Comparison of Patient Experiences in Three Differentiated Antiretroviral Delivery Models in a Public Health Care facility

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KEYWORDS

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90-90-90 Strategy

Test and Treat

ABBREVIATIONS AND ACRONYMS

AC: Adherence Club

ART: Antiretroviral Therapy

ARV: Antiretroviral

CAC: Community Adherence Clubs

CAGs: Community ART Groups

CCMDD: Central Chronic Medication Dispensing and Distribution

DCM: Differentiated Care Models

NDP: National Development Plan

NDoH: National Department of Health

NSP: National Strategic Plan

PLHIV: People Living with HIV

PODI: Community Drug Distribution Point

QPUP: Quick Pharmacy Pick Up

UNAIDS: United Nations Programme on HIV/AIDS

UTT: Universal Test and Treat

WHO: World Health Organisation

ABSTRACT

Background: HIV remains a global concern. Consequently, global institutions such as the World Health Organisation (WHO) and United Nations Programme on HIV and AIDS (UNAIDS) continue to work towards ending HIV/AIDS by facilitating innovative strategies to improve service delivery of antiretroviral therapy (ART). In 2016 WHO issued the 'test and treat' policy recommendation in line with the UNAIDS 2020, 90-90-90 target of reaching 90% people to know their HIV status, get 90% of these on ART treatment and to have 90% of those on treatment virally suppressed. Differentiated Care Models (DCMs) has been put in place for all stakeholders, from global, institutes, government departments and civil society to improve patient access to treatment and retention in care. While various evaluation studies have shown that DCMs improve the retention in care and adherence to medication behaviours of patients on ART, little is known about the patients' experiences and preferences.

The aim of the current study was to explore and compare the experiences of patients in three DCMs (Facility Adherence Clubs [FAC], Community Adherence Club [CAC] and Quick Pharmacy Pick-up [QPUP]) in a community health care facility in a township in Cape Town, South Africa.

Methods: An exploratory qualitative study design was used. Data were collected through semi-structured interviews (12) and focus group discussions (6) with purposively selected participants from six DCMs. Thematic analysis was done using Atlas.ti version 8.0.

Results: Patients found DCMs easily accessible and convenient and presented positive experiences in relation to the National Health Services (NHS) patients experience principles. FACs and CAC presented attributes of patient-centeredness as prescribed by the NHI. We found that the QPUP model fell short on attributes of patient-centeredness such as coordination and integration of care, information sharing, communication and education, and emotional/psychological support.

Conclusions: The principles of DCMs acknowledge the diversity and preference of PLHIV in addressing the barriers they face in accessing ART while empowering these patients to self-manage their disease. Understanding the experiences of patients using DCMs could improve our understanding of how DCMs promote self-management among PLHIV (or not) and some of the challenges faced by the patients using these care models. This understanding could inform strategies to tailor ART delivery services that suit the patients' needs and enhance their abilities to achieve optimal retention in care and viral suppression.

DECLARATION

I declare that “Comparison of Patient Experiences in three Differentiated Antiretroviral Delivery Models in a Public Health Care facility” is my own work, that it has not been submitted for any degree examination in the University and that all the sources I haven used and quoted have been indicated and acknowledged by complete references.

FULL NAME: SIBUSISO NDLOVU

SIGNED: **DATE: 21 November 2019**

DEDICATION

I dedicate this work to my most adorable children; son – Shelton and daughter – Zizi and my father Mr C. C. Ndlovu

- ALUTA CONTINUA!

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CHAPTER ONE

Framing the study

1.1 Introduction

Sub-Saharan Africa is the region hardest hit by the HIV epidemic with an estimated 25.7 million people living with HIV (PLHIV) in 2018 (UNAIDS 2019). It was estimated that 87% of PLHIV were receiving antiretroviral therapy (ART) in 2016 (Kharsany and Karim, 2016). The UNAIDS, in 2013, launched the "90-90-90" goals to accelerate progress to end the HIV epidemic. These goals are to ensure that by 2020, 90% of PLHIV are diagnosed, 90% of those diagnosed are linked to ART, and 90% of those on ART achieve viral suppression (UNAIDS, 2013). Increasing and scaling-up innovative approaches to HIV care is critical to achieving these goals (Braul, Desrosiers and Watson, 2011). The repercussion of this success reflects in the increased congestion of the primary health care facilities (Holtzman, Brady and Yehia, 2015) cascading to poor retention in care of patients and suboptimal adherence to treatment.

The need to decongest the primary health care facilities prompted innovative thinking towards a differentiated approach to care for PLHIV. The International AIDS Society (IAS) (2016) defines differentiated care as "a client-centred approach that simplifies and adapts HIV services across the cascade to reflect the preferences and expectations of various groups of PLHIV while reducing unnecessary burdens on the health system". Differentiated care models (DCMs), therefore, aim to enhance patient's care experience, putting the patient at the centre of service delivery while ensuring that the health system is functioning in a medically accountable and efficient manner. The principle underpinning differentiated care is to provide ART delivery in a way that acknowledges specific barriers identified by clients and empowers them to manage their disease with the support of the health system (Shubber *et al.*, 2016). Therefore, by providing differentiated care, the health system can refocus human and financial resources to those most in need.

South Africa has the largest number of PLHIV with a prevalence of 7.9 million and incidence of 270 000 in 2016 (UNAIDS, 2016). The sustained high prevalence of HIV in South Africa calls for innovative strategies such as DCMs to harness patient access to treatment and retention in care (Médecins sans Frontières [MSF], 2014). The National Adherence Policy (2016) on Differentiated Care for Stable patients, in 2016 called for all nine provinces in South Africa to implement DCMs. This initiative is in line with the National Development Plan (NDP) 2030, the UN Sustainable Development Goals, UNAIDS 90-90-90 targets of 2020 and WHO's Universal Test and Treat (UTT) policy guidelines.

The Western Cape Province of South Africa has been pioneering the implementation of DCMs, often working in conjunction with civil society organisations as partners to strengthen the health system (McGregor *et al*., 2016). The Western Cape Department of Health (WCDoH) in partnership with MSF piloted the Adherence club model in an ART clinic in Khayelitsha, Cape Town. As the number of HIV positive people increased in health facilities, key stakeholders have facilitated decentralising HIV services to decongest the health facilities between the years 2000-2004; Goemaere, 2016; Gale *et al.*, 2013; Mukumbang *et al.*, 2017).

The Adherence Club model was adopted as policy in the Western Cape Province because of its successes in sustaining suppressed viral loads and retaining patients in care (Grimsrud *et al.*, 2016). Enrolling patients in adherence clubs were in some facilities considered a measure to reward adherent and stable patients with quick and flexible services to access ART (Luque-fernandez *et al.*, 2013; Goemaere, 2016). Since the piloting of adult Adherence Club intervention, other models such as the male clubs, integrated clubs, youth clubs and family clubs to target different populations have been tested and implemented (Mukumbang, Orth and van Wyk, 2019.

1.2 Differentiated antiretroviral therapy delivery models

DCMs are HIV diagnostic, treatment and care models designed to improve the HIV diagnosis, linkage to care, treatment and care for PLHIV towards achieving the 90-90-90 goals of UNAIDS. Differentiated ART delivery is a component of differentiated care, which focuses on the last two 90 percent of the HIV continuum – retaining people in ART and maintaining viral suppression. Therefore, a differentiated model of ART delivery focuses on improving the retention in care and adherence to medication of PLHIV on ART (Figure 1).

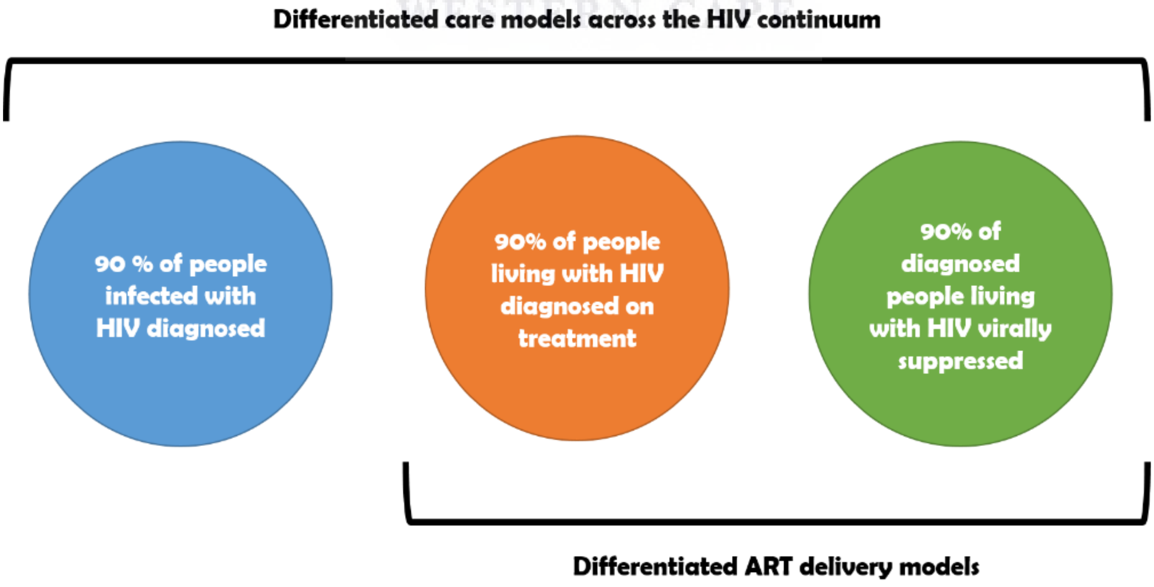

Figure 1: Aligning differentiated care models on the 90-90-90 by 2020 goals. Adapted from the International AIDS Society (2016).

DCMs need to be relevant, appropriate and responsive to the needs of PLHIV (UNAIDS, 2013; Medecins Sans Ffrontiers, 2014). The aims of DCMs are: (1) to improve clients' lives through the provision of quality and effective care; (2) to improve health systems' efficiencies and outcomes; (3) to support the 'treat all' agenda; and (4) to reach the 90-90-90 target (IAS, 2016). WHO's HIV treatment and care guidelines of 2015 advocate for the adoption of different care packages to address diverse needs. DCMs are usually facility-based or out of facility and individual-focused models (e.g. quick medication pick up), or health care worker managed group models (e.g. adherence clubs) and client managed group models (e.g. community adherence groups) (IAS, 2016).

The South African National Strategic Plan (NSP, 2017-2022) framework supports the implementation of differentiated care strategies to fast-track of health facility procedures, enable stable patients to use alternative options of care and drug dispensing within and outside of health facilities (Republic of South Africa, 2016). In 2016, the National Department of Health of South Africa sent out a circular instructing the rollout of differentiated care models (Republic of South Africa, 2017). Patients choose their preferred medication collection service (client-centred) through three options that are reflected in the adherence policy and service delivery guidelines: (1) Adherence Clubs; (2) Spaced and fast lane appointment system or quick pharmacy pick-up; and (3) Central Chronic Medication Dispensing and Distribution.

