which refers to the processes by which HIV care is delivered [19], was the primary source of perceived costs for clinical care engagement among study participants. These findings are consistent with the growing literature on patient satisfaction and the continued use of services [37–41]. Consistent with our findings, long waiting times, multiple clinic visits, lack of privacy and/or confidentiality, and demeaning attitudes by

service providers have also been identified in other studies as barriers to care engagement [13, 42, 43]. In our study, these costs undermined initial and sustained engagement in HIV care even among individuals who initially expressed value in clinical care and desired management of HIV disease.

Importantly, many of the clinic costs could potentially be reduced. Shifting to patient-centered care, including eliminating queuing and organizing clinic systems around the patient rather than the provider, could substantially reduce costs. Clinic systems that minimise clinic visits and reduce waiting times have been shown to reduce disengagement from care in other settings [44–47]. This was the predominant cost of clinical care utilisation across the different stages of the care continuum in our study. According to Shippe’s model of patient complexity [18], interventions such as same day ART initiation [47], differentiated ART delivery for stable patients [44–46], and efficient appointment based systems [48] can be viewed as facilitating early and sustained engagement in care by reducing the ‘patient workload’ to a level within the ‘patient’s capacity’. In addition, single stream queueing for health services and increased professionalism among health care workers regarding patient confidentiality may reduce concerns regarding clinic-associated disclosure of HIV status [49] [13, 43]. Rural community-based programmes may need to be especially cognizant of the closely interlocked and overlapping social systems within these communities [50, 51]. In other findings, adolescents and young people were disproportionately impacted by demeaning staff attitudes and the lack of privacy in delivery of clinic services. Adolescent-friendly services need to be rapidly scaled up in order to adequately cater for this priority population.

The prospective design of this study, starting from the point of HIV diagnosis, provided a longitudinal understanding of how value-cost mechanisms influenced engagement in HIV care over time. In addition, because we sampled clients at the time of diagnosis, our study sample included a mix of participants who were subsequently either engaged or did not engaged in clinical care. This allowed for a balanced view of the different value-cost outcomes across the participants. Lastly, the study included both rural and urban participants, giving multiple perspectives on the role played by clinic factors on the continuum of care in both settings.

However, our study is not without limitations. First, we relied on participant self-report with regards to their HIV care engagement status. This may have caused participants to over-report entry-into-care as has been seen in some quantitative studies, with self-reported entry being 20–30% higher than verified entry [52, 53]. To minimize this, our interview guide had multiple questions at different points in the interview to ascertain clinic details and the type of care received. An additional limitation is that our findings are primarily representative of the value and

Table 2 Selected study participant quotes by main clinical care engagement pattern

1. Failure to enrol in care within the first 3 months of diagnosis	No clinic visits Costs of making initial clinic visits 1.1 “I don’t want to go to the clinic because at clinic they talk a lot and they like coming to our homes and I don’t want that. No, I don’t want to be visited. I will go to the clinic by myself... I cannot explain what they [community health workers] do because I just see them visiting the HIV positive people and I don’t know what exactly goes on.” - <i>Month 3, F, 29y</i> 1.2 “My uncle’s wife is a home-based care worker at the clinic and the sisters [nurses] know me. And she speaks a lot. There is a certain lady who tested HIV positive, and we have all since known that she is [HIV] positive.” - <i>Month 3, F, 27y</i> 1.3 “I clock-in in the morning and knock-off at 5 pm even on Fridays and Sundays. I only take a day off on the 15th of every month. When I am at home I have some other commitments that I need to take care of and as a result I fail to go to the clinic.” - <i>Month 3, F, 33y</i> Moderators to the value placed on clinical care 1.4 “One day when I do HIV tests I know I will test HIV negative. That is why I am saying I don’t want to go to the clinic for treatment... The thing is, our church doesn’t want people to mix medications. I can’t take pills [at the clinic] while I am also drinking tea [church medication]. When I am drinking tea, I am drinking tea, it ends there!” - <i>Month 3, F, 27y</i> 1.5 “I think that it is possible that they can tell me that I am HIV positive whereas I am not...I think that I don’t have HIV and I need to go to the clinic for HIV retest. At the clinic most of the people tested HIV positive but when they went to other HIV testing facilities they tested HIV negative.”-<i>Month 3, F, 29y</i>
Failure to enrol in care after clinic visits	Costs of enrolling into clinical care 1.6 “When I got there, they told me to come back the following morning, and I didn’t get time to go back again since I am working...I never went there again and I haven’t gone to any clinic since, but I told you at the beginning that I haven’t noticed anything wrong with my body and I am still healthy. I don’t see a need for me to go there.”- <i>Month 1, M, 47y</i> 1.7 “The thing is that from Monday to Friday, I am busy studying. I only get time during the weekends...I went to the clinic and they told me that it was late and they had to cut the queue. They then told us to come back the following day. I didn’t go back again...” - <i>Month 3, F, 25y</i> 1.8 “At the clinic there are always a lot of people and I am not satisfied with crowded areas. I always hate waiting for a long time on the queues whilst in need of help. Two hours to three hours is just too much for me. I think that 1 h at the clinic is fine because I can still go and do some other things.” - <i>Month 3, M, 28y</i> Diminution of value placed on clinical care following failed enrolment 1.9 “...I am using some traditional medicine which will boost my immune system and keep me strong...I just buy it and use it especially if I am getting weak because it helps boost my immune system so that I can be always strong...”- <i>Month 3, M, 47y</i> 1.10 “I am taking an immune booster since I was told it strengthens my immune system. I went to the Pharmacy to buy it and it is the only thing that I am taking since it gives me energy and also increases the CD4 Count”- <i>Month 3, M, 36y</i>
Care enrolment after 3 months of diagnosis	Competing priorities in the first three months of diagnosis 1.11 “My employment contract ended yesterday. I want to go to another farm because I have another contract there. After I secure my contract, I will go to the clinic for my treatment.” - <i>Month 3, F, 39y</i> 1.12 “I don’t meet my needs and at home there is no one who is working.... I will go to the clinic at some point, but I am currently still looking for a job. I want to have money first so that I will be able to go to the clinic.” - <i>Month 3, F, 25y</i>

Table 2 (continued)**2. Disengagement from care after initial enrolment**

Complete disengagement from care	Costs leading to disengagement after initial enrolment in clinical care 2.1 “...I tried to go to the clinic because I wanted to know my CD4 count. I then asked them to test me, but they kept on telling me to come back the following day up until I gave up going there... That is why I am saying, me and the clinic, is a NO!” - <i>Month 3, M, 28y</i> 2.2 “I used to go there [clinic] every week on Tuesday [to check laboratory results] and when I arrived there, they used to tell me that the person who is taking bloods was not available and I had to come back the following week... I have also given up going there and I told myself that I will see what will happen to me as the time goes on...” - <i>Month 6, M, 43y</i> 2.3 “I do not like their treatment and they take time and I am busy at school. They will then tell me to come on a certain date and I will go there and don’t get help and I become demotivated.” - <i>Month 6, F, 22y</i> Decline in perceived value of clinical care after disengagement 2.4 “...I am still healthy and I am not getting help that I deserve... I will try by all means to live positive, but when the time comes for me to die, let it be.” - <i>Month 3, M, 28y</i> 2.5 “I am not receiving any other care and I just told myself that I won’t use anything because I saw that it was just a waste. I haven’t noticed any difference in my body since I didn’t get any help from the clinic and I went to check for my weight and it was 85 kg” - <i>Month 6, M, 43y</i>
Cyclic engagement in and out of care	Costs leading to initial disengagement from clinical care 2.6 “I don’t want to go back anymore. Yes, because people at the clinic know the queue for people who are taking HIV treatment and all that. So I don’t want to go there anymore.” - <i>Month 1, F, 21y</i> 2.7 “I didn’t go back to the clinic and I should go there to do other blood tests, but I fear that I will find home based care workers, because they are working at the clinic as well. I fear because I don’t want them to know my HIV status. I have stopped going to the clinic since then.” - <i>Month 3, M, 40y</i> 2.8 “...There was a certain nurse at the clinic and she liked shouting when she spoke. After that, I left the clinic without going in for HIV care.” - <i>Month 1, F, 20y</i> Increase in value of clinical care leading to re-engagement 2.9 “I am currently thinking of going to the clinic because I am even losing weight. If I don’t go to the clinic I don’t think that there is anything that will help me.” - <i>Month 6, F, 20y</i> 2.10 “I took five months without going to the clinic. Then I developed flu and had it for quite a long time... I was coughing and I thought that perhaps it was TB.” - <i>Month 1, F, 21y</i>

3. Early and sustained engagement in care

Changed clinics	Costs leading to change of clinics 3.1 “I went to the local clinic over the weekend and they were closed. I then decided to go to a private doctor and I paid a lot of money ... My problem is that I am always at work and I can’t go to the clinic over the weekend. I am also scared of how am I going to tell employer because there was another guy who was working and his employer suspected that he was HIV positive and he was fired from work.” - <i>Month 1, M, 34y, changed to private care</i> 3.2 “When I went back for my results, they told me that those people who were responsible for taking bloods were on strike and they used to come around 11 and they knock of early and they had a lot of stories...I have to repeat the tests at another clinic.” - <i>Month 3, M, 47y, changed to another public clinic</i> 3.3 “Sometimes you end up waiting for nurses while they are busy chatting and you won’t even understand if they all went for lunch and you won’t know how possible that is that and you end up waiting for them. That day I was on my way to work and I had to wait because I wanted to know my CD4 Count results and I wanted to start there before I went to work and I ended up being stressed and got scared as if it was my first time to get tested” - <i>Month 1, M, 24y, changed to another public clinic</i> 3.4 “They told me to wait for the people who take bloods and they didn’t come. I then went there for several times and I then decided to change that clinic since time waits for no man. I then went to a private doctor and I explained everything to him and I also told him about my clinic visit.” - <i>Month 1, M, 36y, changed to private care</i>
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Table 2 (continued)

Remained at initial enrolment clinic	Adjusting to clinic costs for sustained engagement in care 3.5 “I was demotivated [after demeaning encounter with nurse] of going to the clinic but I quickly got over it because it only happened once and now things go well.”- <i>Month 6, F, 41y</i> 3.6 “It’s only the long queues. When I go there, I need to prepare myself that I will stay for the whole day there.” - <i>Month 1, M, 55y</i> 3.7 “I don’t care about what they say [demeaning attitudes by clinic staff] because when I am in the clinic, it is my time and I am going to use it for the betterment of my health.”- <i>Month 3, M, 37y</i> 3.8 “One Monday morning I asked to have a conversation with him [employer]. He took me to his office and I told him that I am living on [HIV] treatment. I told him that I love my job because even if I stay home that won’t help. I told him that I am taking my HIV treatment in town. I asked him to give me time to go home every time when my appointment date for treatment collection arrives. He kept quiet and looked at me. Then he said that there is no problem.” - <i>Month 3, F, 45y</i> 3.9 “...I didn’t receive the complete course of treatment when I went to the clinic but I just forgot their names. But the nurse brought them to me later because she doesn’t stay far away from where I am staying. It is not the first time we ran short of the pills at the clinic because they were out of the stock but when the stock comes in she delivers the pills to me because she knows that I didn’t get chance to go back.” - <i>Month 6, M, 37y</i> 3.10 “I haven’t experienced many challenges besides that I sometimes do not get all the treatment. However, the Clinic Manager then came to address us, and told us about people at the clinic who were stealing our treatment and selling it. He said that they were going to change some of the Doctors and one of them is gone already” – <i>Month 6, M, 54</i> Promotion of value placed on clinical care 3.11 “A lot of people [at the clinic] made me accept my HIV status...I sometimes just go to them, even though I don’t know them. I tell them that I know that people who are this side are here for HIV treatment, and I ask them if they are also HIV positive. They respond by saying that they are indeed HIV positive and, they encourage me to take treatment.”- <i>Month 3, F, 45y</i> 3.12 “There is a nurse that I go to when I have issues. She only allows me to speak with her when there are not busy at the clinic. If she is busy she will tell me to come during lunch time. When I meet her, we talk and she will tell me a lot of things.”- <i>Month 6, M, 29y</i> 3.13 The treatment they gave me at the clinic is helping me a lot since I am now able to walk faster than before when I used to walk slowly... I also think that my sugar diabetes is now getting better since I started ARVs because when I went to the clinic, it used to be 20, 17 or even 11 and now is around 5, 7 or even 6 and they told me that it was normal.” <i>Month 3, F, 49y</i> 3.14 “I have realized that a lot has changed since I started going to the clinic. I am able to do chores at home the whole day and I am also able to eat well now unlike before. Before I was initiated on treatment I was unable to eat... I have also gained weight because I was weighing 71 kg when I started going to the clinic and I am currently weighing 80 kg. I am happy because I am regaining my normal body weight.” <i>Month 6, F, 41</i>
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costs identified or expressed by participants which may not be inclusive of what operates subconsciously, what they cannot put into words, what doesn’t seem reasonable to explain to someone, or what is too sensitive to say.