1.2.1 Adherence club model

The adherence club model was designed to decongest healthcare facilities of PLHIV on ART and to encourage peer support among patients (Wilkinson *et al.*, 2016). The adherence club model groups stable patients (15 – 30) who meet and get ARV supply every two months and only given four months' supply of medication during the festive season to accommodate the migration of patients during this period (Medecins Sans Frontiers, 2014). The groups are run and facilitated by a lay health worker who provides education session where patients discuss health or non-health related issues for social-support, weighs the patients and give them pre-packed medication. The club facilitator makes sure that logistics pertaining to the club model are prepared so that they are able to provide quality service to the patients. The intervention was first rolled out in facilities in the Western Cape to relieve clinic congestion, improve retention in care and enhance treatment adherence (Mukumbang *et al.*, 2016).

The success of the adherence club intervention in the Western Cape Province led to its inclusion in the national policy for the delivery of ART (Republic of South Africa, 2016). Stable patients – on the same ART regimen for at least six months with an undetectable viral load, and having no medical condition requiring regular clinical consultations – are eligible to join the adherence club if they are aged 18 years or more (Médecins Sans Frontières and UNAIDS, 2015).

The adherence club model can be hosted in a facility (facility-based) and out of the facility (community-based) depending on the availability of space. The model requires limited clinical support rendering it flexible to be implemented remotely from the facility. The model can be implemented in the facility in any safe and secure space where up to 30 patients can be accommodated. Community spaces such as community halls, church halls, libraries and patients’ homes are commonly used to host community adherence clubs Wilkinson, 2013) . Patients in community clubs have to return to the facility to have their viral load tests and clinical consultation (once a year). Quick service, social empowerment and the flexibility of sending a trusted person to collect medication on their behalf are some of the benefits of being in a club.

1.2.2 Quick pharmacy pick-up

The quick pharmacy pick-up (QPUP) model is a model of care where patients pick their medication in the facility and can return to their daily activities (Goemaere, 2016). This model was designed to include more patients for differentiated ART delivery based on its quick service centeredness, because it can accommodate up to 50 patients per QPUP group. The qualifying criteria for the QPUP are the same as those in the adherence club. The QPUP model is considered a flexible approach because it allows patients to send people they trust to pick their supply if they cannot come to the facility. They can send somebody on multiple occasions to collect on their behalf and can only attend to draw blood for viral load measurements and comprehensive clinical consultation once a year in the host facility (Wilkinson, 2013).

1.3 Problem statement

The growing number of PLHIV places more burden on the under-resourced public health care facilities in South Africa. This challenge manifests in the form of congestion in the clinics leading to increasing number of patients defaulting medication and some being lost to follow up (MacGregor *et al.*, 2016). DCMs promise to enhance the adherence to medication and improve the retention in care behaviour of PLHIV on ART by improving their care-seeking experiences through streamlined services. While various evaluative studies (Medecins Sans Frontiers, 2014; Bannet *et al.*, 2013; Mukumbang *et al.*, 2017) have shown that DCMs improve the retention in care and adherence to medication behaviours of patients on ART, little is known of their experiences of using these DCMs. In addition, while conducting a systematic review on differentiated ART delivery models, Davis *et al.* (2018) identified gaps in understanding the desirability of these models for PLHIV. To this end, in this study, we explored the experiences of PLHIV using three forms of DCMs – community and facility-based adherence clubs and QPUP.

1.4 Aim

The aim of this study was to explore and compare the experiences of patients using differentiated ART delivery models in a Community Health Care facility in Khayelitsha, Cape Town, South Africa.

1.5 Objectives

- To explore the experiences of patients using different ART delivery models.
- To compare the experiences of patients using different ART delivery models

1.6 Rundown of thesis

This thesis is divided into five chapters.

Chapter 1: Conceptualising the study

Chapter 2: Review of relevant literature

Chapter 3: Research methodology and methods

Chapter 4: Results

Chapter 5: Discussion

Chapter 6: Conclusion and recommendations

CHAPTER TWO

Review of relevant literature

2.1 Introduction

The literature reviewed describes health system barriers to ART service delivery from the health system's and patients' perspective and their effect on retention in care and adherence programmes. Common differentiated models of care are discussed and presented and highlight different settings in which these models work or not. The chapter further summarises identified relevant knowledge gaps related patients' experiences in these models, which this study aimed to explore.

2.2 The Burden of the HIV epidemic on health systems

The health system experiences barriers to delivering adequate services to PLHIV globally (Ehrenkranz *et al.*, 2018; Khabala *et al.*, 2015). The burden of HIV/AIDS in the context of inadequate infrastructure, limited health human resources, lack of conducive working environment and medication stock outs constitute barriers to delivering adequate healthcare services in South Africa. These barriers lead to unmet health needs and delays in patients getting appropriate care. Failure of the health system to meet the supply and demand of healthcare services is contrary to what the National Development Plan optimistically described that by 2030 "each community will have a clinic with nurses who love caring for people" (RSA National Planning Commission, 2014).

HIV/AIDS has, over the years, emerged as a major health challenge. The burden of HIV/AIDS increased by 394% between 1990 and 2010, moving from the 33rd cause of burden in 1990 to the 5th cause of burden of disease in 2010 (Statistics South Africa (Stats SA), 2017). There is an unequal distribution of the HIV burden across settings and demographics and the majority of the disease burden is concentrated in countries with large number of the epidemic (Ware *et al.*, 2009). Although HIV is a global epidemic, Eastern and Southern Africa, Central Africa, the Caribbean and South East Asia carry the highest burden. In the Southern Africa region, South Africa has the highest number of PLHIV and the 4th highest adult prevalence rate (UNAIDS 2016). HIV continue to represent the leading cause of disability adjusted life years in South Africa, which is defined as a measure of overall disease burden expressed as the number of years lost due to ill health, disability or early death (Statistics South Africa (Stats SA), 2017; Mody *et al.*, 2018).

PLHIV need lifelong treatment, which places a significant strain on the health system. There is need for budget for continued drug supply, continued health follow-ups, laboratory and facility demands associated with the expanding HIV patient population. Weaknesses in the provision of the above may further lead to drug resistance and treatment failure, which additionally burdens the health system (Kharsany and Karim, 2016).

The health systems of countries in Africa still grapple with depleted human resources for health. Brain drain has been one of the many factors that has negatively affected the shape, function, and sustainability of the health system (Wu *et al.*, 2017; Tshuma, 2018). Brain drain refers the migration of trained or skilled people involved in activities primarily aimed at enhancing people’s health from their country of origin to work in other countries (WHO, 2006). The migration of health workers between cities and countries also poses as concern for service delivery as most rural areas suffer the brunt of limited human resources resulting in poor service provision. In light of the HIV epidemic, low-income countries have not been in a position to address the attrition of their scarce healthcare resources as health workers remain exposed to poor working conditions, congested health facilities and ever increasing demand of HIV patients (Mannell, Cornish and Russell, 2014; Wilkinson *et al.*, 2016). The stretched scarce human resources contributes to the drop in the quality of care. Shortage of staff reduces the rates of patient retention in care as patients wait in long queues owing to the inability of the health facility to serve the large volume of patients efficiently (Ssonko, *et al.*, 2017).

Poor and limited health infrastructure hinder health workers to perform at their best. Overcrowded facilities often function without access to reliable basic resources such as water and electricity and lack functioning quality assurance systems (Govindasamy *et al.*, 2014). This has pushed healthcare professionals to migrate to countries with fully equipped and functioning health systems thus severely affecting the already struggling health systems. With the increase in HIV epidemic, shortage of human resources for health has been one of the impediment to the successful implementation of HIV programmes (Long *et al.*, 2011; WHO, 2018).

Drug supply services have not been immune to the burden of HIV (Wilkinson *et al.*, 2016; Vogt *et al.*, 2017). An audit in one of the South African health facilities found deficiencies in pharmacy services regarding drug supply (Masquillier *et al.*, 2016). Reports on ARV stock-outs since 2009 have had devastating consequences as these stock-outs result in treatment interruption (Bannet et al, 2013). Public confidence in the ART programme may be compromised as patients are asked to return for their drugs, which is very costly and can affect adherence resulting in additional burden to the health system (Duncombe *et al.*, 2015a).

2.3 Health system barriers to ART service delivery

There are many factors influencing patients' access to ART services and ultimately influencing their adherence and retention in care. These have essentially had an effect on ART service delivery (Chesney, 2018; Davis *et al.*, 2018). Social, economic, cultural and religious factors have been pivotal in determining how patients perceive and access ART (Azia, Mukumbang and van Wyk, 2016). Poverty, lack of health insurance, high HIV-related stigma, poor social support, lack of disclosure, rural area residence have been identified as barriers to accessing care in South Africa (Bemelmans *et al.*, 2014; . Taking time off from work and paying for transportation to reach facilities is understood to strain patients who live below the poverty line to continuously engage in their ART (Mukumbang *et al.*, 2018; Wilkinson, 2013).

Long waiting-times, resulting from understaffed facilities and poor patient-provider relationships, were identified as impediments to accessing ART (Ware *et al.*, 2009). Patients continue to move from one clinic to another to avoid long waiting times, which impacts on their adherence and retention in care (Mukumbang, Orth and van Wyk, 2019). With the ever-increasing numbers of PLHIV on ART, concerns of overcrowding in the facilities are noted, which potentially expose them to infection such as Tuberculosis (Bango *et al.*, 2016). Geographic location often poses a constraint to access ART care for rural populations as they travel long distances to access their ART (Goemaere, 2016). Rural remote areas are often without access to basic services and are resource-limited forcing populations to travel long distance to where adequate services are.

Kriel (2017) in his thesis conceptualised the barriers to adherence and retention into categories comprising of: Individual-related factors such as age, mental health, forgetfulness, substance abuse, literacy levels and perceived health status. Medication-related factors focusing on side effects, treatment duration and dosage frequency. Health system-related factors such as access to ART, availability of medication, relationship with health care providers, and quality of services. Finally, he discusses socio-economic and cultural related-factors such as poverty, family support, transportation, disclosure, food, discrimination, stigma, religion and traditional health-seeking behaviours as having an impact on adherence and retention of patients.

2.4 Differentiated care models

In light of challenges PLHIV face with regard to remaining in care and adhering to medication, various strategies have been suggested to improve the ART care seeking behaviours of PLHIV. DCMs have shown potential to improve the experiences of PLHIV on ART by addressing the health systems-related barriers of ART. The successful implementation of DCMs have contributed in mitigating health systems related challenges as good outcomes have emerged after their implementation as evidenced by numerous studies (Long *et al.*, 2011; Lall *et al.*, 2015; Khabala *et al.*, 2015; Duncombe *et al.*, 2015a).

Different strategies are required for different contexts as there is no one-size-fits-all to reduce the burden for both health systems and patients when proving care in high HIV prevalence settings (Duncombe *et al.*, 2015b). According to Dibenedetto (2008) and Goemaere (2016), models should be context-specific and also informed by a range of factors such as individual patient barriers to retention; geographic barriers to accessing care; extent of service decentralisation; fast tracking of medication refills; HIV prevalence; capacity of health service and task shifting to lower health cadres.

Taking into consideration that HIV funding from global international organisations such as PEPFAR and the Global Fund have dwindled as the epidemic is coming under control in recent years, innovative models to provide efficient and cost-effective HIV programmes.

Differentiated care and treatment models employ a people-centered framework, which focuses on the needs of groups of people in an effort to improve service quality and access; adherence and retention outcomes; and efficiency and cost of services (Duncombe *et al.*, 2015b; Mukumbang, Orth and van Wyk, 2019). Different individuals in the HIV cascade require different types of services in terms of location of services provision, the provider of the service and the frequency of these service (Mukumbang *et al.*, 2017; Duncombe *et al.*, 2015a) thus the need to develop models of care designed to suit people's different needs and preferences.

Duncombe *et al.*, (2015a) state that differentiated care is driven by the desire to provide care which people will be easy to adopt and increase the effectiveness and efficiency of HIV care delivery. The delivery of care should be underpinned by the notions of flexibility, convenience and acceptability for both the patients and health systems (Long *et al.*, 2011; Pienaar *et al.*, 2006). The differentiated care framework advocates for 'the delivery of the right care, at the right frequency, to the right individuals, by the right care providers, in the right location and at the right time" (Duncombe *et al.*, 2015a).

The needs of the patients stable and adherent to ART are different from those who are clinically unstable and non-adherent (Wilkinson *et al*, 2016). There is a strong link between close proximity to the health facility, user-friendly facilities and retention in care (Goemaere, 2016; Médecins Sans Frontières and UNAIDS, 2015). Poor adherence and people leaving care has been mainly influenced by long distance to the facility and associated transport costs, payment of services in some contexts, long queuing and waiting times and the impact on competing demands, where one needs to be at work to support their family. A look into facility clinical conditions, social and economic situations of patients, urban and rural settings, patient mobility patterns, educational levels (Duncombe *et al.*, 2015a; Mukumbang, Orth and van Wyk, 2019) may contribute to the improvement of patient retention and care outcomes (Wilkinson *et al*, 2016; Ware *et al.*, 2009). According to Bannet *et al*, (2013), there is no 'one size fits all' strategy to reduce the burden for both the health system and patients when providing HIV care to an ever-increasing population. They allude that selecting the suitable model of care have to be context specific and dependent on individual patient's barriers to retention in care.

The implementation of differentiated care will vary according the populations and context so as to best serve individual needs (Decroo *et al.*, 2012; Duncombe *et al.*, 2015a; Ehrenkranz *et al.*, 2018). These models of care are often organised according to three categories which are mainly detected by the location at which people will receive their care. The overall aim remains to maximise the benefits for both patients and health care services (Medecins Sans Frontiers, 2014; Goemaere, 2016).

2.4.1 Centralised models

Facilities can provide flexible models of ART care within the facility by adjusting the frequency by which patients pick their ART refills and also task shifting service provision to lay cadres to allow clinicians to focus more on new and failing patients (Wilkinson, 2013). The Western Cape Differentiated Models of Care Policy Framework (WCDMCPF) (2017) recognises two DCMs at facility level: FACs and QPUP.

Quick pick up models

Quick pick-up (QPUP) fast track models allow patients to collect their medication from a 'fast track' window at the pharmacy or other designated facility venues. The key principles to this strategy is that patients have direct access to an ART dispenser for individual drug refill, thus reducing their frequency of clinical consultations. QPUPs are often combined with longer duration of medication supply to accommodate for longer periods, for example two months' supply as opposed to the standard one month's supply. This is a model of care for clients to quickly collect their treatment (Tshuma, 2018; Davis *et al.*, 2018). Implementation of the QPUPs allows patients, instead of patients having five clinical appointments per annum, only have one with the other four appointments scheduled to pick up their medication (WCDMCPF, 2017).

Facility-based Adherence clubs

This Facility Adherence Club (FAC) model is facilitated by lay counsellors and managed by nurses (Goemaere, 2016). Between 25 -30 patients, depending on context, are recruited into FACs if they are above 18 years, stable on treatment, have good clinic attendance records with the most recent viral load undetectable (<400 copies/mL) (Khabala *et al.*, 2015). Club patients meet every two months and during these sessions, they receive brief health screening and weight checks. Short health education talks are given and medication is distributed by the lay counsellor (Mukumbang *et al.*, 2017). Patients in these models benefit from group care and spend less time waiting to collecting their medication as their medication is usually available at each session (Mukumbang, Orth and van Wyk, 2019). The model is flexible in the sense that patients may send people to collect their medication packages on their behalf and only attend on their annual blood and clinical consultation visits.

2.4.2 Decentralised models

Decentralised options of care include community options and out-of-facility care where patients are initiated and managed out of the premises of the health facilities. DCMs provided further into the community including patients' homes include Community ART Adherence Clubs (CACs), Home-based ART Adherence Clubs, Community ART Groups (CAGs), Alternative Community Drug Distribution Sites, and Wellness Hubs (Goemaere, 2016).

Accessing treatment closer to their homes has been one of the benefits of community models of care (Goemaere, 2016).

Community-based Adherence clubs

Community Adherence Clubs (CACs) are similar in form and function to FACs but for that they are located outside of the facility premises. Another crucial difference is that CAC patients return to the facility for their annual blood draws and clinical consultation (Mukumbang, Orth and van Wyk, 2019). CACs can take place offsite close to the facility in community venues such as libraries and community halls. They can also be located further from the facility in the community closer to people's homes. Venues such as community venues and people's homes are common venues used. Depending on size of the venue, CACs can have membership of fifteen to thirty patients.

Community ART groups

Community ART Groups (CAGS*)* are self-formed groups of four to eight stable ART patients from the same community area. Each group elects a group leader, who acts as the group reference person responsible for the organisation and information exchange between members. Group members rotate the responsibility of going to the clinic to collect ARVs refills for all members of the group thus reducing patient frequency to the facility (Mannell *et al*., 2014; Rasschaert *et al*., 2014). The main objective of the model is to facilitate access to ART care to save time and money. The cost and time saving benefits have contributed to improved treatment outcomes as patients find mutual adherence support and protective environment. The model addresses social drivers of HIV resulting in active patient involvement and participation in health activities, decreased stigma and better HIV awareness in the community, improved health seeking behaviours and better quality of care (Duncombe *et al.*, 2015a; Decroo *et al.*, 2012). Patients present at the facility or are referred by other CAG members when they experience other health problem in the community. Regular supervision visits from facility staff (clinician and counsellor) take place to link people into the group, create and monitor group dynamic, and strengthen CAGs- facility linkage (Goemaere, 2016).

Community drug distribution points

Community Drug Distribution Points (PODI) are ART distribution points managed by PLHIV who are trained to provide ART refills, adherence support and follow-ups. The eligibility criteria of being enrolled in a PODI is being six months on ART, no opportunistic infections and considered stable and eligible to participate in the model. This model is popular in rural settings where health services are very far from the people and where transport costs outweigh people's means (Medecins Sans Frontiers, 2014; WHO, 2018). They also offer a quick and easy access to ART to patients as a care option.

Central Chronic Medical Dispensing and Distribution

South Africa has established the Central Chronic Medical Dispensing and Distribution (CCMDD), which is similar to the PODI in an effort to move ART to communities and decanting congested facilities (Long *et al.*, 2011). These have been very popular and successfully implemented in rural KwaZulu Natal and Limpopo provinces. Patients attend distribution points every three months for drug refill and present at the facility annually for blood draws and comprehensive clinical consultation. Referral to the facility is done by PLHIV lay workers who are the points of contact from the community. Defaulter tracing is done through phone calls and commonly through network of local support groups. Patients at community ART distribution points spend on average 12 minutes collecting ART refills, seven times less than patients receiving ART at a health facility (Jouquet, 2011).

Not only are the patients able to decongest the facility's waiting room when joining these models, these groups provide social support to patients and have been empowered through sharing their journey with their peers who are in the same situation as them (Wilkinson, 2013). Studies have shown that such groups have resulted in stress reduction associated with lifelong treatment and has boosted patients' self-esteem and adherence. A supportive network is established and patients do not feel isolated and alone (McGregor, et al, 2016; Medecins Sans Frontiers, 2014). Table 2.1 summarises DCMs as discussed in the above and illustrates the different benefits of both the health and patient perspectives; concurrently highlighting the different resources for the model to be effective.

Table 2.1: Summary of Differentiated Care Models for ARV collection

Key objective		**ART Adherence Clubs**		**Community ART Distribution Point (CADP)**	**Community ART groups (CAG)**	**Quick pick up at Health /Community facility**
		Facility-based club	**Community-based club**			
Patient Perspective	Reduce cost (time + transport)	• Reduction of clinical visit • Less time spent at clinic for drug refill	• Reduction of clinical visit • Less time spent a clinic for drug refill	• Reduction of clinical visit • Less time spent at clinic for drug refill	• Reduction of clinical visit • Less time spent at clinic for drug refill	• Reduction of clinical visit • Less time spent at clinic for drug refill
	Increase peer support	At club in health facility and potentially beyond into community	At club in community and beyond	At distribution points by expert patients	At CAG meetings in community and beyond	No
	Enhance community participation	No	Potentially	Potentially	Potentially	No
Healthcare service perspective	Reduce workload • Nurse • Pharmacist • Counsellor/CHW Expert patient	Yes No No (facilitate on by club)	Yes No No (facilitation by club)	Yes Yes No (Distribution and monitoring)	Yes Yes No (formation, training and supervision of CAGs)	Yes No No
	Maintain/improve health outcomes • Adherence • Retention	Yes Yes	Yes Yes	Unknown Yes	Unknown Yes	Yes Yes
	Improve self-management of patient	Adherence support	Adherence support and tracing	Organisation of service for drug refill, adherence support, tracing and testing	Drug refill, adherence support, tracing and testing	Yes
	Decongest facility	No	Yes	Yes	Yes	Yes

2.5 Understanding how, why and under what contexts DCMs work

Considering that this study focuses on patients' experiences in DCMs in a local health facility, there is need to zoom into what aspects of these models works, for what patients, in which settings and for what health services conditions (Mukumbang *et al.*, 2019). There are five modalities associated with the adherence club model intervention and these could be generic to other DCMs interventions such as CAGs, CCMDD and QPUP.

According to Mukumbang *et al.* (2018; 2019), for the adherence club interventions to work, the following need to be in place; (1) convenient space for meeting and venues for pick up points. (2) Continuous support of the facilitator by the clinician is vital to offer quality services and linkage. (3) Buy in from both the health facility and the community is pivotal to the successes of the intervention. The authors suggested that 'an intervention that groups clinically stable patients on ART in a conducive space to receive a quick and uninterrupted supply of medication, health talks, counselling and immediate access to a clinician when required works because patients' motivation, self-efficacy and self-management improve'.

Lack of conducive space or venue to access medication is an inconvenience to the patients as it exposes them to inadvertent disclosure and contributes to non-adherence and poor retention (Mukumbang *et al.*, 2019; Grimsrud, Lesosky, *et al.*, 2016). What make DCMs work is the availability of standard operating protocol (SOP), which guides the operational aspects of the intervention (Mukumbang *et al.*, 2019). The guidelines are able to direct patients on what to and what not to do to remain in the model's care. For example, patients need to be adherent to their appointment dates; they may send someone to collect the medication on their behalf. Failure to do that in five days renders the patients a defaulter and is taken out of the model of care (Wilkinson *et al*, 2016). The availability of personnel to support the day-to-day activities of the interventions is vital to DCMs' success (Decroo, Mondlane, Dos Santos, Dezembro and das Dores, Cumba, Remartinez, 2012). This includes, availability of medication, which is at the centre of the intervention's success.