Conclusion

The value-cost model provided a useful explanatory model for our analysis. In addition, through the use of this model, we have identified starting points to design strategies to improve initial care engagement, counteract disengagement after care enrolment, and promote sustained care engagement. Our overall findings suggest that re-engineering care delivery can start with interventions

to promote the value HIV patients place on clinical care while identifying pragmatic approaches to reducing costs. Several of our participants eventually engaged or re-engaged in clinical care when the value of clinical care increased while clinic costs remained unchanged. HIV care that reassures of the continued possibility to achieve life goals, non-infectivity with an undetectable viral load, and that provides personal interaction, should be emphasized at clinics. Without addressing costs and assuring perceptions of the value of clinical care, the number of people engaging in HIV care is likely to fall short of goals.

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Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical Approval All procedures performed in this study were in accordance with the ethical standards of the institutional review board and with the 1964 Helsinki Declaration and its later amendments.

Informed Consent Informed consent was obtained from all participants included in the study.

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Is HIV post-test counselling aligned with universal test and treat goals? A qualitative analysis of counselling session content and delivery in South Africa.

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ABSTRACT

Early identification of people living with HIV (PLHIV) and subsequent engagement into HIV treatment is the key to reducing HIV-related illness, HIV-related deaths, and HIV transmission through universal test and treat approaches. With the scale-up of antiretroviral therapy (ART) programmes, counselling provided after the diagnosis of HIV (post-test counselling) is aimed at leading to linkage to care and ART initiation. We sought to assess whether the delivery of post-test counselling sessions in a routine HIV programme was consistent with person-centred approaches of counselling and whether the health messages were aligned with the goals of universal test and treat as articulated in local and international HIV testing service guidelines. We analysed transcripts of 40 post-test counselling sessions performed by 34 counsellors for clients who tested positive in ten public sector health facilities in the Ekurhuleni District of South Africa. We used thematic analysis to identify key aspects of counselling technique and content provided to the patient. We identified five key themes of counselling messages: (1) behaviour changes that are required to maintain or improve health when living with HIV, (2) the benefits of ART, (3) misinformation supplanting the health benefits of ART, (4) behaviour changes required for ART to be effective, and (5) a need for caution with ART due to a wide range of severe side effects. The counselling sessions were didactic, which limited the opportunities for patients to express concerns or counsellors to address patient's needs during the counselling session. Based on our observations, a substantial re-adjustment is needed to deliver best practice counselling. This may include a combination of digital media-based counselling, counselling scripts, and truly person-centred counselling for a sub-set of individuals who are at risk of not linking to care, or not initiated ART within a specified time period.

BACKGROUND

Early engagement in HIV care and treatment services following HIV diagnosis, is key to reducing HIV-related illness, HIV-associated deaths, reducing HIV transmission, and improving the quality of life for people living with HIV (PLHIV). [1-4]. Over the years, the World Health Organisation (WHO) has regularly revised its recommendations on when PLHIV should start antiretroviral therapy (ART), with a move towards promoting earlier, and now immediate initiation of ART. In 2015, WHO and other global and national bodies, including the government of South Africa, endorsed policies to provide ART to all people living with HIV, to reduce the time between HIV diagnosis and ART initiation. Despite the considerable progress in ART scale-up, the proportion of people diagnosed with HIV who promptly engage in HIV care remains suboptimal [5,6]. Globally, 79% of PLHIV know their status, but only 62% of those diagnosed are receiving ART. Similarly, in South Africa, a country with the largest HIV epidemic, 85% of PLHIV in 2017 were aware of their status, but only 71% of these were receiving ART.

The role of HIV testing services (HTS) in the HIV epidemic response has evolved from the time of limited availability of ART to the current era of treatment scale-up. Early in the epidemic response, HTS had an HIV prevention focus and was often delivered through voluntary counselling and testing (VCT) sites set apart from health facilities. [7,8]. The role of VCT on HIV prevention was based on the premise that behaviour change communication provided as part of post-test counselling could lead to changes in sexual behaviours among those testing HIV-negative. Also, people with newly diagnosed HIV were expected to change their sexual behaviour and place their partners at lower risk of HIV infection [9-11]. As a result, behaviour change communication and risk reduction counselling formed the core of HIV pre- and post-test counselling. Additionally, in the absence of ART programmes, health messaging for those testing -positive encouraged 'healthy eating' and 'active lifestyles', as alternative approaches for maintaining health. With the scale-up of ART and the advent of interventions for the prevention of mother-to-child transmission (PMTCT), the offer of HTS to all pregnant women receiving antenatal care (ANC), saw the emergence of health facility-based HTS and the shift in counselling content towards ART preparedness, linkage to ART, and ART adherence [12-15]. This was later followed by expansion of health facility-based and provide initiated HTS coverage in settings with generalized HIV epidemics. In the same era, counselling approaches also evolved based on WHO Guidance in 2007, which recommended reduced pre- and post-test counselling to essential core elements (including ART access, person-centred interviewing, and providing information necessary for informed consent) to allow for effective and narrowly targeted counselling.

Critically, post-test counselling sessions offer the first opportunity, for patient-provider dialogue based on the HIV test result. For clients testing HIV positive, the counsellor can guide the client in assessing the balance between the value of initiating ART and their perceptions of the material, social and psychological costs of engaging in HIV medical care. This balance may be the critical factor for initial engagement (commonly referred to as 'linkage') in HIV care and retention on ART[16,17]. Within this balance, when value exceeds costs, engagement in care is likely; whereas, when costs exceed the value, entry into care may not occur, or disengagement from care is more likely [18]. Person-centred counselling techniques, such as motivational interviewing and strengths-based counselling, can assist a client in identifying how to align the benefits of ART to their life goals [19-21]. These techniques may be most effective when the counsellor demonstrates an understanding of the value-cost balance, engages the client in deliberative dialogue, and supports informed healthcare decision making.

We sought to describe current post-test counselling communication techniques and content related to linkage-to-care and ART initiation among clinic attendees diagnosed with HIV during routine HTS in public sector health facilities in South Africa. Specifically, in this analysis, we sought to assess whether the delivery of post-test counselling sessions was consistent with patient-centred approaches of counselling and if the health messages aligned with the goals of promoting the value of ART to increase ART coverage among all people living with HIV.

METHODS

Study setting

This study was conducted in ten public sector health facilities in the Ekurhuleni District of South Africa (SA) from March 2017 to August 2018. The study sites consisted of six primary health care centres (PHC), three community health care centres (CHC) and one district-level hospital. Facilities were selected in coordination with the district-level Department of Health to achieve geographic diversity. All facilities had dedicated HIV counselling and testing personnel (lay counsellors) and routinely provided HTS free of charge according to the 2015 National HIV counselling and testing (HCT) guidelines [22]. Under these guidelines, healthcare providers were encouraged to offer HTS to a person attending healthcare facilities as a standard component of medical care. All persons diagnosed with HIV in South Africa were eligible to start antiretroviral therapy (ART), regardless of the CD4 count [23].

For this study, we audio-recorded 160 post-test counselling sessions; 48 (30%) among male clients and 112 (70%) among female clients. Of these, 40 sessions (25%) were with participants who had an HIV positive test result (equally distributed across participating study sites). Enrollment was restricted to patients who underwent HIV testing at the selected study sites, ≥ 18 years of age, and provided informed consent for participation. Informed consent for participating in this activity was obtained from both the counsellor and the patient. The counsellors were consented once for participation in this assessment (with an option of voluntary withdrawal, and re-consenting if willing to re-join the assessment). Informed consent was administered to patients before the pre-test counselling. To maximize confidentiality and encourage participation, we only collected information on the patient's sex. Audio-recordings were translated from local languages into English and transcribed in preparation for analysis.

After all data were collected, two researchers (TM and CJH) read and summarized all transcripts to familiarize themselves with the counselling techniques applied and content delivered during post-test counselling. A preliminary coding structure was generated *a priori* from two frameworks, and inductively from the available data. Firstly, we used the HIV Counselling and Testing Guidelines for South Africa, as the first coding framework for counselling technique and content provided to the patient. Briefly, guidelines for post-test counselling generally recommend using a patient-centred approach [22]. The core components of this approach are (1) open questions, (2) affirmations, (3) reflections, and (4) summaries. All topics covered in the sessions were also coded to describe the information provided, including misinformation. Using the same HTS guidelines, we also explored the inclusion of core post-test counselling components; the medical meaning of an HIV positive result; HIV as a chronic long-term condition; the medical benefit of ART to maintain or restore health and allow living a normal life; the recommendation of ART for all HIV-positive people; the prevention benefits of ART in reducing sexual and mother-to-child (MTC) transmission of HIV; the importance of starting ART as soon as possible; and how disclosure to supportive family or friends can help with coping and treatment success. In additional analyses, we applied the 'value versus cost' theoretical framework as the second coding structure [18]. Using this framework, we explored how the counselling content and techniques may have influenced the patient's perception of values and costs of engaging in HIV medical care. Both *a priori* coding structures were tested on a selection of transcripts and revised to ensure that they captured relevant patterns from the narratives with minimal overlap [24].

Coding was performed by TM and CJH using NVivo 10™ (QSR International Pty Ltd., Melbourne, Australia, Version 10, 2012). Themes were further developed from the coded text, considering code frequency, connections between codes, and consistency with the text [24]. We purposefully framed

and organized the themes to provide a pragmatic lens to identify opportunities for developing strategies to improve the content and delivery of post-test counselling sessions.

RESULTS

Study participants

A total of 45 counsellors across the ten facilities (range 4 – 6 counsellors per facility) participated in the study; most were female (41/45, 91%), all were employed by the Department of Health, and had worked as HIV counsellors for a median of 12 months (Interquartile range (IQR) 6 months, 2 years). None of the counsellors had prior clinical training. However, all counsellors had gone through a standardised 3-day curriculum required for practising as a lay counsellor; some had received refresher training. Of the 45 counsellors, 34 (76%) conducted at least one post-test counselling session in which a patient was issued with an HIV positive result. We only collected information on the participant's sex; of the 40 patients with sessions that were analysed, 13 (33%) were male, and 27 (67%) were female.

Themes

We identified five general themes related to counselling messages:

- Behaviour changes are required to maintain or improve health when living with HIV
- ART has potential benefits for health and prevention of mother to child transmission (PMTCT)
- Critical steps to maintaining health do not involve ART (misinformation)
- Behaviour changes are required for ART to be effective
- ART has a wide range of severe side effects for which vigilance is required

This information was provided as predominantly didactic information with delivery characterised by lists of instructions. We did not observe any interactions fitting within strengths-based counselling or motivational interviewing techniques nor any generally patient-centred dialogue. This didactic approach limited the opportunities for patients to participate in the counselling sessions. There were no notable differences in counselling content or technique by counsellor's sex, patient's sex, nor by the clinic; therefore, results are combined for all counsellors.

Theme 1: Behaviour change “necessary” to maintain or improve health for people with HIV

Counsellors provided lists of behaviours required to maintain or improve health when living with HIV. These behaviours generally focused on avoiding some foods and eating other foods, drinking eight glasses of water daily, exercising regularly, and getting plenty of sleep. The need for behaviour

change was generally explicit and imperative: “The important thing is changing your lifestyle”. Actual current behaviour was not explored by any of the counsellors. Messages related to nutrition were uniformly directed at the need to increase vegetable consumption and to reduce or eliminate fatty foods and sometimes spicy foods (Quotes 1.1 – 1.5). The stated benefits of the recommended foods and changes in diet were diverse: improving digestion, cleansing the gut, helping to fight infection, giving energy, and avoiding weight loss. One counsellor explained these food requirements to their patient as follows:

“The important thing is changing your lifestyle. On food, you need to take lots of fruits and fresh vegetables; they will help to fight other infections in your body. You must also take brown rice, brown bread, pap and samp; they will help to give you energy. And then you must eat beans, lettuce, chicken, fish and eggs, they will help to build your body, and they also will keep you strong. And then you must take butter, peanut butter, nuts, cooking oil and fresh milk, they will help you to stop losing weight, and they will also give you energy. You must also take yoghurt and milk they will help you with digestion. Again, you must take eight glasses of water.” - Counsellor

These changes to diet may have immediate potential financial implications. Some of the counsellors sought to address financial concerns by briefly explaining the food options that the patient could choose from:

Client: “As you speak about eating the right food. If I don’t have the right food, what must I do?”

Counsellor: “By the right foods, I don’t mean expensive food. Cabbage from street vendors is five rands you can eat that cabbage; beetroot is also five rands, carrots are also five rands. Try to have one vegetable in your plate every day and drink water, two litres a day which is about eight glasses of water.”

Beyond the economic cost of switching to generally higher cost foods, was the potential for opportunity costs of being directed to give up pleasurable foods or activities, and the possible need for disclosure to make those changes. One patient explained his challenges to the counsellor:

Client: “It will take some time for me to adjust from the food that I am eating to the food that I am only supposed to eat. It will take me some time.”

Counsellor: “Why is it that it will take you some time?”

Client: “I don’t know where to start with the woman that I live with. I don’t know how I will start the topic. I am stressed about where I will start, although I must tell her?”

Theme 2: The benefits of ART

Generally, the discussions on the benefits of ART were not framed in terms of the client’s concerns because the counsellors did not engage clients in a discussion of their concerns. In most counselling sessions, the conversations on the value of ART were limited to general statements of benefit, mostly emphasising that living with HIV was no longer a ‘death sentence’ because of the availability of ART. In one typical example, the counsellor explained:

“There is no grave for an HIV positive person. It is only the person who wants to die who would be killed by HIV. Yes, before the introduction of treatment, people died of HIV but now that there is treatment. Life goes on.” - Counsellor

In most sessions, counsellors sought to describe the general biomedical benefits of ART, in terms of preventing damage to the immune system and controlling the multiplication of the virus (Quotes 2.1 – 2.9). However, the benefits of ART in reducing the risk of transmission to sexual partners (i.e. treatment as prevention) were not mentioned in any of the counselling sessions, even though test and treat policies were being fully implemented at the time. The only contextualised information regarding the benefits for ART was provided to pregnant women presenting for HIV testing (Quotes 2.10 – 2.12). In this setting, a standard description of the role of ART for PMTCT of HIV was provided. In one of the post-test counselling sessions with a pregnant patient, the counsellor explained:

“Look, the baby will not get infected; it’s good that you knew about your status early because you’ll drink your ARVs (antiretrovirals) early. ARVs suppress the virus and then by the time you get the baby, your viral load will be low, and then after you deliver, they will check the baby, and they will give the baby nevirapine drops. You will also be drinking nevirapine while you’re pregnant and the baby will have treatment that he or she will take.” - Counsellor

The PMTCT information was provided as a routine listing or description rather than in response to patient concerns. Because of failing to identify client goals concerning ART, counsellors often gave information on PMTCT to women regardless of pregnancy status or intent. An example of describing PMTCT to one patient started as follows:

Counsellor: Alright, thank you, my dear. When you want a child, you will get one.

Client: I don’t want a child. I’ve got two kids already.

Theme 3: Misinformation supplanting the health benefits of ART

Nearly all sessions included misinformation on non-medical ways to maintain health and a normal CD4 count. This misinformation often occurred ahead of or in place of information on ART. The most commonly described method for maintaining health was to use condoms consistently. Condom use was presented in nearly all counselling sessions as essential to prevent HIV related complications, CD4 decline, and HIV re-infection – supplanting the health benefits of ART. Counsellors often told clients that failure to use condoms would lead to a weak immune system (CD4 count decline) and could lead to non-suppression of the HIV viral load – essentially making ART ineffective (Quotes 3.1 – 3.6). For example, one counsellor explained:

“Sometimes, when you are taking pills, and you do not use a condom - it will be like doing nothing. The most important thing is that you must always use a condom and on the other hand you take the pills.” - Counsellor

The quote below is an example of instances where condoms were promoted ahead of the importance of ART (Quotes 3.7 – 3.9).

“Yes, life goes on. It doesn’t mean that just because you tested positive today, it is the end of the world. What you must do is take care of yourself, use condoms, and then move on with life.” – Counsellor

Theme 4: Essential behaviour changes required for ART to be effective

Some counsellors either directly stated or strongly implied that specific behaviours were not compatible with ART. Specific changes needed in behaviour included the cessation of smoking or drinking alcohol before initiating ART (Quotes 4.1 – 4.4). Similar to other guidance provided during the counselling sessions, the need for these lifestyle changes lacked context. Notably, counsellors failed to engage patients on whether they drank alcohol or smoked tobacco, nor did they explore how the ‘stopping’ would be achieved. The need for these changes was generally incorrectly justified as incompatibility or making ART ineffective, rather than potential adherence considerations with alcohol or general health problems from smoking. The following quote is illustrative:

“The medication that you are going to take counteracts with other things. Alcohol is strong and neutralises the medication. So, stop drinking (alcohol), stop smoking drugs, any drug, you don’t use any drug.” - Counsellor

ART patients were also told they should make changes to their daily routines in order to assure taking ART at the same time each day. While overall, a reasonable suggestion to help with ART adherence, the changes to routine and need for taking ART at the same time each day, were at times, presented as necessary for ART to work. Some counsellors stressed the need for strict adherence to the timing of taking doses of ART (Quotes 4.5 – 4.7).

Some counsellors were less prescriptive; and others were appreciative of unforeseen events or changes in routine and told their clients that if the scheduled time was missed, they could still go ahead and take their medication (Quote 4.8 – 4.10).

“You choose the time you take your medication; maybe you will drink it at 8, make sure that if you have a clock, you set your alarm when it is 8 o’clock you will know that it is time for you to take your treatment. Someone might choose half-past seven. Someone might want to drink it in the afternoon when you know that you have done all your duties and you are relaxed because others get dizzy, you see. And the pill does not have Monday it does not have a weekend, it is not like Panado or Grandpa which you only take when you feel a headache. This pill is for a lifetime; this means if you agree that you will take treatment today, you are committing to this for the rest of your life.” – Counsellor

Theme 5: The inevitable and severe side effects of taking ART

ART side effects were generally stated either as a substantial danger or as something requiring understanding and vigilance from the patient. Both actual side effects and the need for vigilance, added cost to taking ART (Quotes 5.1 – 5.2). One counsellor explained:

“Sometimes, it (ART) will make you dizzy. Sometimes you will have a rash. Sometimes you will have nightmares. Sometimes it will make you vomit. You will have bad dreams you will end up thinking that you are bewitched only to find that it is the medication that is doing that. You might have diarrhoea but just because you are experiencing these things it doesn’t mean that you should stop taking your treatment and say that it is making you sick. No, you must continue, that thing (side effects) might happen for 2 or 3 months.” - Counsellor

In contrast, some of the counsellors presented information on side effects as minor and only as a possibility (Quotes 4.3 – 4.4).

“Our pills have side effects, some of the side effects are rash, but they don’t do anything to other people; nothing at all. Someone else prefers to isolate themselves, someone else has nightmares when they are sleeping, others hallucinate, but these do not happen to everyone. You know that when you are drinking some pills, you feel like sleeping...these ones are the same as well. Isn’t we are not the same as people and the side effects are only for a certain period? You will not have them forever; you only have them when they are still getting used to your system.” - Counsellor

DISCUSSION

Our findings create a concerning picture of the delivery of post-test counselling in the era of treatment for all. In analysing 40 post-test counselling sessions for clients who tested HIV-positive performed by 34 counsellors, we observed a highly didactic approach with counsellors seeking to instruct clients on how to manage or improve their health and comply with the requirements of ART. The didactic information stressed the costs of ART to the client over the potential benefits. Costs included needed lifestyle changes, behaviour changes, and the range of severe possible side effects of ART. Little health communication was focused on the benefits of ART for individual health or to prevent transmission. Instead, the use of ART was often presented as secondary to the use of condoms or “lifestyle” changes as an intervention to maintaining health. These are particularly discouraging findings given that most counsellors had started their work as counsellors and received counselling training during the test and treat era.

The failure to engage with client’s concerns or goals, overshadowed by the dominance of hierarchical instructions from the counsellors, meant that patient-centred counselling did not occur. Patient-centred counselling places emphasis on the clients own understanding of their situation instead of the counsellor’s interpretation of it [25]. This is important because, beyond the biomedical implications of living with HIV (i.e. a weak immune system, low CD4 counts, and high viral loads), when people experience unwanted or aversive life events, such as an HIV diagnosis, they assess the potential threat of the event to what they value and the goals they desire to achieve [26]. Commonly referred to as the “significance” or the “situational meaning” of the HIV diagnosis, the ascribed personal meaning influences the weight individuals assign to the diagnosis and how they decide to respond, if at all [26,27]. Persons who assign less weight to the significance of the diagnosis may not perceive any need to adapt by altering their behaviour, perceptions, or emotional responses. On the other hand, persons who consider the diagnosis to be hugely significant may start exploring and evaluating what they can do in response to the HIV diagnosis [26]. Therefore, without creating an enabling environment for effective interpersonal communication, counsellors in our study missed opportunities to understand their clients’ immediate concerns and most salient needs, in response to the HIV diagnosis. In turn, as observed in several transcripts, counsellors failed to provide relevant health education and health promotion messaging. This failure to elicit and understand the client’s perspective may have reduced the chances of bringing the clients to move more rapidly from testing HIV-positive to engaging in care [28]. Another study in South Africa which reviewed counselling transcripts for 132 HIV-negative and 18 HIV positive clients in routine HTS programmes before the current UTT era, also identified deficiencies in the use of interactive counselling skills such as summarizing, reflecting, or questioning [29].