There are five modalities associated with the DCMs, model rules and regulations, group dynamic and groupthink, social support, quick medication pick-up and health talks, facilitator/ patients relationship (Mukumbang *et al.*, 2019). The model rules govern the functioning of the model and patients are reminded of these on each visit. These rules direct the entrance into and exit from the model and patients follow these so they do not lose the benefits of the model ; Mukumbang *et al.*, 2018). Grouping of patients stimulates formation of relationships among members and construct social support for their lifelong medication journey (Ssonko, Gonzalez, Mesic, Da Fonseca, *et al.*, 2017; Mukumbang *et al.*, 2019). Quick medication pick is one of the modalities that address long waiting times (Wilkinson, 2013). This has been one of the most important benefit of the in an AC and it motivates patient to be adherent and retained in care. Health talks in adherence clubs constitutes a form of empowerment and motivation for self-efficacy and self-management. Patients are empowered with health information, which enhances treatment literacy (Mukumbang *et al.*, 2018; Ssonko, Gonzalez, Mesic, Da Fonseca *et al.*, 2017). The interactions with health workers provide a platform for psychosocial support as patients receive support and encouragement when they are experiencing stigma, medication side effects and any other obstacles (Mukumbang *et al.*, 2019).

For health interventions to work, the user plays a pivotal role. With the health system providing a health service, the responsibility lies with the patients in adopting and making use of the resources, services and opportunities provided in adherence and retention enhancing interventions (Mukumbang *et al.*, 2019). Effective and active participation of patients in these interventions is pivotal to their success.

2.6 Benefits of differentiated care models

The WHO and UNAIDS guidelines have been pivotal in supporting innovative thinking on addressing issues around HIV adherence and retention in care. These organisations have been central in spearheading the out-of-facility and community engagement approaches in the delivery of ART to improve viral suppression and retention (IAS, 2016). Social support and improved adherence to treatment relationship has been established through the use of these models.

Outcome-based evaluations show that DCMs improve the rates of retention in care and adherence to medication compared to the standard clinic ART programme (Luque-Fernandez *et al.*, 2013; Grimsrud *et al.*, 2015; Tsondai *et al.*, 2017; Barker *et al.*, 2017, Bongo *et al.*, 2016). Implementers of DCMs suggest that they also decongest public health care facilities (Mukumbang *et al.*, 2016). In Tanzania, community-based volunteers, who deliver ART drugs at the community-level highlighted that fewer patients were lost in follow-up in these models. Community-based ART delivery models in Uganda matched the positive outcomes in the facility-based ART on retention and viral suppression (Barker *et al.*, 2017; Lall *et al.*, 2015). Zimbabwe and South Africa have adopted Community ART groups, which have been very successful in retaining patients on treatment and virally suppressed (Bango *et al.*, 2016).

The relationship between social support and improved adherence to treatment has been established using the DCM models. DCMs facilitated a community-based treatment social support network, which empowered patients to continue taking their treatment as they had peer support (Goemaere, 2016). Other studies have found that DCMs provide patient support and improve their adherence to treatment (Agaba *et al.*, 2018). These models have also been found to empower patients to self-management their disease delivery (Mukumbang *et al.*, 2019).

In a qualitative study exploring the experiences of ART patients in accessing care in Nigeria, Agaba *et al.* (2018) uncovered that difficulty and cost of travelling remained a fundamental barrier to accessing HIV care outside urban centres. The findings suggest that increased availability of community-based ART services was appreciated by the communities in such areas to counter the barriers as the majority of participants preferred decentralised service provision. With multi-months prescriptions, fast-track refills and community ART groups, patients managed to pursue their daily activities while taking their treatment. On the health system side, there was a reduction in patient load as clinicians focused on new cases and failing patients, with stable patients being managed in DCMs (Prust *et al.*, 2017).

Several studies show that DCMs are cost-effective not only to the patients but to the health system as well. Tsondai *et al*. (2017) established that the adherence club model was more cost-effective compared to mainstream delivered ART care. Barker, Dutta and Klein (2017) also established that there are significant efficiency gains in terms of reduced costs and health workforce needs when DCMs are used to deliver ART care.

In challenging operational environments such as where there are conflicts, wars and natural disasters, the provision of basic healthcare needs is disrupted resulting in multiple health needs (Ssonko, Gonzalez, Mesic, Silveira, *et al.*, 2017). MSF successfully implemented DCMs in South Sudan, Central African Republic (CAR), Mozambique and Democratic Republic of Congo (DRC) and had great outcomes. Patients interviewed in these studies remarked that the

DCMs gave them access to care through their emergency remote programmes (Medecins Sans Frontiers, 2014).

2.7 Issues to consider on differentiated ART delivery models

DCMs are health systems innovations designed to bring ART closer to where people are, respond to patients' different needs and to harness the ever-increasing number of people on ART in resource-limited settings (Wilkinson, 2013). Decongesting health facilities and giving patients options of care that suit them have been presented as the characteristics of DCMs worth scaling up. Although DCMs have shown positive attributes, there is, however, the need to recognise the risks that comes with task-shifting and scaling up. Human resources as well as medical resources such as supply of drugs need to be stable and coordinated to support the smooth running of the models (McGregor *et al*., 2018). Sufficient and reliable resources should be at the centre of the planning and implementation of DCMs (Wilkinson, 2013).

Implementing DCMs should address the needs of populations and take into consideration their social, economic, cultural and environmental aspects, which will have an impact on the way they perceive the intervention and their participation (IAS, 2016). The South African National Health Act, Act 61 of 2003 supports this notion by stating that patients who are treated with dignity and are well-informed and able to participate in treatment decisions are more likely to comply with their treatment plans. Strategies that put emphasis on the needs and attitudes of patients, to enhance the use of preventive services and improve management of chronic conditions have been found to be successful approaches to encourage patient participation and inclusion in the health system. Thus, this study focused on DCMs as an approach to addressing the needs of PLHIV on ART.

2.8 Gaps identified

The chapter has highlighted the DCMs implemented in different settings and contexts expounding on their benefits to both the health system and the patients. While various evaluative studies (Medecins Sans Frontiers, 2014; Bannet, *et al*, 2013; Mukumbang *et al.*, 2017) have shown that DCMs improve the retention in care and adherence to medication behaviours of patients on ART, little is known of their experiences of using these DCMs. There has been limited research exploring patients' experiences in DCMs. Furthermore, patients' experiences have not been compared across models. Thus, this study will address these gaps by exploring and comparing patient experiences in DCMs. In addition, while conducting a systematic review, on differentiated ART delivery models, Davis *et al.* (2018) identified gaps in understanding the desirability of these models for PLHIV. To this end, in this study, explored the experiences of PLHIV using three forms of DCMs – CACs, FACs and QPUP.

2.9 Concluding remarks

The chapter introduced the DCMs approaches and interventions that have been implemented in different contexts in an effort to get patients adherent to their treatment and retained in care. Barriers which hinder patients' access to ART were highlighted. Examples of DCMs were outlined and their functionality discussed. The benefits of DCMs were further discussed and how their scale-up and replication could benefit both the burdened health system and patients. The notion that DCM as a framework aims to streamline services offered to patients in order to improve patients' experiences within the health system and enhance long term retention in care is critical in fighting HIV. Thus, the need for continued financial and technical support in sustaining DCM programmes. Investment in DCMs may potentially achieve broader impact in transforming health care services (Wilkinson et al, 2016).

CHAPTER THREE

Methodology

3.1 Introduction

This chapter describes the methodology that informed this research study. The research design that was used is explained and justified. Study setting, study population, data collection, data analysis and data verification are discussed.

3.2 Research Design

An exploratory/descriptive qualitative research study design was used to explore the experiences of people accessing ART through DCMs. Exploratory research study design aims to identify the boundaries of the environment in which problems, opportunities or situations of interest are likely to reside and to identify salient factors or variables that might be found there (Van Wyk, 2016). According to Lambert and Lambert (2012), the goal of qualitative descriptive studies is to provide a comprehensive summarisation in everyday terms, of specific experiences of individuals and groups of individuals. Baum (1995) reported that qualitative research methods allow the researcher to document and interpret the different ways in which people make sense of their experiences of health and disease.

3.3 Study Setting

Michael Maphongwana clinic is a Community Health Centre in Khayelitsha, which was identified by the Khayelitsha-Eastern Sub-Structure management in November 2015 to pilot three DCMs, FACs, CACs and QPUP. As of June 2017, Michael Maphongwana CHC had

7091 patients retained in ART care. Of these, 2483 were retained in the adherence club care amounting to 35% of patients getting their care in either FACs or CACs. The facility has 110 adherence clubs 50 CACs and 60 FACs. The QPUP model has 28 groups of patients with each group having on average 45 patients. Total patients retained in QPUP as of June 2017 was 1054 amounting 15% of total retention in care.

The Michael Maphongwana facility was selected because it is one of the facilities in the sub-structure with the highest HIV cohort and waiting time for patients was high as patients wait between two and four hours to be seen by a clinician. Most of the patients on ART are stable patients. The adherence club model in the facility had reached maximum capacity as determined by the available resources, putting its quality of care at risk. The facility consequently introduced the CACs model and the QPUP to further decentralise ART delivery and broaden patients' preferences on the option of care to reduce clinic congestion.

3.4 Study population

The inclusion criteria of the study population were PLHIV (18 years plus) who at the time of the study were receiving ART in a differentiated ART delivery model at the Michael Maphongwana clinic since 2015. The facility has 60 FACs, 50 CACs and 28 QPUP and the study participants were selected from these models to represent the respective samples. The researcher randomly selected two facility-based adherence clubs, two community-based adherence clubs and two QPUP groups for interviews, depending on the clinic scheduling of appointment dates.

3.5 Sampling

Purposive sampling was used to recruit participants for the study. Alkaabi (2017) defines purposive sampling as the selection of individuals and groups of individuals based on specific purposes associated with answering a research study question. This allowed the researcher to focus on the specific category of individuals who were knowledgeable about the issue under consideration. This sampling approach intended to maximize the chances of getting rich information about PLHIV's experiences and perceptions in the differentiated models of care (Robson, 2011).

The researcher purposively selected 6 to 10 PLHIV from the three different models provided in the facility: two facility clubs, two community clubs and two QPUP groups, for participation in focus group discussions (FDGs). Four patients who participated in the FGDs were selected from each model to participate in individual one-on-one in-depth interviews. Participants were included based on the following criteria (1) were enrolled in one of the differentiated ART delivery models and (2) had been receiving care for more than six months.

Participants were approached during a model visit and informed of the study. Those who consented to participant were informed of their potential participation in a FGD session for their next appointment. Participants identified by the researcher during the FGDs to have rich information as required by the study objectives were purposely selected to take part in one-on-one interviews. Therefore, in addition to the FGD, four participants from each model participated in-depth interviews. The selection of these participants was to explore individual reflections on their experiences in using the particular model.

3.6 Data collection

The researcher collected data through FDGs and semi-structured interviews. Marshall and Rossman (2006) state that to understand human behaviour, one has to understand the dimension in which participants interpret their thoughts, feelings and actions. With this in mind, in-depth interviews were a feasible option in exploring the participants' experiences and their thoughts on differentiated care. Discussion and interview guides were used for the FGD and the in-depth interviews respectively. The researcher conducted each discussion or interview session at the clinic in a prearranged room and each session was recorded using a tape recorder with permission from the study participants.