Health messages that were provided often contained misinformation about the role of condoms, generally conflating condoms to have a similar position as ART in terms of maintaining health. Further, counsellors emphasised the need for disclosure and lifestyle changes as imperatives to adjusting to living with HIV or as a requirement for taking ART. Broadly, these messages appear to perpetuate the thinking held in early HIV programmes when HTS had an HIV prevention focus and emphasis in post-test counselling sessions was placed on voluntary HIV status disclosure and the use of condoms for reducing the risk of HIV transmission [9,10]. Similarly, in the absence of ART programmes, health messaging for PLHIV encouraged healthy eating, active lifestyles and discontinuation of alcohol and tobacco use, as alternative approaches for maintaining health [9,10]. Barring misinformation, while these are ideal strategies, they may have unintended consequences which raise the costs of timely linkage-to-care. Firstly, the costs of disclosure and negotiation of condom use may be impractical for some clients. In turn, clients may delay engaging or returning for medical if they are unable to fulfil communicated requirements, and fear reproach from healthcare providers [30,31]. On the other hand, when the effectiveness of ART is described to be contingent upon condom use, PLHIV who are unable to negotiate condom use may choose not to start ART, increasing their risk of onward HIV transmission, and early mortality [2,32,33]. The need for lifestyle changes when taking ART has also been shown to increase the costs of engaging in medical care, yet there is limited evidence to support the scientific basis of such messages [34]. Given the life-long commitment to ART, some PLHIV may not be psychologically ready to make the required lifestyle adjustments, even though they might be highly motivated to start ART [35-37]. Besides, some counsellors appeared to place moral judgements on their clients' lifestyle choices, and such demeaning attitudes have been shown to result in poor care engagement outcomes [38,39].

Health messages regarding ART often included a list of severe potential ART side effects for which the patient needed to be alert. This was coupled with an imperative that medications need to be taken at precisely the same time each day. In this regard, counsellors require training to understand that the way information is described and presented, significantly influences the decisions a person makes – a phenomenon known as the 'framing effect' [40]. Through structured health communication, information can be presented in a manner that highlights either the negative or positive features of a decision, modifying how a person responds. For example, as South Africa moves to the roll-out of dolutegravir, there are concerns about its use in pregnancy and its effect on higher weight gain compared to other drugs [23]. Counsellors can be guided to discuss these side effects together with the improved tolerability, an increased barrier to resistance, and the broader value of ART for the patient. By framing the health messages in such a manner, the perceived costs of taking dolutegravir by PLHIV can be moderated than if only the potential adverse effects are described.

In addition to often being false, many of these messages served to continue exceptionalism of living with HIV and taking ART. This contrasts with contemporary views of presenting the possibility of a normal life through adherence to ART. As Bury (1979) suggests, the diagnosis of chronic illnesses such as HIV can be viewed as a disruptive event which requires a person to adjust and rethink their biography [27]. This broadly involves trying to repair the disconnect between one's body (i.e. living with HIV), one's self-identity, and the society in which they live. Evidence from qualitative studies points to the reformation of identity or reconstruction of biography as a major challenge for most PLHIV diagnosed with HIV [34]. Therefore, health messages which exceptionalize HIV and ART, are likely to fuel the negative symbolic and socially constructed meanings of living with HIV which have a weighty effect on how PLHIV may view themselves and how they think others perceive them [27]. Inadvertently, such messages may drive internalised stigma, which relates to feelings of disgrace, distress and guilt [41-43]. Such affective states have been shown to result in inflated perceptions of the costs of engaging in care and low self-efficacy to navigate medical care[38,44].

While the impact of these messages on ART initiation and adherence cannot be assessed in this study, the counselling we observed did not promote the value of ART or encourage rapid ART initiation. At the worst, some of these counselling sessions may have led some clients to decline ART. We acknowledge that beyond the individual-level competency of counsellors, contextual factors such as the rationalisation of limited counselling rooms, the large number of clinic attendees requiring HTS services, or the pressure of same-day ART, can bias counsellors towards didactic and scripted approaches to accelerate the counselling process [45,46]. However, even in such scenarios, misinformation and failing to establish the personal meaning of the diagnosis are fundamental flaws that warrant urgent attention. Creating a continuum of counselling support that extends to clinicians when they initiate ART, and to case managers who can provide ongoing support, is important to ensure timely linkage-to-care and sustained engagement in care.

We also believe that this training will need to guide counsellors on correct information, counteract prevalent misinformation internalized by counsellors in our study, and develop confidence and skills in providing patient-centred counselling (e.g. motivational interviewing). Once trained, ongoing oversight and mentoring are essential for quality assurance. While these approaches may be appropriate, the cost of achieving specific quality measures in counselling needs to be balanced against the benefit [47,48]. Developing skills required to provide person-centred counselling approaches, such as motivational interviewing or strengths-based counselling, takes considerable time and training. Ongoing oversight, monitoring, and quality improvement of counselling delivery require dedicated time from effective managers. Overall professionalization of HIV counsellors in South Africa and elsewhere may require considerable additional resources for training, monitoring,

and salary[49]. In the sessions we analysed, emotional support was not being provided, nor was there messaging promoting early ART initiation. If these two components were delivered, it is plausible, but uncertain, whether there would be an increase in ART initiation or retention in care. Such questions should be answered before redirecting substantial resources to improving post-test counselling.

We are unaware of any similar work describing post-test counselling sessions among recently diagnosed PLHIV using audio-recordings or direct observation of counselling sessions in public sector health facilities in the current UTT era. Several studies have used interviews conducted at a time point after HIV testing to assess quality. A study using in-depth interviews of people who had recently tested HIV positive sought to assess patient satisfaction and reported that satisfaction was related to how test results were delivered [50]. A study from South Africa used a quantitative survey among 498 clients from 56 HTS sites who had undergone HTS (the proportion testing HIV-positive was not noted). In that study, 98% reported being satisfied with services. The health communication provided and counselling approach used were not assessed [51]. A study evaluating barriers to providing quality counselling in South Africa interviewed 32 counsellors and concluded that a lack of standardized training, low morale, and poor remuneration were barriers to service delivery [52]. Another study of in-depth interviews of 16 clients reported overall positive experiences with HIV counselling; long queue times before being tested were the major complaint [53]. Finally, an evaluation of counselling provided by a highly trained group of HIV counsellors employed as part of a randomized trial reported excellent delivery of content and patient satisfaction. The 11 counsellors evaluated in that study had undergone intensive didactic training, a four-month in-service training, and had ongoing oversight with direct observation. That study suggests that with dedicated and intense resources, a level of quality can be achieved. However, it remains unclear what health communication should look like when that quality is achieved. A recent review of counselling guidelines identified that current post-test counselling content recommendations lack an evidence-base and are based on expert opinion [54].

Strengths of our study include audio-recording of actual counselling sessions with the recording starting prior to obtaining test results, the inclusion of a substantial number of counsellors (34) and performing the study during routine care at public clinics. We believe that our approach has led to findings that are likely representative of the post-test counselling occurring in many public clinics in South Africa and possibly elsewhere in sub-Saharan Africa. We do note potential limitations. One is that the counsellors or clients may have changed behaviour in the presence of the digital audio-recorder. It is possible that counsellors switched from a patient-centred approach to more of a didactic approach due to the presence of the audio-recorder in order to impress the research team

with their comprehensiveness. We doubt that this occurred partly because the counsellors received guidance on optimal counselling approach and content from the study team during the study period, and the evidence of such training was not reflected in any of the recorded counselling sessions. Besides, audio-recording started much earlier during an HTS session, before pre-test counselling, and the recording device was placed to the side (on a cupboard) allowing for the counsellor and client to easily ignore the presence of the recording device by the time post-test counselling occurred.

In conclusion, our findings should lead implementers to assess their post-test counselling delivery. They should also lead policymakers and researchers to interrogate the current role and effectiveness of post-test counselling. In its current form, post-test counselling undermines the anticipated benefits of ART in reducing HIV transmission and may negatively affect the demand for ART by those who need it. Based on our observations, a substantial re-adjustment is required in order to deliver best practice counselling. This may include digital media-based counselling provided through an interactive media display or counselling scripts to increase the validity of health information and assure that counsellors communicate priority messages. A highly trained cadre of professional counsellors could be available to a subset of individuals who do not link to care or initiate ART within a specified period.

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TABLES

Table 1: Baseline characteristics of participants included in the analysis of case management sessions

Baseline characteristic		N=28
Site	Urban	13
	Rural	15
Gender	Female	18
Age (in years)	Median, range	34 (18-66)
	18 – 30	10
	31 – 40	5
	41 – 50	3
	>50	10
Education	No school/preschool education	3
	Primary school education	7
	Secondary or tertiary school education	18
Employment status	Employed	9
	Unemployed	19
Previous HIV test	No	15
	Yes	13
CD4 count value cells/mm ³	≤ 350 cells/mm ³	15
	> 350 cells/mm ³	13

Table 2: Selected participant quotes by themes

1. Behaviour change “necessary” to maintain or improve health for people with HIV	
Required diet changes for	1.1. “...And then you will have to eat healthily, don’t eat food with a lot of oil, do not eat deep-fried food, ensure that your food has vegetables when you prepare it, make sure that you eat at least one fruit a day.” (Counsellor)

people living with HIV	1.2. "You have to eat the right food. You eat vegetables and fruits and drink water every day. You are going to stop drinking alcohol." (Counsellor)
	1.3. "...The only food that we don't eat is that which cleanses the gut. Not that you shouldn't eat, you can eat occasionally. There are some people when they eat spinach, it cleanses the gut, and you will find them regularly eating because they love it, and whenever they eat the spinach, it cleanses their gut. And there are people when they eat pap (staple food) and milk; they cleanse the gut. You don't eat such food. You eat occasionally." (Counsellor)
	1.4. "From today you need to watch what you eat. Eat vegetables, eat fruits. When I say you should eat vegetables, I am not saying you must get home and tell them that you must eat at vegetables, they said I should not eat meat or pap (staple food). What I am saying is that you need to eat vegetables at least two times a week. Vegetables are nutritious so you will be helping the pill to fight off the virus so that the body soldiers can come alive. The pill assists the body soldiers. You have to assist the pill by eating vegetables and fruits." - Counsellor
	1.5. Patient (P): What is important is that I must drink two litres of water. I should drink it well so that the virus must not defeat the immune system. My immune system must suppress the virus immune increase and win the battle. I forgot the others. Counsellor (C): We boil the food most of the time, we don't fry P: Yes, we do not fry C: Because when you fry your vegetables you add cholesterol. You must boil your food.
2. The benefits of ART	
General framing of the benefits of ART towards longevity and maintaining a high quality of life	2.1. "If you are positive, know that the only thing that will keep you alive is the ARV's only." - Counsellor
	2.2. "Take a deep breath and say whatever you want to say (Silence). You know very well that there are people who are HIV positive and they are healthy. It is not a life sentence this thing. It is not a death sentence. It is not a death sentence; you can live well with ARVs." - Counsellor
	2.3. "...If you take your treatment properly, you stay normal, but if you stop the treatment and default, you are going to get AIDS. When you have moved into AIDS, it is going to be difficult. Everyone will see that you are ill, but if you take your pill properly, no one is going to see that you are ill. You can work and do anything you want." - Counsellor