3.7 Data analysis

The researcher used the Framework Method for the analysis of the data. The Framework Method is a part of the family referred to as thematic analysis (Gale *et al.*, 2013).

Transcription – The researcher transcribed the recorded interviews verbatim in isiXhosa and translated by the researcher to English who is fluent in both languages. This process also provided the researcher an opportunity to be immersed in the data.

Familiarisation with the interview **–** The researcher became familiar with the recording and transcripts by continued listening and reading of transcripts. Contextual or reflective notes were recorded during the interviews and these assisted the researcher in data interpretation.

Data coding - A CASQDAS (Computer Assisted Qualitative Data Analysis Software), Atlas.ti version 11 was used to manage the data analysis. The researcher carefully read the translated transcripts line by line (open coding). She summarised and paraphrased (coded) what she interpreted from the passages read. Coding everything that deemed relevant to the gist of the study from different perspectives was done.

Developing a working analytical framework – Codes were grouped into categories and clearly defined. This was helpful for the researcher as she managed to also think around different themes that could inform the data interpretation.

Applying the analytical framework – This was done by indexing subsequent transcripts using existing categories and codes of the dataset. The indexing of the open coded data was informed by the National Health Services (NHS) Patient Experience Framework (discussed below).

Charting data into the framework matrix – Charting the data involved summarising data from each transcript by the categories of the NHS Patient Experience framework.

Interpreting the data – interpreting data is useful through-out the research. The researcher had a notebook to write down impressions, ideas and anything of interest. This was helpful for the early interpretation of data. This also allowed the researcher to break-off at any stage to explore interesting idea, concept and potential theme (Gale *et al.*, 2013).

3.8 Theoretical framework

The NHS Patient Experience Framework (outlined in table 2) was used to explore the experiences of PLHIV using the different DCMs in this study. This framework guided the data analysis and the comparison of the experiences of patients in the three differentiated ART delivery models. The framework outlines crucial and critical elements to patients' experiences of NHS services.

Table 3.1: Elements of the Patient Experiences Framework

Aspect	Example
Respect for patient-centred values, preferences, and expressed needs	Cultural issues; the dignity, privacy and independence of patients and service users; an awareness of quality-of-life issues; and shared decision making;
Coordination and Integration of care	Health and social health care system
Information, communication and education	Clinical status progress, prognosis and processes of care, so as to facilitate autonomy, self-care and health promotion
Physical comfort	The venues and settings where patients access their care
Emotional support	Social/peer support, alleviation of fear and anxiety about clinical status and the impact of the illness on patients, their families and finances
Welcoming the involvement of family and friends	Whom patients and service user rely on decision making and demonstrating their awareness and accommodation their needs as care-givers
Transition and continuity	The information that will help patients care for themselves away from a clinical setting; coordination, planning and support ease transition

NHS views the need to engage with communities and citizens directly in new ways and directly involving them in decision making in issues affecting their healthcare services. Access to information and knowledge by patients regarding their care enables patients to own their healthcare enables them to truly embrace the opportunity to become partners and engage in decision making that affects their care (Wellings and Evans, 2013). Involving patients as partners in their care will support strong and confident response to their care and create an environment where people’s perspectives are valued and acted upon (WHO, 2018). The following are the Principles of the NHS Framework.

3.8.1 Respect for patient-centred values, preferences, and expressed needs

WHO (2018) states that a people-centred approach is an approach to care that consciously adopts the perspectives of individuals, carers, families and communities as participants in and beneficiaries of trusted health systems that are organised around the comprehensive needs of people rather than individual diseases, and that respect social preferences. Facilitating a patient-centred perspective will improve high quality services, assist in people getting desired care services, allow patients to be actives in looking after themselves and reduce pressure on health and social services (NSHIII, 2013). The study explored if patient-centred values, preferences and needs were considered in their choice of particular DCM model.

3.8.2 Coordination and Integration of care

Coordination of care relates to a situation where health and social healthcare systems speak to each other. WHO (2018) states that the continuity and coordination of care addresses the conditions and ongoing relationships needed to support seamless interactions among multiple providers within interdisciplinary teams and/or across care settings and/or sectors. This is a proactive approach to bringing together care professionals and providers to meet the needs of service users to ensure that they receive integrated, person-focused care across various settings. The study thus sought to understand how DCMs ensured coordination and integration of care.

3.8.3 Information, communication and education

This aspect of patient care considers patients' clinical status progress, prognosis and processes of care to facilitate autonomy, self-care and health promotion. Empowerment and support through sharing of information and education of people in taking control of their own health, resulting, for example, in healthier behaviour or self-management of illnesses is one of the objectives of NHS. Communication in a healthcare setting is one of the most important tools we have for providing great patient care and improving patient satisfaction. The South African Policy (RSA, 2007) states that informing patients and educating them on the importance of their participation and partnership in the health system will improve the effectiveness and their satisfaction of care. Patients in the DCMs were asked if they had enough information pertaining to the model they were in.

3.8.4 Physical comfort

Patient comfort relates to the venues and settings where patients access their care as pivotal in accessing their care. Healthcare facilities are places where patients with health conditions go for treatment, thus the need for them to be user-friendly. The environment can facilitate or discourage interactions among people (and the subsequent benefits of social support). The environment can influence peoples' moods, behaviour and motivation to act; and these can play a crucial role in improving health outcomes. The study explored the environment or setting in which these models operated from as this informed reception or not, of the particular DCM.

3.8.5 Emotional support

Emotional support is important for the alleviation of fear and anxiety about clinical status and the impact of the illness on patients, their families and finances forms part of a bigger picture in their access of care. Support groups for HIV/AIDS have been pivotal in providing a safe and confidential space where individuals can express themselves in an atmosphere of mutual respect and encouragement. Patient-related, structural and provider-related factors need to be adjusted to enhance adherence and ultimately, retention in care. This was one of the pivotal aspects of the research to address social empowerment and support as ART is lifelong medication.

3.8.6 Welcoming the involvement of family and friends

Involving family and friends to patients' care and decision making is crucial for better health outcomes. The health system should demonstrate patients' awareness and accommodate their needs to organise, manage and deliver care that best meets people's comprehensive health needs, irrespective of setting or social status. The South African polity on Quality Assurance views community participation, where not only individuals are encouraged to participate in their healthcare, but also whole communities is pivotal in achieving better health outcomes. The importance of community action has been clearly demonstrated in the fight against HIV/AIDS (RSA, 2007).

3.8.7 Transition and continuity

Transition and continuity relate to the availability and accessibility of information that will help patients care for themselves away from a clinical setting. Appropriate coordination, planning and support to ease the transition as patients self-manage outside of the routine health system should be enhanced (NHS, 2016). The continuity of relationships between the healthcare system and patients empower, enable and increase adherence to treatment by creating the conditions for better support of people in understanding and managing their conditions, thus increasing patient satisfaction.

3.9 Rigour and trustworthiness

Rigour in qualitative research designs refers to the strategies the researcher adopts to achieve, ensure and establish confidence in his/ her design its findings (Malterud, 2001). The researcher used the notions credibility, transferability, dependability and confirmability to establish rigour and trustworthiness (Lincoln and Guba, 1985).

Credibility is the confidence that can be placed in the truth of the findings. Shenton (2004) and Creswell and Miller (2001) suggest that credibility establishes if findings represent plausible information drawn from participants' original data. The researcher used 'audit trail', which means that she provided information and took the reader from events in the field and personal reflections of the study through reflexivity. Peer examination, peer debrief and member checking, where the participants give feedback and validation were used to encourage confidentiality.

Transferability is the degree to which the results of the research can be transferred to other contexts with different participants altogether (Mays, 2000). Transferability could be ensured through providing 'thick description' and conducting 'purposeful sampling'. The researcher provided a detailed description of the enquiry from the study context and data collection to the presentation of the final report.

Dependability refers to the ability of the enquiry to ensure that the researchers' evaluation, interpretations and recommendations are supported by the data received from the informants of the study (Anney, 2014). The researcher provided a detailed account of how the data was collected, recorded, analysed and safely kept to enable cross checking (Shenton, 2004). The researcher used the support from her supervisor and colleagues. This stimulated guidance and improved the quality of the enquiry. The researcher presented the study processes to peers in the Operational Research platform at her workplace to receive comments and feedback.

The degree to which the findings of the enquiry could be confirmed or corroborated by other researchers is referred to as confirmability in qualitative research (Moon *et al.*, 2016). This was achieved through an extensive literature review before and after the study.

3.10 Ethics considerations

Ethics approval for the study was obtained from the University of the Western Cape Biomedical Research Ethics Committee (BMREC) and Department of Health. The following relevant ethical issues were addressed in the study:

Informed consent – The researcher gave participants a detailed background of the study to recruit them (Strydom, 2013). A consent form was signed to obtain permission from the participants and to emphasise confidentiality of the shared information.

Confidentiality – Reamer (1998) views confidentiality as central to research, hence, it has to be promoted at all times so as to gain trust from respondents. Participants were assured of the confidentiality of the information they shared. Pseudonyms were used to ensure confidentiality when reporting or presenting the findings of the study.

Voluntary participation – Reamer (1998) describes voluntary participation as the free will to participate and withdraw by the individual in an interview process. The researcher informed participants at the start of each interview and through the signing of a consent form that they were free to withdraw from the interview without any consequence should they decide. Permission was sought and given by the Provincial Department of Health to access the Community Health Facility.

Data storage and distraction – To protect the privacy and confidentiality of the participants, the researcher arranged safe storage of collected digital data in the password protected computer. Adequate data back-up arrangement was set up by the researcher through a password protected hard-drive which was only accessible to the researcher and her supervisor. As stipulated by the University of Western Cape Policy on research ethics, if no publication based on the data set have appeared within the last five years, the stored soft data set may be physically destroyed by the researcher.

3.11 Chapter conclusion

This chapter described the methodology that informed this research study. The research design that was used was explained and justified. Study setting, study population, data collection, data analysis and data verification was discussed. Presentation and discussion of the findings will be done in the next chapter.

CHAPTER FOUR

Results

4.1 Introduction

This chapter presents a description of the study participants and the results of the Framework Analysis of the transcribed focus group discussions and in-depth interviews with patients in the three Differentiated Care Models in a community health care (CHC) facility.

4.2 Characteristics of Participants

The study sample consisted of 59 participants, of which 24 were male and 35 female (Table 4.1) and between the ages of 25 and 56 years. Of the total participants, 40 were formally employed with 19 not formally employed but earned a living by selling items such as second-hand clothes, fruit and vegetables, groceries and alcohol. Some participants, however, depended on their children's social grants for survival. Looking into relations, 26 participants were single and 21 stated that they were married. Seven were in relationships, one divorced and four widowed.

It is clear from the socio demographic characteristics of the participants that the majority were employed or involved in some kind of economic activity which translates to DCMs allowing the flexibility for them to pick up their medication but continue with their day-to-day activities.