	2.4. "HIV does not mean that you have to stop things that you used to do. Just live a healthy lifestyle, use condoms, take your treatment and continue with your life. HIV does not stop anything. Your life doesn't stop today because you are HIV positive. Ok?" - Counsellor
	2.5. "There is no grave for an HIV positive person. It is only the person who wants to die who will be killed by HIV. Before treatment was available, yes, people died of HIV, but now that there is treatment, life goes on." - Counsellor
	2.6. "I beg you, don't harm your body. You may end up feeling stigmatised and being afraid to look at other people. I would like to see you maintain the way that you are, even when you start with treatment. Seeing you not getting sick and being able to take your treatment well. Do you want it (HIV) to knock you out with shingles, give you scars?" - Counsellor
General framing of ART benefits concerning CD4 count and viral load	2.7. "ARVs help with your CD4 count and your viral load will go down." - Counsellor
	2.8. "ARVs will help with bringing your CD4 count up and bringing your viral load down. Isn't it?" - Counsellor
	2.9. "The ARVs will help your CD4 count to go up and your viral load to go down. Those are the benefits of ARVs isn't it? And then it will also help with reinfection so that HIV does not multiply." - Counsellor
Benefits of ART in pregnancy	2.10. "Now that you are positive, today you are going to start with treatment so that you can protect the baby from HIV. Also, it is possible for a mother that is HIV positive to have a baby that is HIV negative." - Counsellor
	2.11. "When you start with treatment today, it will build up your immune system to position the virus in one place so that it doesn't multiply every day. As long you take your pills every day and at the same time and use a condom when you have sex the virus won't replicate. The immune system goes up. It becomes strong. The baby gets protected, and the baby will be alright. That means it is all in your hands to protect the baby to be alright?" - Counsellor
	2.12. "Now that you are positive, today you are going to start with treatment so that you can protect the baby from HIV, and it is possible for a mother that is HIV positive to have a baby that is HIV negative." - Counsellor
3. Misinformation supplanting the health benefits of ART	
Misinformation on condoms and replication of the virus	3.1. "Viral load is the amount of virus in your body. When you take ARVs, they suppress the virus, they bring it down, and your CD4 count goes up, but only when you drink them well, and you use condoms. Because I said if you do not use condoms, the virus multiplies." - Counsellor

	3.2. “Now that you have tested you have to accept that you have this virus, and when you have sex use a condom because the more that you don’t use a condom, the more the virus multiply.” - Counsellor
	3.3. Counsellor (C): For you to be protected, you need to use a condom as you also mentioned that you heard from the radio that when you are not using protection, what do you do? Patient (P): You multiply the...(patient trying to remember) I: You increase the viral load in your body. What happens if you don’t use the protection? P: You increase the viral load
	3.4. “Use a condom always when you have sex because when you don’t use a condom while taking the pills, they are not going to work for you those pills.” - Counsellor
	3.5. “Viral load is the amount of virus in your body. When you take ARVs, they suppress the virus, they bring it down and your CD4 count goes up, but only when you drink them well and you condomise. Because I said if you do not use condoms the virus multiplies.” - Counsellor
	3.6. “And as from now on you have to use condoms no matter what because the viral load will increase instead of going down although you are taking treatment if you don’t use a condom every time you have sexual intercourse.” - Counsellor
Condoms promoted ahead of ART	3.7. "When you do not use a condom, or maybe you do not do the right things, we will see it when we check your viral load. When you are taking your treatment yet your viral load is not going down, that is when the nurses will see that there is something wrong here. It’s either you are not drinking you pills on time or you are not using condoms or you are not eating fruits or veggies which are bodybuilders.” - Counsellor
	3.8. “If you are going to use traditional medicine, it will give you diarrhoea, and then you will become dehydrated. You will start getting ill until the virus becomes AIDS. Then you will be bedridden, that is why I am saying leave all other remedies, use a condom.” - Counsellor
	3.9. “You must use a condom and stop saying sometimes; it is going to be your everyday job to use condoms.” - Counsellor
4. Essential behaviour changes required for ART to be effective	
Required lifestyle changes	4.1. “And when you take these pills, make sure that you don’t take alcohol so that the pill helps you well. Make sure that you don’t take alcohol.” - Counsellor

	4.2. “And please, please, please, no smoking, no alcohol, no using syringes no drinking medicine from traditional healers, please I beg you. I am not commanding or imposing. We are advising each other.” - Counsellor)
	4.3. “The medication that you are going to take is affected by other things. If you are drinking alcohol, it counteracts with it because alcohol is strong. It will neutralise the medication. Stop drinking (alcohol), stop smoking drugs, any drug, you don’t use any drug.” - Counsellor
	4.4. Counsellor (C): You bought a packet of 20 (cigarettes), and you have five left? Patient (P): Yes, from yesterday morning C: No bhuti (brother) you smoke too much; you need to reduce the levels of your smoking. Do you know that the virus target where there is more damage in your body?
Scheduling when to take ART	4.5. Patient (P): So how does it work? Counsellor (C): If you drink it at 8 (pm) it must be like that. You drink them only at night. P: Only at night? C: Yes, if you drink them at 7pm it must be 7pm, if it’s 8pm it must be 8pm. Don’t change the time, because if you change the times the medication will not be able work its work in your body. Because they help with your body soldiers to go up and your viral load to go down. Do you know viral load? P: No.
	4.6. “You are supposed to take them at the same time. You will choose your time. If you choose seven, it must be seven. If you choose eight, it must be eight and what you need to know is that the pills that you are going to start taking have side effects.” - Counsellor
	4.7. Counsellor (C): As long as you take your tablets at the same time; every day isn’t it. Like you have said that you don’t miss days as you have said, isn’t it? Every day you take the pills at the same time. When you miss your pills, what is going to happen? Patient (P): You are getting hurt, you are inviting illness because the virus will go up. C: Yes, the virus will go high, and the CD4 count goes where? P: Down.
	4.8. “And then again, if you take your treatment at 8 (pm), and you go somewhere telling yourself that you’ll come back and drink your medication, but you end up

	getting home before or after 9 (pm). As soon as you get home, you must take your medication it is better to drink it late than not to drink it at all, alright, mama.” - Counsellor
	4.9. “And then again when you are going out thinking that you will come back in time to get your treatment and it happens that you do not come back on time, you end up getting home before or after nine. It’s better to drink it late than not to drink it at all.” - Counsellor
	4.10. “When you take your medication at 8 (pm), and your sister calls you to come and visit, and maybe you return before or after 9 (pm) and your time to take your medication has passed, as soon as you get home you must still drink your medication. It is better to drink it late than not to drink it at all. Timing is critical because no one is perfect, isn’t it?” - Counsellor
5. Essential behaviour changes required for ART to be effective	
Side effects of ART	5.1. “And then there are other (side effects) that when you see them you must come to the clinic. Side effects such as thrush, swollen feet, when your eyes turn yellow it means that you have a liver problem and then a headache that doesn’t stop. You should come to the clinic and report that since I started taking treatment this is what I have been experiencing. And then if it is vomiting and feeling dizzy, these are things that will happen for a few days and they will pass because the treatment will be getting used to your body. And then let’s say you drink your pills and then you vomit, when you are done vomiting, sit down, take a deep breath and then drink water after two to three minutes try to drink another pill again...” - Counsellor
	5.2. “ARVs have side effects. You may experience the side effects, or maybe you will not experience them. Also, there are those side-effects which when they appear, you need to come to the clinic immediately. For example, rash, eyes that turn yellow, which are an indication of a liver problem, when your feet get swollen or a severe headache you come to the clinic since you will be on ARVs. And when you feel dizzy, that will happen for a few days, and then it’ll stop. And then vomiting, you will vomit and if you do, sit down, take a deep breath and then relax, drink water then after two to three minutes, try again. Think about the time you vomited and ask yourself if it was before or after your meals. What is causing the vomiting, then you take it from there. You will know that this pill treats me well when I have eaten or when I have not eaten.” - Counsellor

	5.3. “Someone will have side effects. I don’t know how I can put it in isiZulu (local language), someone else might develop a rash after drinking them, someone else may vomit. Yet, another person might get diarrhoea after drinking the medication. It does not mean that you should stop taking medication when you see all these things happening to you. You should not say that “the pill is making me sick” . This pill works, and I am asking you to please stick to the pills.” - Counsellor
	5.4. Counsellor (C): But it (side effects) is not going to happen for the rest of your life, it will be for that small period where it made your dizzy and nauseous. Maybe feel like vomiting and feeling tired, but once your body gets used to the treatment, it becomes alright. Patient (P): I will feel like vomiting and dizzy. C: Yes, for the time being when you start, but some people don’t experience like that as our bodies are not the same.

Title Page

Factors associated with poor-linkage to care among ART-eligible adults in South Africa: perspectives from the era before universal test and treat

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ABSTRACT

Background: In many sub-Saharan African countries which bear the brunt of the HIV epidemic, high attrition occurs between the time of a HIV-positive diagnosis and initiation of antiretroviral therapy (ART). In the recent years, most countries have increased investments for routine HIV programmes in line with universal testing and treatment (UTT) policies which make ART available for all PLHIV. We sought to explore factors associated with linkage-to-care among ART-eligible adults diagnosed through mobile HTS before the UTT era, with the goal of projecting possible individual outcomes and potential areas of intervention in the transition towards optimised UTT services.

Methods: We performed secondary data analysis on a cohort of ART-eligible participants enrolled in the Thol'impilo trial - an unmasked individual randomised pragmatic trial conducted from 2013-2015 in Gauteng and Limpopo provinces of South Africa. We used Cox regression methods to identify socio-demographic factors associated with time to linkage-to-care.

Results: In this cohort of ART-eligible participants diagnosed through mobile HTS, verified linkage-to-care was low. Just over half of the participants (55%) had engaged in HIV medical care within 180 days of testing HIV-positive. In adjusted analyses being in a relationship (adjusted hazard ratio (AHR) 0.69, (95% CI 0.51 – 0.94) and having a previous HIV-positive diagnosis (AHR 1.52, 95% CI 1.04 – 2.21), we associated with linkage-to-care. We also identified disclosure of HIV status as a facilitator for linkage-to-care. However, the effect of disclosure on the hazard of linkage-to-care was stronger among men (AHR 4.56, 95% CI 2.79 – 7.43) compared with women (AHR 1.84, 95% CI 1.27 – 2.67).

Conclusions: Our findings are among the first from mobile HTS programmes in the pre-UTT era, to signal potential pitfalls to the anticipated benefits of universal ART coverage, if similar levels of linkage-to-care observed among our ART-eligible participants, persist. Effective health communication is key to unlocking barriers faced by PLHIV in relationships and to promote the value of HIV medical care among PLHIV who may use HIV testing as a gateway to enter care after periods of delay. Similarly, patient-centred communication is important to maximise the benefits of disclosure, especially among men.

INTRODUCTION

In 2014, the Joint United Nations Programme on HIV/AIDS (UNAIDS) developed a global blueprint to accelerate the pace towards ending the HIV epidemic as a public health threat by the year 2030 [1]. This global response is built on the pillars of early diagnosis of HIV, timely initiation of antiretroviral therapy (ART), and virologic suppression among most people living with HIV (PLHIV). However, in many sub-Saharan African countries which bear the brunt of the HIV epidemic, high attrition occurs between the time of a HIV-positive diagnosis and ART initiation [2]. In 2018, UNAIDS estimated that there were 25.6 million PLHIV in the sub-Saharan African region; of these, 75% were aware of their

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HIV status, yet only 59% of those aware of their status were on ART [2]. Further, while South Africa has the most extensive ART programme globally, with about 4.4 million PLHIV on ART; this only represents 71% of the people who know they are living with HIV and only 58% of all PLHIV in the country [3]. These gaps in linkage-to-care are associated with an increased risk of mortality, including early death after starting ART [4,5]. Also, delayed ART initiation often results in longer time to virologic suppression, which increases the risk of onward transmission [6,7].

Where people receive their HIV diagnosis, whether in the community or at a health facility (e.g. clinic or hospital), has a bearing on the timeliness of linkage-to-care following diagnosis [8-10].

Community-based HIV testing services (HTS) such as testing in people's homes, testing through mobile unity, and more recently HIV self-testing, are valuable in increasing the reach of HTS [11-13]. These approaches reach persons less prone to utilise clinic services, those who have a low perceived risk of being infected by HIV, and those who are unlikely to have ever tested for HIV. Unlike clinic-based HTS clients who are already engaged in the medical system; when community HTS clients receive an HIV diagnosis, they are usually not seeking clinical care and may not otherwise utilise services from health facilities. Among the few studies that have compared linkage-to-care outcomes between community-based and facility-based HTS approaches, most have reported inferior linkage-to-care outcomes among persons diagnosed through community-based HTS [8-10,14].

In the recent years, most countries have increased investments for routine HIV programmes in line with universal testing and treatment (UTT) policies which make ART available for all PLHIV [2,15]. UTT approaches bear the promise of increased engagement in HIV medical care due to increased ART availability and the inclusion of PLHIV who previously did not qualify for ART [1,16]. However, evidence over the years has shown how PLHIV have consistently linked to care at CD4 count levels well below the policy thresholds [17,18]. It is likely that poor linkage-to-care will likely compromise the anticipated benefits of UTT, especially among PLHIV who are diagnosed through community-based HTS and may face more barriers to engaging in medical care compared with individuals diagnosed through clinic-based HTS. We sought to explore factors associated with linkage-to-care among ART-eligible adults diagnosed through mobile HTS before the UTT era, with the goal of projecting possible individual outcomes and potential areas of intervention in the transition towards optimised UTT services.

METHODS

Study design and setting: The Thol'impilo trial

The Thol'impilo trial was an unmasked individual randomised pragmatic trial conducted from 2013-2015 in Gauteng and Limpopo provinces of South Africa [19]. Clients testing positive from seven mobile HTS units deployed in a rural district and an urban district in South Africa were invited to participate in the study following post-test counselling. HTS teams in the rural district concentrated activity in either Elias Motsoaledi and Ephraim Mogale sub-districts or Greater Tubatse sub-district; all in Limpopo Province with a population density of about 65 people per km² [20]. In the urban area, HTS teams concentrated activity in Ekurhuleni district, one of the three metropolitan regions of Gauteng Province (population density 1609 people per km²) [21]. Mobile units were deployed in communities, workplaces, commercial shopping areas, and at special events as part of routine service delivery. Small incentives were provided for HIV testing (value \$0.25-\$1.00) as part of the routine HTS program (and not part of study participation). Clients testing positive and interested in participating in the trial were screened for eligibility.

Clients were eligible to participate if they were ≥18 years old, able to provide informed consent, planned to remain in South Africa for at least six months, and not reporting current HIV-related care (receiving ART or other regular ongoing HIV-related care). Individuals with prior positive HIV tests or who previously received HIV care but were no longer engaged in care were eligible to participate. At study enrolment, participants were randomly allocated to receive either routine referral to HIV clinic of their choice (standard of care [SOC]), or three additional interventions: (1) point-of care (POC) CD4 testing, (2) POC CD4 testing and on-going care facilitation counselling, or (3) POC CD4 and transportation assistance vouchers. Participants were followed up by telephone and/or home visits at 90, and 180 days to assess disclosure of HIV status and self-reported linkage to HIV care.

Self-reported linkage-to-care at any public or private health facility in South Africa was verified by the study team, who visited the facility to perform clinical record abstraction using clinic charts, registers and/or electronic records. If no records were found, the participant was re-contacted to clarify which facility they had attended and possible alternative names they may have used. Additional searches were then performed using this information. National Health Laboratory Service (NHLS) data, (matched on name, date of birth, clinic and date range), were searched for further evidence of linkage-to-care for all participants, irrespective of self-report. Individuals were defined as having verified linkage-to-care if any evidence of registering for or receiving HIV care was found, including but not limited to ART initiation. Study enrolment occurred between March 2013 and October 2014, during which time the South African Department of Health CD4 threshold for ART initiation was <350

cells/mm³ [22]. The primary outcome of the parent Thol'impilo trial was self-reported linkage-to-care within 90 days of testing HIV-positive and has been reported elsewhere [19].

Population included in this secondary analysis

For this analysis, we included individuals from the Thol'impilo Intervention Study who: (1) had a POC-CD4 test done, (2) received POC-CD4 test results and counselling regarding ART eligibility at the time of study enrolment, and (3) had a POC-CD4 count ≤ 350 cells/mm³. Using these criteria, we established a sub-group of participants who knew they were eligible to start ART on the day of HIV diagnosis. By selecting participants who knew they were eligible for ART, it allows for contextualisation of the study findings within the current treat-all era, where all persons diagnosed with HIV are eligible for ART.

Definition of outcomes and explanatory variables

Sociodemographic data were collected at study enrolment. Participants were asked to choose (or if unable to choose, were recommended) a suitable HIV clinic to which they could be referred for ongoing HIV care. Distance from home to HIV referral clinic was calculated using global positioning system (GPS) data [23]. Participants were asked at follow-up contact times whether they had disclosed their HIV status, and if so, the date of disclosure. These data were used to generate a time updated explanatory variable for disclosure prior to linkage-to-care. In follow up interviews some participants acknowledged inaccurately reporting linkage-to-care to the study team, presumably due to social desirability bias. Therefore, for this analysis, verified linkage-to-care by 180 days after testing HIV-positive was used as the primary outcome. We further excluded from this analysis, participants who reported linkage at private health practices if we were unable to access records at those practices. Individuals who had no verified linkage-to-care were censored at death or at 180 days after testing HIV-positive (whichever was earliest).

Statistical methods

A descriptive analysis of the data was performed to explore the baseline characteristics of the study population. Associations between baseline variables and time to linkage-to-care were analysed using Cox regression and Kaplan Meier proportions [24]. Ordered categorical variables were tested for a linear trend and departures from linear trend using the likelihood ratio test (LRT). Sociodemographic variables which were associated with linkage-to-care in univariable analysis (LRT $p < 0.1$), were included in a multivariable Cox regression model and retained if $p < 0.1$. Proportional hazards were assessed by testing for interactions between each variable and time period (0-90 days versus 90-180 days in accordance with recommended timelines for analysing linkage-to-care).

Stata 14.0 was used for all analyses (STATA Corp. College Park, Texas, USA). Ethical approval for this secondary analysis was obtained from the London School of Hygiene & Tropical Medicine Ethics Committee (ref: 11180 /RR/4515). Overall approval for the Thol'impilo study and linkage to care analysis was obtained from the University of the Witwatersrand and Johns Hopkins University. The Thol'impilo trial was registered with ClinicalTrials.gov, NCT02271074. All participants completed written informed consent.

RESULTS

Participants

From March 2013 to October 2014, a total of 2558 participants were enrolled in the Thol'impilo Intervention Study (Figure 3-6). After enrolment, 1,807 (71%) were randomised to an intervention arm that offered POC-CD4 testing, of which all participants agreed to perform the test. Eighty-six participants (5%) were not issued with their CD4 results on the day of diagnosis, the primary reasons being: machine failure at the time of testing (44, 2.4%) or participants leaving before the machine produced the result (42, 2.3%). Of the 1721 participants issued with a CD4 result, 616 (36%) had a CD4 count ≤ 350 cells/mm³, and were eligible, per guidelines in place at the time, to start ART. Of those issued with a result and eligible to start ART, we could not access medical records to ascertain linkage-to-care for 29 (5%) participants referred to private healthcare facilities or self-reported receiving care at private healthcare facilities. For the remaining 587 (95%) participants, the study team went to the clinics that participants self-reported receiving care, or to the clinic that participants had been referred to at enrolment if they could not be contacted during follow-up.

A total of 587 participants were eligible for analysis (Table 1). Overall, 295 (50.2%) were women, the median age was 35 years (Interquartile range [IQR]: 28 – 42 years), the median CD4 count was 242 cells/mm³ (164 – 300), and the majority were enrolled from the more urban study sites (385, 65.6%). With regards to HIV testing: 254 (43.2%) were first time testers, and about a third were testing because of suspected exposure to HIV infection (203, 34.6%). Data on disclosure were collected for 491(84%) participants; 327 (66.6%) participants reported voluntarily disclosing their HIV status to another person within the first 182 days of follow-up, and a further 164 (33.4%) disclosed after 182 days of follow-up. Information on distance to the referral clinic was missing for 30 (5%) of participants, for whom information on the home address was not accurate to establish GPS coordinates which were required to calculate the distance.

Linkage-to-care outcomes

Participants were followed up for 57,107 person-days or 156 person-years. At 180 days, 323 (55%) participants had verified linkage-to-care (Figure 1). The median time to verified entry into care among those who achieved the primary outcomes was 12 days (IQR: 3, 39). 264 (45%) of the participants had no verified linkage-to-care, of these 140 (53%) were still in follow up; 137 (52%) were lost to follow up despite multiple attempts to contact them telephonically or via home visits, and searching both national electronic laboratory records and national registries for death records. An additional 3 (2%) died before entering care

Factors associated with linkage-to-care

In univariable analysis (Table 2), being male ($p=0.053$), being employed ($p=0.003$), a higher number of workdays in a week (test for linear trend $p = 0.01$), being in a relationship ($p=0.005$), a higher CD4 count (test for linear trend $p = 0.07$) were associated with a reduced hazard of linkage-to-care. Further, participants who reported previously testing HIV-positive were substantially more likely to enter care compared with first-time testers ($p=0.003$). Having ever disclosed HIV status to another person within 180 days of follow-up was associated with increased linkage overall with a stronger effect size for men than women (p -value for interaction $p = 0.006$). Testing in the more urban area, participant's age, country of origin, the highest level of education, the reason for testing, knowing partner's HIV status at the time of diagnosis, and distance to referral clinic, were not associated with time to linkage-to-care (all $p>0.1$).

In adjusted analyses ($n=491$), being in a relationship (adjusted hazard ratio (AHR) 0.69, 95% CI 0.51 – 0.94) compared to no relationship was associated with lower linkage-to-care (Table 4-2). Participants with a previous HIV-positive diagnosis, but who had not previously engaged in care were more likely to link-to-care compared with first-time testers (AHR 1.52, 95% CI 1.04 – 2.21). However, there was no difference between first-time testers compared with those who had previously tested negative (AHR 1.05, 95% CI 0.81 – 1.35). The interaction between disclosure and the participant's sex remained significant (p -value for interaction = 0.002). The effect of disclosure on the hazard of linkage-to-care was stronger among men (AHR 4.56, 95% CI 2.79 – 7.43) compared with women (AHR 1.84, 95% CI 1.27 – 2.67). Results for multivariable analyses are presented in Table 4-2 and represented for each significant variable in Figure 4-2. In adjusted analyses, there was no evidence of non-proportional hazards for all the variables using Schoenfeld residuals.