Table 4.1 Socio-demographic Characteristics of Participants

	QPUP	CAC	FAC	TOTAL
Gender				
Male	8	10	6	**24**
Female	10	13	12	**35**
Age (in years)				
25 – 35	5	6	5	**16**
36 – 45	8	12	6	**26**
46+	5	5	7	**17**
Marital Status				
Married	8	8	5	**21**
Single	6	10	10	**26**
Divorced	0	1	0	**1**
Widowed	1	2	1	**4**
In a relationship	3	2	2	**7**
Employment Status				
Employed	14	15	11	**40**
Unemployed	4	8	7	**19**

QPUP: Quick Pharmacy Pick- Up**, CAC:** Community Adherence Club**, FAC:** Facility Adherence Club

4.3 Summary of Themes and Sub-themes

The NHS Patient Experience Framework was used to explore the experiences of patients using the different DCMs in this study. The NHS's seven principles were used as categories for analysis. Themes emerged from the sub-themes, illustrating the different experiences of patients in the DCMs in relation to the NHI framework. The themes and sub-themes were used to direct the presentation of results (**Table 4.2**).

Table 4.2 Themes, sub-themes and codes

CATEGORIES	THEMES	SUB-THEMES
Respect for patient centred value, preferences and expressed need	- Selection of model of care as preference and expressed need	- Model selection - Quick service - Shorter waiting times - Easy access to medication - Flexible - Buddy support
	Service delivery as patients' expressed need	- Effective service rendered
	Addressing patient needs	- Patient-centeredness
	Self-management as a patient centred value	- Patient empowerment
Coordination and integration of care	Amalgamation of Complementary services in DCMs	- Health promotion - Psychosocial support
Information, communication and education	Provision of health education	- Health empowerment
	Relationship with facilitator as an information and communication tool	- Psychosocial support
Physical comfort	Venue/location convenience	- Safe space - Good infrastructure
	Environment convenience	- Stigma free environment - Safety
Emotional support	Camaraderie	- Peer-to-peer support - Psychosocial benefits - Group empowerment
Welcoming the involvement of family and friends	Inclusion of the social structure (family and friends) as psychosocial support	- Coping mechanisms - Family support
Transition and continuity	Allocation of health practitioner to support running DCMs	- Clinical support system
	Supporting mobility of patients (migration period)	- Longer supply of medication (festive season)
Access to care	DCM visit preparation	- Easy access to ART medication
	Travel to point of DCM care	- Easy access to point of care

Table 4.3 Comparison of Codes in the 3 Differentiated Care Models

Identified codes based on patients' experiences	FACs	CACs	QPUP
Respect for patient-centred value, preferences and expressed need			
• Model selection	√	√	√
• Quick service	√	√	√
• Shorter waiting times compared to standard clinic care	√	√	√
• Easy access to medication	√	√	√
• Flexible	√	√	√
• Buddy support	√	√	√
• Effective service rendered	√	√	√
• Patient-centeredness	√	√	√
• Patient empowerment	√	√	√
Coordination and integration of care			
• Health promotion	√	√	X
• Psychosocial support	√	√	X
Information, communication and education			
• Health empowerment	√	√	X
• Psychosocial support	√	√	X
Physical comfort			
• Safe space	√	√	X
• Good infrastructure	√	√	-
• Stigma free environment	√	√	-
• Safety	√	√	-
Emotional support			
• Peer-to-peer support	√	√	X
• Psychosocial benefits	√	√	X
• Group empowerment	√	√	X
Transition and continuity			
• Clinical support system	√	√	X
• Longer supply of medication (festive season)	√	√	√
Access to care			
• Easy access to ART medication	√	√	√
• Easy access to point of care	X	√	X

√: Yes X: No : Not applicable

4.4 Respect of patient-centred values, preferences and expressed needs

It is paramount that healthcare systems facilitate patient-centred values, preferences and expressed needs to have better health outcomes. Themes identified in this category include model of selection with quick service and shorter waiting times, easy access to ART medication and the general flexibility of the models in aligning to patients' day-to-day activities. These sub-themes and emerging codes thereof highlight the importance of facilitating patient-centred values, preferences and expressed needs. Patients in the study highlighted the different benefits and efficiencies of the DCMs in relation to their day-to-day activities and their access to medication.

4.4.1 Preferences

Patients in the FACs indicated that the selection of patients to join the model did not actually follow the notion of patient preferences. According to most participants in the FACs, they were not offered the opportunity to choose which of the three DCMs they preferred as only the FACs existed. The following excerpts from patients using FACs support this notion.

> I did not choose the club. I was told to come here by the nurse after seeing that I was up-to-date with all my appointments and my blood results were always good and that the club was very easy and quick than in the clinic. That is how I joined the club. (Male, FAC)

> I was told I was doing well my dates of coming to the clinic. They told me that there was something called a club where you get your treatment easy unlike queuing for long hours in the clinic. (Female, FAC)

Although the whole range of DCMs was not in operation in the early stages, patients were offered the choice between joining the FACs or remaining in the main stream care or at least, they were presented with the opportunity to leave the mainstream care and join the FACs. A female participant had this experience:

> For me, the nurse asked if I liked waiting and sitting all day waiting to access the services. I told them I did not like it. They then asked me if I could join the club and I said I would be very happy to. She then explained to me about the club how it works and all its benefits and then I joined. (Female, FAC)

Patients receiving care in CACs and QPUP models were, unlike FAC patients, were offered the three options of care to choose from when they fulfilled the criteria for joining a DCM. With the move to provide options of care that suited patients' preferences, the facility offered FAC, CAC and QPUP for patients to choose from. The excerpts below indicate how some of the patients were offered the opportunity to join DCMs and the choices they made:

> For me, I joined QPUP when the nurse told me of the different options. I cannot remember all the things she said but I know I had to choose and I chose QPUP… and there was a form I needed to sign'. (Female, QPUP)

> The sister [nurse] realised that I always came to the clinic on my appointment date and that I was never sick, and she told me that I am fit to be in the three programmes that offer ARVs in the clinic. She mentioned them and she asked which one I chose. She explained all these programmes and I told her it will be ok for me to join QPUP. (Male, QPUP)

4.4.2 Service delivery as patients' expressed need

Service delivery as patients' expressed need is achieved in the DCMs through quick services or short waiting times. Patients in all the three DCMs stated that they experienced quick service concerning getting their ART. They indicated less time spent in the DCMs compared to when they were in the facility's routine system of care; where they would almost spend the whole day waiting to get their medication. Patients indicated that the time they spent was shorter and more convenient for them to go to work and continue with their day-to-day activities other than spend the whole day in the facility.

> I like QPUP because we get our medication quickly. Even when I am supposed to draw blood, I go and have my blood drawn and go straight to the window and collect my medication and go. There is nothing that makes me to wait. (Male, QPUP)

> I hate queuing in the clinic, here [FAC] you find everything ready for you and you go (Female, FAC)

> Yes, it is quick here and we find our things (medication) prepared for us…you do not spend more than an hour here. (Male, CAC)

Another aspect of patient-centred care is related to addressing the expressed needs of the patients. This is achieved through easy access to ART without the need to queue in every service point of the clinic (reception, triage, and clinician) before getting their medication in the pharmacy. Each patient's medication is prepacked and prepared prior to their attendance.

> QPUP has helped a lot. There are no long queues and waiting here. It is very convenient for us unlike in the facility where you spend the whole day. (Male, QPUP)

> It is easy to come here in the evenings because you are done with work and everything. You just come and pick your medication then you go home. (Male, QPUP)

> I like it more here because you do not wait long. See now, I will be able to go to work and I have not even asked for a day off work but I have my medication. This community club is really helping us. (Female, CAC)

The models addressed patients' healthcare needs and accommodated their social lives, as they were able to continue with their day-to-day activities while accessing and taking their medication.

> I chose this one for the morning because it was working for me. I am a person who works. So, starting here for me is very easy. I can also inform my work place that I will be a bit late then I come here and I get my medication. So, I know I can start here. (Male, FAC)

> We are more comfortable here in this venue because it is not like in the clinic where there is a lot of people. Here you even forget that you are coming to the clinic and that is why I like it here. Here we have all come for the same thing, we get our medication and we are also not delayed at work. The process here is very smooth (Male, CAC).

Self-management is an important aspect of long-term HIV treatment. It entails the motivation and ability to take responsibility to one’s health condition over long term, including adherence to ART by the patient on a daily basis. Most participants in all the DCMs, who had been long on treatment did not see the need for other services to be offered in the models but were happy with the quick ART refills.

> Most of us have been long on treatment. They said we could manage ourselves in the community as compared to the new ones who still needed to be in the facility and monitored by the nurses there close by. (Male, CAC)

4.4.3 Patient-centred care

Flexibility is related to providing patient centred care refers to the convenience of time scheduling of DCMs when patients come and collect their medication. The scheduled time for patients to collect their medication varied across the DCMs. Patients in both FAC and CAC collected their medication early in the morning before they could go to work.

> It is very quick such that you can go to work from here unlike in the clinic where you spend the whole day. You come to the club at 7:30 in the morning, at about 8:30 you know you are going to work. (Female, CAC)

> However, here when you come to the club like now at 7 in the morning. You know by 7:30 and 8 o’clock you are gone when you are late. It is very quick than in the facility. That is why I like it. (Female, FAC)

Nevertheless, patients in QPUP have the option of collecting their medication in the evening between 4:00 and 6:00, which they expressed as convenient for them being after working hours.

> I like QPUP because you understand that we are working and the time for us is convenient. You know that even when you are from work you pass through here and get your parcel and go home. There is nothing, apart that for me it is the better time for collecting my medication. It is a very good programme. (Male, QPUP)

> The time for QPUP is really, flexible for me. QPUP is easy for me to come after work that is why I chose it. (Male, QPUP)

Although there were some things that needed to be reviewed in the models as stated by participants interviewed across all DCMs, the overall opinion was that, as compared to the mainstream health facility, service delivery in the different models of care was effective.

> Here you find all your medication ready to pick up unlike there where you queue for folders and you also need to queue at the pharmacy after you would have waited for the nurse to see you. (Male, QPUP)

> So far, I have not seen anything wrong, I do not want to lie. Everything is going accordingly so far. I do not see a need for improvement. For now, it is fine. (FAC)

> No, these ones are 100%. We come here and all our things are ready for us. (Female, CAC)

> No one in this club that I know of has experienced such a thing as going home without medication. Everyone comes here and we have our medication ready for us. (Male, CAC)

Another aspect of patient-centred care is patients' participation, where patients are offered the opportunity to play active roles in their care. This is what some of the participants had to say.

> Yes, we do have the contact for the facilitator so that we ask questions when there is something that we do not understand. She often encourages me to take my medication everyday so that my viral load remains suppressed (Female, CAC)

The above highlights the importance of patient participation in their own health. To be empowered meant that they are able to take responsibility in their adherence to medication and felt in control in as far as their health is concerned as they have been capacitated to do so by their facilitator.

4.5 Coordination and integration of care

Coordination and integration of care refers to a collaboration between the health and social health care systems. Where care addresses the conditions and ongoing relationships needed to support seamless interactions among multiple providers within interdisciplinary teams and/or across care settings and/or sectors (WHO, 2018). Apart from receiving their medication, patients were asked if they accessed any other services in their models of care and if not, what could be provided.

Complementary services in the DCMs varied among participants interviewed as different models varied with services provided. Adherence clubs provide health promotion aspect through the education or health talk session where club patients engage with each other on different topics and discussion affecting them in a more general platform. Most participants interviewed identified health talks as some form of psychosocial support that they got from adherence clubs in addition to their medication pickup:

> No, we only get education with the facilitator. We talk about different things and most of the times she talks about the importance of taking treatment as expected and nothing else. (Female, FAC)
>
> We come here and we give our facilitator the cards. After that, we get onto a scale and then we chat as a group. Most of the discussion we talk about making sure people take their treatment. (Female, CAC)

The psychosocial support aspect of the adherence club model was strongly presented in the CACs where patients interact and engage with each other and even contact each other outside of the adherence club space.

> I have a number of one of the women in this club. I call her at times when I feel very low or maybe when I am not well. (Female, FAC)
>
> In this club, we have a WhatsApp group where we not only remind each other of club appointment, but people also post different things. Most people ask in the group if they have symptoms that they do not understand. (Female, CAC)
>
> We always advise each other on the importance of taking medication in our group. We are few women that are in the club and we also have a "Stokvel" (CAC, Female)

Unlike the adherence clubs, QPUP was not designed to have health talks sessions as the idea was mainly to provide quick access to medication.

> We only give them the card and they write the return date, they give us our medication and we go (Male, QPUP)
>
> We only get condoms from inside the clinic. Here (QPUP) we only get our medication and go. There is no other sessions that we have (Male, QPUP)

Although the QPUP did not have any form of interaction between patients and healthcare provider as in the adherence clubs, patients are advised when joining QPUP on accessing support (psychosocial/counselling) these should the need arise.

4.6 Information, communication and education

Patients in the DCMs were interviewed to ascertain if, as part of their care package, they received any information pertaining to their health and treatment journey to enhance their disease management in their model of care.

4.6.1 Access to health education and information

Access to health education was identified by the participants interviewed and supported the framework's category of patients accessing health information, communication and education. Patients in community and facility adherence clubs stated that they had health education in their club sessions. They indicated that it is in these sessions they were encouraged on their treatment journey and to remain adherent.

> In the club we chat as a group. Most of the discussion we talk about making sure people take their treatment in the right way. The facilitator also encourages us to take our medication so that we do not have high viral load and become sick-then you are taken out of the club. (CAC)
>
> Here in the club we arrive and we give them our clinic card. We take the weights and we sit. After that, we have a talk session where they ask about how we are doing. We also state we are ok, if we are not they tell us to go to the clinic and meet up with the sister. We are also encouraged to take ARVs as expected so that we are not taken out of the club. (Female, CAC)

4.6.2 Communication: relationship with club facilitator

Facilitator are health care workers that have been the immediate face of the health system to the patients. They are the link between the health system and the patients and have capacity to communicate, educate and provide health information to the recipients of health services. The health education session in the adherence clubs allowed patients to form a relationship with the club facilitator. Participants stated that this created an environment where they are able to interact and ask for information from the club facilitator if they expressed a need.

> The club facilitator always has something to say to us. We do not just come here and get our medication. (FAC)
>
> Yes, the facilitator often talks and advise us on the importance of taking medication and how we need to make sure we have drawn blood every year to see if the medication is working in the blood. (FAC)

Patients in adherence clubs indicated a very good and interactive relationship with their club facilitators and that emotionally supported their continued adherence to medication and retention in care.

> You know you come here and the club facilitator is already waiting for you. In the clinic, you would not even know a person assisting you. You are told sometimes that the person helping you is not there and then someone else comes. Here we know this lady is the one who will help us. (Male, CAC)
>
> We even have her phone number. If there are things that we do not understand we can WhatsApp her. (Female, CAC)

In the same vein, however, patients in QPUP indicated that although they did not have any health talk sessions in their model of care, QPUP facilitator was approachable and gave them necessary information if they asked.

> He [QPUP facilitator] definitely gives you information and answers you… If he does not know, he will suggest that you meet up with the nurse but for what he knows, he is very helpful. He does not leave you without any help. (Female, QPUP)

> Here [QPUP] the person who helps us does not have any issues or attitude. You can even ask anything, they politely explain to you in a kind manner. (Female, QPUP)
>
> Although I have never asked for anything, he [facilitator] is approachable. I have seen people talk to him and I think he is a nice person. (Male, QPUP)

4.7 Physical Comfort

Physical comfort considers elements such as venues and settings where patients access their care. Patients in the DCMs were asked of their thoughts about the environment or setting in which their models operated from. FAC and QPUP models held their care in a selected venue in the facility. CAC used a community hall as their venue in the community.

4.7.1 Venue convenience

Patients in all the DCMs indicated that the spaces where they met and got their ART refills were convenient for them. Patients in the QPUP model expressed that the venue was convenient for them as they spent less time in the facility.

> For me, I like it here because we are in the clinic like anyone else. No one knows or cares who is here for what (Male, QPUP)
>
> The venue is good for me because, honestly, I have never waited long time. I just come here and get my medication, within a few minutes I am gone. (Female, QPUP)

Furthermore, patients in CAC not only enjoy the experience of accessing care in the community, but they explained that the nature of the venue they met in was good and patients report being comfortable accessing care there. The CAC met in the community hall run by a local Community Based Organisation. This further indicates collaboration between and among stakeholders in making sure that patients access their care in a convenient place.

> It is ok to collect our medication from this place… there are even chairs here where we can sit comfortably. (Female, CAC)

> We always find the door open and there is a security guard here and we feel safe. The place also has a heater especially now in winter and it is always warm (Female, CAC)

Patients in FAC accessed their care in the facility's old facility boardroom which is currently used as tea room for facility staff. This venue has been allocated strictly for running of clubs before 9 in the mornings.

> I like it here because we do not get to mix with the whole patients in the clinic. We are on our own here. (Male, FAC)
>
> This venue is ok for me. If I need to see the nurse or doctor on the day, I only go to the reception and get my folder just around the corner. We do not que and there is no crowding. It is only club patients. (Female, FAC)

Patients interviewed across DCMs highlighted the importance of how the environment had a contribution and had an impact in how patients felt when accessing care.

4.7.2 Environmental convenience

Most participants indicated that the DCMs offered a stigma-free environment. This was because they met with people in the same situation as them. Most participants interviewed indicated that they disclosed their status and got support from friends and family.

> My family knows that I take [ART] medication and they support me. Even late when it is time to take medication, they remind me to take my tablets. I mean, I do not have to hide or what. No one have ever judged me about my status. I am free to take my medication. (Male, CAC)
>
> My partner also supports me although he is not on medication. He has never discriminated me. Therefore, I have someone to talk to when I am not well. (Female, FAC)

Participants further highlighted that being away from the mainstream facility and being in their own space with people in the same situation as them, gave them the freedom to come and pick their ART without fear of being seen and judged.

> For me, the space is right because we are here in the clinic like anyone else. No one know or cares who is here for what. (Male, FAC)
>
> People would come when we are seated there to collect and ask ‘which one is QPUP line” so no one knows what QPUP is except for the people who are in this programme and that is fine for me. (Female)

Although some patients found safety in their own space, some patients in the DCMs indicated that they did not mind being seen taking any ARVs as they are putting their health first.

> For me, I am just concerned about my health and nothing else. I do not care what they say or not. The other thing people should not judge other people because you do not know what made them to be here. Tomorrow it might be you. (Female, QPUP)
>
> Here even if we are seen, it does not bother me because, I am concerned about my life. (Female, FAC)

In-as-much-as there was freedom and safety to take ARVs in the DCMs and disclosure to family and friends done, some participants in adherence clubs on the contrary highlighted fear of experiencing stigma and discrimination in the community. They reiterated that they were afraid to be known in their communities of their status, as they feared being stigmatised and discriminated.

> We are free to talk about HIV at home but in the community, there is also some frustrating situations because they do not call it as HIV, they say that thing, they call it “Omo” and that is not nice. I fear what they will say to me if they know that I am HIV positive. (Female, CAC)
>
> I once had challenge at work. My boss knew about my status but they accepted me with her husband. So now, this month I received a call from her and there is someone who wants me to work for them. But now she told that person that I have a lady who can help you but she is HIV positive. I did not like that. (Female, CAC)
>
> It was difficult to tell my older sister because she tells everything to the world. (Female, FAC)

Although participants were comfortable with their status being known among family and friend, they felt confidentiality still had to be maintained in the outside world as they feared their reaction to their status if they found out.

4.8 Emotional support from peers and health workers

This segment sought to explore the extent to which each of the DCMs provided emotional support to their patients as this has been viewed as a motivator for patients to be adherent to their medication and be retained in care.

4.8.1 Group camaraderie and peer support

Emotional support among patients in the three options of care varied as they expressed different opinions regarding peer-to-peer support. Most patients in CAC highlighted that they offered each other peer support as they had built relations within the adherence club.

> I do have the number of someone here and I also have the number of the facilitator... this is for us to remind each other of the club date and even when there is blood draws and we need to go to the facility, I remind her. (Female, CAC)
>
> Also, just to encourage each other. For example, when I come early and she has not arrived yet, I send her a WhatsApp and ask where she is because it might be she forgot that it is the day of the club today. (Female, CAC)

Although not as visible and tangible as in the CAC, patients in FAC highlighted that they interact with other club members, outside of the club appointment date.

> I have a woman in the club that we exchanged numbers and we contact each other. Even today, she gave me her card to come and get her medication. (Female, FAC)
>
> I have someone I know but she moved to another club. If I am not feeling well, I can call her and we talk because she is also with this disease. It is easy to interact with her. (Female, FAC)

The structure and nature of the QPUP model led to some patients in QPUP indicating that they never interacted with their peers in the same model of care outside of the facility space. Patients highlighted that they most of the times come at different times to pick up their medication and in most times highly unlikely that they interact or see each other.

> Most of the time we just come in here and pick up our medication and go. We often do not come at the same time (Female, QPUP)
>
> We have not met each other. Even today, we met because you called us. Otherwise, we just come and get our medication and go. I have never met other group members prior to this meeting. (Female, QPUP)

Patients were however, advised on the importance of peer support and some showed interest in pursuing the idea.

4.8.2 Group empowerment

Adherence clubs have been reported to be a source of peer-to-peer empowerment for patients to navigate common challenges. Patients using the clubs suggested that they received group empowerment.

> Here I am free to take my medication because all of us here are in this situation. So, there is nothing that makes me to fear, you know. I am free to come to this club because I will meet people who are in the same situation as me and we support each other. (Female, CAC)
>
> If you are not feeling well, they can also advise on what to do since we are all in the same journey. Maybe I might have gone through the same thing. So, I will share my experiences. (Male, CAC)
>
> For me I have someone whom we stay close to in the community...We chat and talk often and we have a good relationship. (Female, FAC)

4.9 Involvement of family and friends

The involvement of family and friends as a principle in the NHI Framework focuses on the importance of family and friends' support and the agency it has in helping communities achieve better health care. The category not only focuses on patients in accessing better health care, but also the involvement of communities to achieving better health outcomes.

4.9.1 Psychosocial support

Actions that support the social and psychological needs of patients are vital in meeting their needs. Most patients across the DCMs indicated that they had support from their family and friends in their ART journey. The majority of participants stated that they have found strength in taking their ART through friends and family support.

> Yes, my girlfriend has been my pillar of strength. We have been in this together. So, we definitely support each other. Because we stay together. (Male, QPUP)
>
> I have my partner who is supportive and she knows my status. Some of my family members know that I take this medication and are very supportive. (Female, QPUP)
>
> For me I am open to my family. Even when it is eight in the evening and I am sleeping, you will hear, 'my sister here is your water and tablets. It is time to take you medication'. Even if there is whoever in the house, they know at that time I need to take my medication. (Female, FAC)
>
> My partner also supports me although he is not on ARV medication. He has never discriminated me or what. So, I have someone to talk to when I am not well. (Female, CAC)

4.9.2 Practical support

Another aspect of family involvement, is the ability of patients to family members, described as a "buddy", to collect their medication on their behalf. Most participants interviewed across the DCMs highlighted knowledge of this option and stated using it.