DISCUSSION

Understanding HIV medical care-seeking behaviour has become an increasingly important area of research, as guidelines and national policies throughout the world are calling for universal access to ART with rapid initiation of therapy after diagnosis. In this cohort of ART-eligible participants diagnosed through mobile HTS, verified linkage-to-care was low. Just over half of the participants had engaged in HIV medical care within 180 days of testing HIV-positive. Our findings are among the first from mobile HTS programmes in the pre-UTT era, to signal potential pitfalls to the anticipated benefits of universal ART coverage, if similar levels of linkage-to-care observed among our ART-eligible participants, persist.

The disquieting picture of poor linkage-to-care among ART-eligible individuals is corroborated by evidence from recent community-based cluster randomised trials; though conducted in more controlled research settings compared to study. The ANRS 1229 TaSP Trial is one of the first studies conducted in South Africa to evaluate the effectiveness of UTT approaches in reducing population-level HIV incidence [25]. In this study, only 47.6% of participants randomly assigned to receive immediate ART initiation had linked to care within six months of receiving the HIV diagnosis. This finding was not significantly different from the linkage-to-care outcomes of participants in the standard of care arm (47.4%) who were only initiated on ART if they met the CD4 eligibility criteria. In the POP-ART trial conducted in South Africa and Zambia, participants diagnosed with HIV in seven communities were assigned to receive immediate ART initiation regardless of the CD4 count [26]. In the three South African communities, 6-month linkage-to-care outcomes significantly fell short of the 90% UNAIDS targets, ranging from 45% - 56%, and 38% - 65% in the four Zambian communities. These findings, combined with ours, highlight that mere expansion of ART services towards universal coverage, is inadequate to be used by all those who require them. Coupling UTT with additional interventions that promote the value and reduce the costs of HIV medical care for PLHIV diagnosed through these approaches is necessary to translate the benefits of the broad reach of community-based HTS approaches into tangible programme benefits.

We observed important associations with linkage-to-care among ART-eligible men and women testing HIV-positive during mobile community and work-place testing in South Africa. Notably, among ART eligible participants, a prior HIV-positive test result, disclosure, and not being in a relationship were all associated with linkage to care. Furthermore, the effect size for disclosure was significantly higher for men than for women. These are important findings in better understanding the role of repeat HIV testing and strategies to improve linkage to care and ART initiation among those testing HIV positive.

The differential effect of disclosure on linkage to care for men and women may be to different responses to the HIV diagnosis and different responses to internalized and anticipated stigma. HIV and care seeking for HIV are well described to threaten hegemonic masculine constructs [27-30]. A possible hypothesis is that the disruption of biography is greater for men than for women and that the step of disclosure is an important step in balancing the threat of the HIV diagnosis and care seeking to masculinity versus the threat of untreated and unaddressed HIV disease [31]. We did not collect any quantitative information on perceptions of stigma after HIV diagnosis. However, it is highly plausible that the men who successfully disclosed their status, represent a sub-group of men with low internalized stigma – a commonly reported facilitator for early linkage-to-care [32,33]. Also, findings from other studies suggest that men are likely to face fewer and less negative consequences of disclosure which may impede engagement in care compared with women [34,35]. On the other hand, women have been reported to be at increased risk of intimate partner violence after disclosure of HIV status [34,36].

In our study, being in a relationship was a risk factor for failure to enter care within 180 days of receiving an HIV diagnosis. The finding on delayed linkage-to-care among people in relationships may reflect the flip-side when PLHIV lack the self-efficacy to disclose their status or when the anticipated costs of disclosure are perceived to outweigh the benefits expected from disclosing. Some participants in relationships may have protracted periods of searching for causal attributions of the HIV diagnosis if they had a low perceived risk of acquiring HIV or when their partners self-reported being HIV-negative [32]. It is also highly plausible that communication provided through post-test counselling sessions may have escalated costs for people in relationships. This includes messages from counsellors which are often reported to make imperatives for clients to disclose their HIV status to implement “required” dietary changes or to negotiate condom use [37]. More deliberative dialogue is required between healthcare providers and their clients to unmask the potential costs to care engagement for people who are in relationships.

Our findings highlight the important role of re-testing in the pathway to engaging in HIV medical care and ART initiation. Repeating an HIV-positive test may aid some individuals in the process of accepting, believing, and coming to terms with the diagnosis [38,39]. The time to adjust to this new reality and define a new course of action – sometimes referred to as disruption of biography – differs among people [31]. It is also likely that participants may have re-tested as an avenue to enter HIV medical care, at a time when their perceived value of HIV had increased. According the value-cost model by Hoffmann et.al., linkage-to-care is more likely to occur when the perceived value of HIV

care outweighs the costs of engaging in medical care [40]. Among participants who re-tested, the value of HIV medical care may have increased due to experiences of disruptive illness symptoms, observing immediate examples of people experiencing losses from non-care engagement, or social pressure in cases of voluntary HIV status disclosure [32]. Facilitating linkage-to-care for this subgroup of HTS clients requires tailored health communication messages which are non-judgmental and empathetic to the process of adapting to the diagnosis of a chronic condition. Lastly, the temporal shifts in the value placed on HIV medical care observed among repeat testers aware of their HIV-positive status underscores the importance of on-going case management and counselling support. Such on-going support allows healthcare providers to develop patient-centred care plans which are concordant with their client's goals at different stages of their trajectory of dealing with the HIV diagnosis.

A key strength of our study was the availability of POC-CD4 results at the time of diagnosis, and the existence of a relatively large cohort of ART-eligible participants. Therefore, our study was able to show the magnitude of the delays in linkage-to-care among ART-eligible PLHIV and forecast the potential pitfalls of UTT programmes in the absence of interventions to improve linkage-to-care. Further, our outcomes were based on verified linkage-to-care. Verifying linkage-to-care involved rigorous paper and electronic record searches at over 200 referral clinics. Verification of linkage-to-care is important, given that some studies have shown that participant self-report may overestimate linkage-to-care by 20% to 30% compared to verified linkage-to-care outcomes [19,41]. However, there are limitations to this study. About 24% of all participants, were lost to follow up despite multiple attempts to contact them telephonically or via home visits and searching both national electronic laboratory records and national registries for death records. In addition, linkage-to-care may have been underestimated due to inadequate record-keeping or backlogs in updating of patient records at the district clinics. Although the use of three distinct sources of verifying linkage-to-care may have minimised this limitation but is unlikely to have eliminated the problem. The lack of unique patient identifiers in South Africa poses a substantial challenge to documenting the journey through the care continuum for a single individual. Other weaknesses of the study include missing data for some variables such as GPS coordinates required for calculating the distance to the clinic, and the non-collection of data to quantify the extent to which migration and mobility of participants, may have influenced care engagement outcomes.

CONCLUSIONS

As South Africa, and other high HIV-burden countries optimise UTT, and increase the reach of HIV diagnosis through community-based HTS, there is even more pressing need to identify ways of

linking asymptomatic individuals to HIV medical care. At the interpersonal-level, the barriers to linkage-to-care among PLHIV in relationships requires further investigation. There is also a need for additional research into the process and consequences of disclosure among men. Such research will help guide the development of core messages to assist with disclosure among men and address issues of masculinity that have been reported to reduce the willingness of men to disclose their status and be seen taking medications. These messages may include individual health communication and mass health communication to reshape community norms.

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1 TABLES

2 Table 1: Participant baseline characteristics by linkage-to-care status at 180 days

		Total N=587		No verified linkage N = 264		Verified linkage N = 323	
		n	%	n	%	n	%
Study arm	POC-CD4 + Transport	185	31.5	86	46.5	99	53.5
	POC-CD4 + Care facilitation	199	33.9	76	38.2	123	61.8
	POC-CD4 only	203	34.6	102	50.3	101	49.7
Age, years	Median (IQR)	35 (28 -42)	-	34(28-41)	-	36(29–43)	-
	18 - 30	196	33.4	95	48.5	101	51.5
	31-40	218	37.1	99	45.4	119	54.6
	>40	173	29.5	70	40.5	103	59.5
Sex	Male	292	49.8	142	48.6	150	51.4
	Female	295	50.2	122	41.4	173	58.6
Country of origin	South Africa	493	84.0	219	44.4	274	55.6
	Other	94	16.0	45	47.9	49	52.1
District of enrolment	Urban/peri-urban	385	65.6	179	46.5	206	53.5
	Rural	202	34.4	85	42.1	117	57.9
Employment status	Employed	288	49.1	117	39.1	182	60.9
	Unemployed	299	50.9	147	51.0	141	49.0
Number of workdays per week	0	299	51.0	117	39.1	182	60.9
	1-5 days	188	32.0	93	49.5	95	29.4
	6-7 days	100	17.0	54	54.0	46	46.0
Highest level of education	None/primary	163	27.8	72	44.2	91	55.8
	Secondary/higher	424	72.2	192	45.3	232	54.7
Dwelling	Formal	381	65.0	165	43.3	216	56.7

		Total N=587		No verified linkage N = 264		Verified linkage N = 323	
		n	%	n	%	n	%
	Informal	206	35.0	99	48.1	107	51.9
*Distance to referral clinic, km (n=557)	≤5	336	60.3	150	44.6	189	55.4
	5-20	84	24.6	42	46.7	73	53.3
	>20	137	15.1	37	44.1	47	55.9
Planned mode of travel to referral facility	Taxi/other	356	60.6	159	44.7	197	55.3
	Walk	231	39.4	105	45.5	126	54.5
CD4, cells/mm ³ at diagnosis	Median (IQR)	242 (164 – 300)	-	247(169-306)	-	237 (157 – 288)	-
	≤ 100	53	9.0	19	35.9	34	64.1
	101-200	153	26.1	72	47.1	81	52.9
	201-300	235	40.0	97	41.3	138	58.7
	> 300	146	24.9	76	52.1	70	47.9
Relationship status	No relationship	84	14.3	26	31.0	58	69.0
	In a relationship	503	85.7	238	47.3	265	52.7
Reason for HIV testing	Suspected exposure	203	34.6	80	39.4	123	60.6
	Routine test	384	65.4	184	48.0	200	52.0
Place where HTS was done	Community	516	87.9	229	44.4	287	55.6
	Workplace	71	12.1	35	49.3	36	50.7
Previous HIV test and result	No test	254	43.2	123	48.4	131	51.6
	Negative	277	47.2	125	45.1	152	54.9
	Positive	56	9.6	16	28.6	40	71.4
Knows partner's status (n=503)	Yes	64	12.7	29	45.3	35	54.7
	No	439	87.3	209	47.6	230	52.3
Willing to disclose status at enrolment	No	277	47.2	160	57.8	117	42.2

		Total N=587		No verified linkage N = 264		Verified linkage N = 323	
		n	%	n	%	n	%
**Disclosed HIV status (n=491)	Yes	310	52.8	104	33.6	206	66.4
	No	164	33.4	105	64.0	59	36.0
	Yes	327	66.6	95	29.1	232	70.9

3 *Distance from a participant's residence and the referral clinic was calculated using the Haversine Formula by inputting GPS coordinates of the place of residence and referral clinic.

4 **Data on disclosure were used to generate an updated explanatory variable for disclosure of HIV prior to engagement in care.

5 POC-CD4: Point-of-care CD4 count at diagnosis; IQR: Interquartile Range

6 Table 2: Analysis of factors associated with verified linkage-to-care at 180 days

		Unadjusted Hazard Ratio (95% CI)	*Adjusted Hazard Ratio (95% CI)
Sex	Female	1.00; P= 0.05	1.00; P=0.74
	Male	0.81 (0.65 – 1.00)	0.95 (0.72-1.27)
Age	18 – 30	1.00; $P^T = 0.19$	-
	31-40	0.29 (0.89 – 1.51)	
	>40	1.29 (0.98 – 1.69)	
Country of origin	South Africa	1.00; P= 0.50	-
	Other	0.90 (0.66 – 1.22)	
Region	Urban	1.00; P= 0.20	-
	Rural	1.16 (0.92 – 1.45)	
**Employment	Unemployed	1.00; P=0.01	-
	Employed	0.74 (0.60 – 0.93)	
Number of workdays per week	0	1.00; $P^T = 0.01$	1.00; $P^T = 0.21$
	5 days	0.74 (0.58 – 0.95)	0.80 (0.61 – 1.07)
	6-7 days	0.66 (0.47 – 0.91)	0.77 (0.53 – 1.12)
Highest level of education	None/primary	1.00; P=0.60	-
	Secondary/higher	0.94 (0.73 – 1.19)	
Dwelling	Formal	1.00; P=0.32	-
	Informal	0.89 (0.70 – 1.12)	
Distance to referral clinic, km	≤5	1.00; $P^T = 0.85$	-
	5-10	0.95 (0.72 – 1.25)	
	>10	1.05 (0.77 – 1.45)	
CD4 count, cells/mm ³	≤ 100	1.00; $P^T = 0.07$	1.00; $P^T = 0.30$
	101-200	0.75 (0.50 – 1.12)	0.96 (0.61 – 1.49)
	201-300	0.85 (0.58 – 1.24)	0.99 (0.66 – 1.50)
	> 300	0.62 (0.41 – 0.93)	0.74 (0.48 – 1.18)
Relationship status	No relationship	1.00; P=0.01	1.00; P=0.02
	In a relationship	0.66 (0.50 – 0.89)	0.69 (0.51 – 0.94)
Reason for test	Suspected exposure	1.00; P=0.06	1.00; P=0.35
	Routine test	0.80 (0.64 – 1.01)	0.89 (0.70-1.13)
Place where HTS was done	Community	1.00; P=0.41	-
	Workplace	0.86 (0.61 – 1.22)	
Previous HIV test and result	No test	1.00; P=0.01	1.00; P=0.72
	Negative	1.05 (0.83 – 1.33)	1.05 (0.81 – 1.35)
	Positive	1.70 (1.19 – 2.42)	1.52 (1.04 – 2.21)
Knows partner's status	No	1.00; P=0.80	-

		Unadjusted Hazard Ratio (95% CI)	*Adjusted Hazard Ratio (95% CI)
	Yes	1.04 (0.73 – 1.49)	
Disclosed HIV status - male	No	1.00; P<0.001	1.00; P<0.001
	Yes	4.48 (2.77 – 7.24)	4.56 (2.79 – 7.43)
Disclosed HIV status - female	No	1.00; P<0.001	1.00; P=0.001
	Yes	1.86 (1.29 – 2.66)	1.84 (1.27 – 2.67)

FIGURES

Figure 1: Selection of ART-eligible participants for secondary analysis

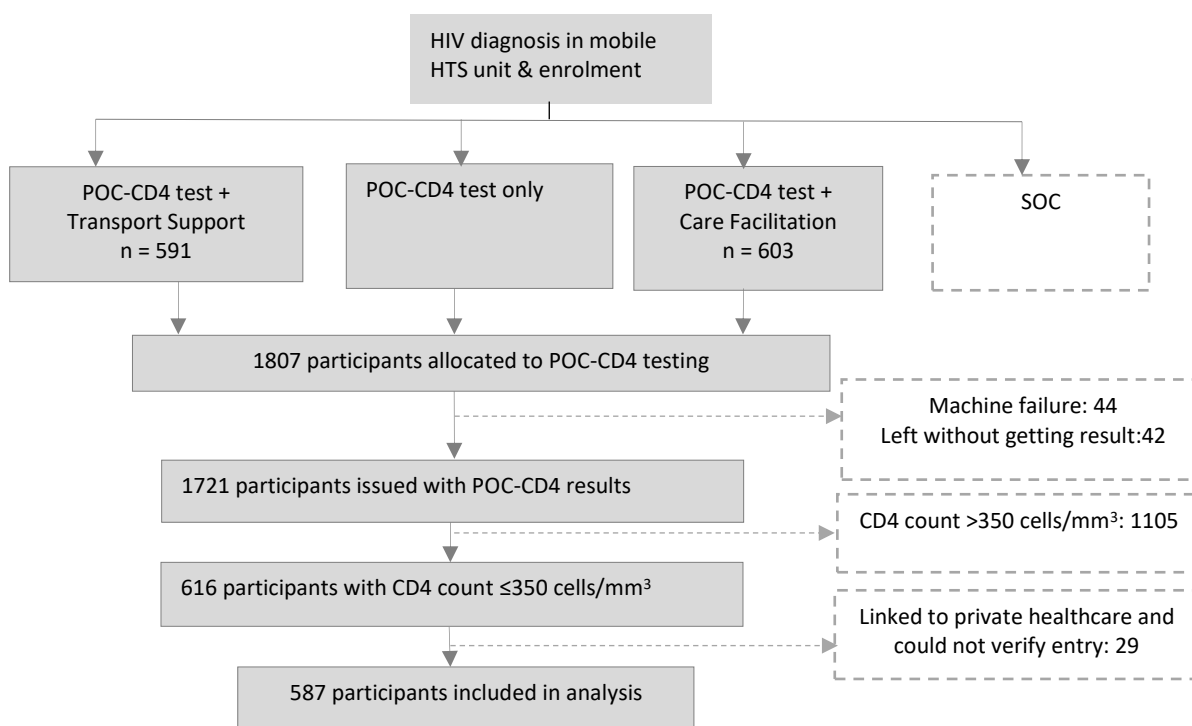
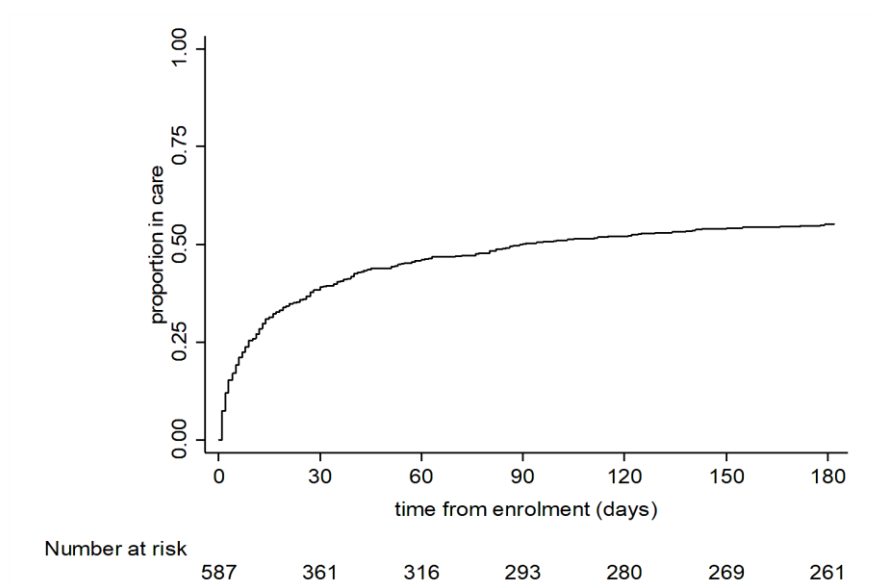
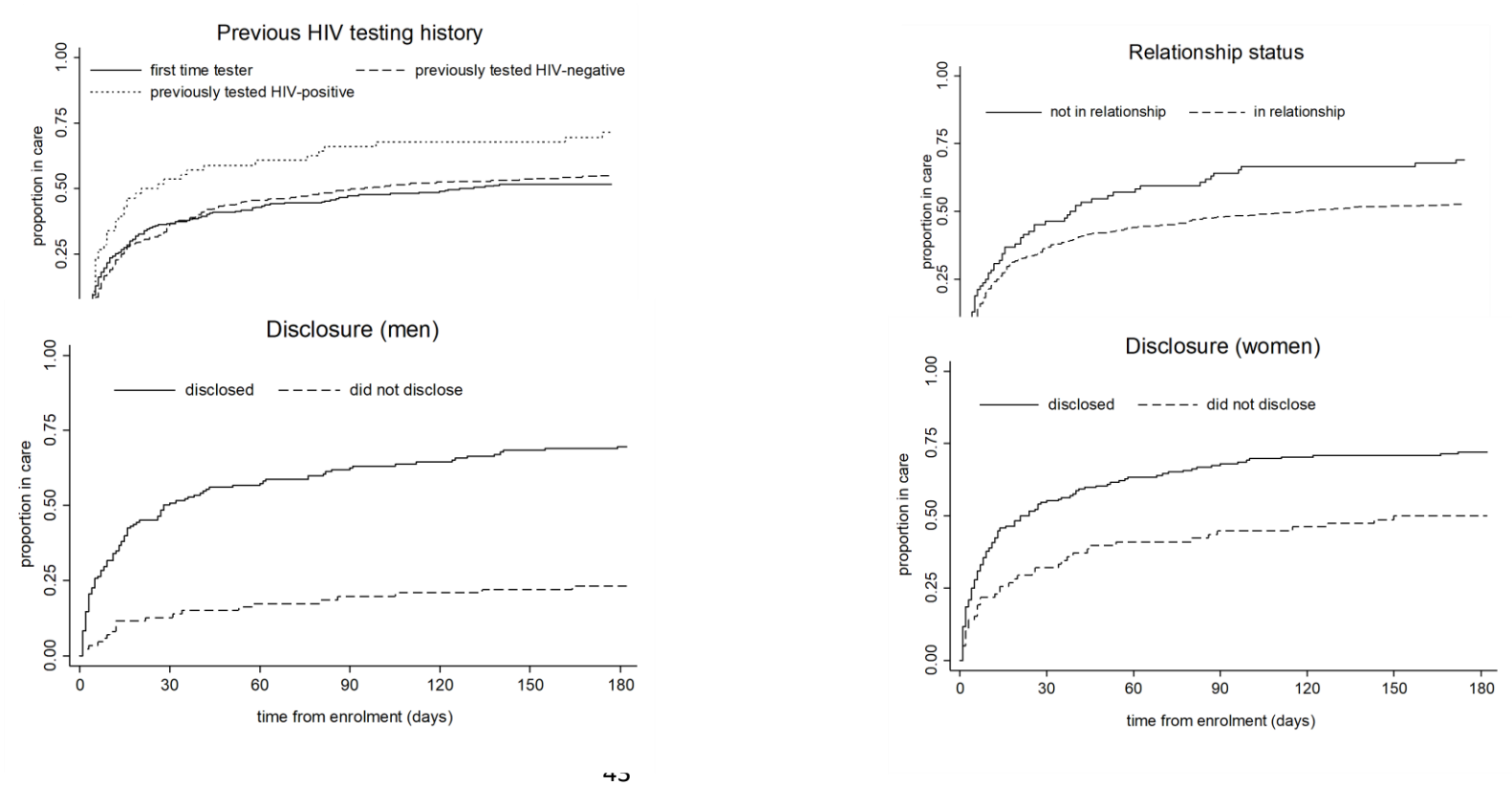


Figure 2: Kaplan-Meier estimates of time to verified linkage-to-care within 180 days of enrolment



31 **Figure 3: Kaplan Meier estimates of linkage-to-care by 180-day, by risk factor in the final multivariable model**



44

45

46

ORIGINALITY REPORT

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