> I always send my child to collect medication for me when I cannot come. All my family knows that I take medication and I do not have a problem. (Female, CAC)

Being able to send someone to collect medication on their behalf has helped DCM patients navigate and maintain a work and life balance and allowing them to continue having access to, and taking their medication. Patients are made aware that they can only send ‘buddies’ on days when they are not due for blood draws and clinical consultations.

4.10 Transition and continuity

It is pivotal that the health care system put measures in place to ensure patients, have continued access to care. Continued patient support in the health system, will not only encourage their adherence but also ensure they are retained in care. Patients highlighted modalities that are currently in place within each model to support their adherence and retention in care.

4.10.1 Allocation of health practitioner

As an attempt to retain patients in care the DCM have continued patient monitoring processes to make sure they are virally suppressed and healthy. Patients in all the DCMs have annual blood and clinical visits to the facility where they have blood draws and comprehensive clinical visits to check their overall clinical concerns and a health practitioner is allocated to support this activity. Patients who were interviewed in the DCM indicated that they came to the facility and a clinician was allocated to facilitate the process of that particular visit.

> The facilitator always directs us to the nurse that will do our blood or clinical visit. (CAC, Male)
>
> Although we stay longer than usual on the clinical visits, we know that we have an allocated nurse for us on the day. (FAC, Female)
>
> I am now not getting used to coming to the clinic because I take my medication in the community. But our facilitator is there and she tells us on which room to go to see a nurse. So, we don’t queue with the people in the facility. (Male, CAC)

With the nature of QPUP, and how the model was designed, unlike in clubs where they have an allocated clinician for their blood and clinical visits, patients in QPUP follow clinic routine like any other patient on their annual clinical visit. When asked on their thoughts around the clinical visit and them having to queue like any other patient, they had this to say:

> When I joined QPUP they told me I will come and pick up my medication in the window and everything else will continue as before like drawing blood and clinical visits. Although it is not easy to queue because we are now used to picking up medication and go, it is also important that I have a nurse check me if everything is still ok. (QPUP, Male)

> I try to come early when I know I need to start at the clinic for clinical visit because if you come late, you will leave after one. We only come early when we draw blood and clinical visit. (Female, QPUP)

4.10.2 Migration/annual transition period

During the festive season period where patients migrate outside of the province, the DCMs provide four months' supply of medication to patients in order to accommodate the migration period. Participants interviewed highlighted that they get four months' supply of medication, which allows them to travel without the worry of running out of medication.

> We get four months medication during December because some of us go to the Eastern Cape. (CAC, Female)

> I like the holiday season because that is where we get four months medication. You get to stay at home and travel without even thinking of coming to the clinic. (QPUP, Male)

> Four months of medication is very good. We get it in November-December there about. We are able to visit people and not worry that you will run out. That is why I like it in the club (FAC, Female)

The four months' supply of ART to DCM members has been popular with patients and has been one of the benefits by the health system to retain patients in care.

4.11 Access to Care

It is important to address the needs of populations, taking into consideration their social, economic, cultural and environmental aspects, which will have an impact on the way they perceive the health system and access to care.

4.11.1 Visit preparations

To provide effective healthcare services, the facilitator prepares for the particular DCMs a day before depending on the type of visit. For all the visits, medication is prepared prior so that all patients in the DCM have their medication ready for their arrival the following day. If it is a blood or clinical visit, appropriate forms and files are also prepared prior. Participants in the study were asked if they got effective service from the DCMs to access their care.

> On blood and clinical visit, we know the facilitator has already drawn our files. We know after that we just pick up our medication and go. There is nothing that will make us wait. (FAC, Male)
>
> We know that when we arrive at 7 in the morning he will be here waiting for us. He always tells us when it is clinical visit to come early because he has organised with the nurse to see us. So that is why we come early (FAC, Female)

4.11.2 Easy travel to point of ART collection

Patients in all the DCMs interviewed highlighted the convenience of accessing their health care services at the clinic for patients accessing care in QPUP and FAC. Most patients highlighted the convenience of walking to the facility. They indicated that the venues allowed them to collect their medication without any travelling challenges

> I walked because I stay very close. (Male, FAC)
>
> I do not know about others no we walk most of us because we stay close to the area. (Female, FAC)

> No, we walk most of us because we stay close to the area. I walked coming here but I do not know about the others. (Female, CAC)

Because of the nature of the model of care running in the evening, most QPUP patients indicated dropping off taxi from work to pick up their medication in facility.

> I took a taxi because I stay very far from the clinic. Because I am from work, I dropped off just close by here. I will then take a taxi home. (Female, QPUP)

> I am currently from work. I dropped off a taxi. I will walk home from here, it is not very far (Female, FAC)

> Most of us stay close to this place. It is central location to almost everyone in the club. (Female, CAC)

As highlighted above, for most patients interviewed across the DCMs, travelling to the different locations where they accessed care was not a barrier for them getting their medication.

4.12 Chapter conclusion

This chapter presented the findings of the study, which compared different experiences of patients in DCMs in a Community Health Centre. The perspectives varied across DCMs. The next chapter will present the discussion on the findings and recommendation thereof.

CHAPTER FIVE

Discussion

5.1 Introduction

The purpose of the study was to explore and compare the experiences of patients in three different DCMs. The key findings presented in chapter four are discussed in this chapter in light of available literature. The common themes are explored and expanded further in the discussion session according to the NHI patient experience framework.

5.2 Discussion

Respect for patient centred values, preferences and expressed need

This study unearthed to what extent DCMs place importance to patient-centred values, patients' preference and responsiveness to patients' needs. We uncovered that patients experienced quick service delivery and shorter waiting times regarding access to their medication across the three DCMs. Patient preferences and needs were addressed by providing flexibility on the times of collection, who to collect and grace period. Effective service delivery and flexibility of the models to addressing patients' needs in DCMs as compared to the standard of care came out strongly in the study as DCMs allowed patients to comfortably collect their medication and continue with their day-to-day activities. This notion is supported by other studies purporting that the flexibility in DCMs increased their appeal to patients as they are patient-centred and speak to different patients' preferences and expressed needs (Eshun-Wilson *et al.*, 2019; Sharer *et al.*, 2019).

Our study also found that patients were given the opportunity to choose the care model they preferred. This is in line with the NHI's principles of preferences. Because FAC were the only option of care besides the clinic mainstream in the facility at the inception, patients in FAC were only offered the opportunity to choose between remaining in the standard care model and joining the FAC. With the introduction of QPUP and CAC to decentralise further ART service delivery, patients were offered the opportunity to choose any of the DCMs models. We uncovered, nevertheless, that patients in various models were comfortable in their respective option of care and did not suggest to prefer any other model apart from where they currently received care. Sharer *et al.* (2019) and Trafford *et al.* (2018) revealed that patients desired to receive care from DCMs that accommodate their daily routine, thus desirability is pivotal in addressing patients' needs and preferences. They further reiterate that DCMs should fit within the health system and match patient preferences in different settings and contexts for them to be effective.

Additionally, this study unearthed that there was no variation in preference amongst participants across the DCMs. Shorter waiting times, flexibility in service delivery, grace period and provision of a buddy system, were among desired DCM attributes amongst participants. Sharer *et al.* (2019) agreed that for DCMs to be effective in retaining patients in care, these features and benefits should be generally acceptable to patients.

Coordination and Integration

Regarding coordination and integration, this study showed that complementary services to support the coordination and integration of DCMs were integral in achieving positive health outcomes to patients in DCMs. Mukumbang *et al*. (2018) unearthed that DCMs such as FAC and CAC have additional treatment and care modalities supplementing the standard ART collection session, where needed. Therefore, there is an opportunity for patients using DCMs having comorbidities to be managed within the model to enhance their adherence to medication and sustain the attendance of the patients' clinic appointments.

The FAC and CAC provide health promotion services through the education or health talk session, whereby patients engage with each other on different topics and discussions related to their treatment and care. This study identified health talks as a form of psychosocial support that patients received in addition to their medication pickup as they had the freedom to share their experiences, challenges and fears with people of the same situation as them. Root and Whiteside (2013) confirmed that health talks cultivate social relationships between the health care workers and PLHIV and played a pivotal and powerful role in their adherence to treatment. They explained that health talks as an intervention given by care workers encourages clients when they experience stigma, side effects and any other obstacles in their adherence journey. Study findings have shown a significant increase in HIV knowledge and perceived psychosocial support when HIV-related services are provided together, which improved patient adherence and retention outcomes (Kaplan *et al.*, 2017; Mukumbang, Orth and van Wyk, 2019). QPUP patients' experiences in terms of education talks varied vastly from those in the FAC and CAC because this model does not have any education modality.

Our study also found that patients in DCMs are more interested in picking up their medication and going on with their day-to-day activities, which is the premise that informed the design of the QPUP model. This notion is supported by a study conducted in Zambia, which discovered that the overall patient preference of the differentiated service was related to the reduced clinic visit frequency (Eshun-Wilson *et al.*, 2019). Reduction in frequenting the facility was presented as valued and acceptable amongst PLHIV as they suggested that it saved time, which translates to reduced transport costs and increased convenience. Contrary to our findings, a comparison of outcomes among FAC members who received 2-month ART to 4-month ART showed no difference in defaulting or viral suppression between both groups of patients (Grimsrud *et al.*, 2014; MSF, 2014).

Physical Comfort

We found that venue and space convenience and the general environment where patients accessed their care is of importance to PLHIV. In congruence to the requirement of healthcare interventions to offer physical comfort, we found that patients were comfortable in the different venues where they met, which enhances access ART care. This notion is supported by UNAIDS (2013) stating that environments and infrastructure positively or negatively influence the mind-set of service delivery, its efficiency and ability to innovate in delivering expanded health services. They go on to state that these venues need to be logistically feasible and reasonably safe, which is what most of the patients in the study affirmed.

Although both FAC and QPUP met in the facility, patients in these models valued that they met separately from the main clinic routine ART service patients. CAC met in a community hall, which offered convenience and comfort for patients as it also addresses the barrier of distance to the clinic. Being close to patients' homes, most patients could walk to the venue. Taking healthcare closer to where people are, supports innovation studies that that found that bringing treatment closer to where people are, responds to patients' different needs and retains them in care Wilkinson *et al.*, (2016). Community facilities such as churches, community halls, crèches have been identified as potential venues to host CACs as presented in different studies (Tsondai *et al.*, 2017; Zanolini *et al.*, 2018; Eshun-Wilson *et al.*, 2019). We uncovered that participants in the CACs liked the locations of their venue because it offered a decongested environment compared to crowded facilities.

One important issue that came up in our study related to comfort was the ability of DCMs to shunt patients from perceived and enacted stigma and discrimination. Patients highlighted the sense of security regarding perceived and enacted stigma based on the biosocial environment offered by DCMs. Patient expressed strong desire to be supported by peers, which gave them the sense of belonging (bio sociality) and protection against enacted stigma. DCMs' role in neutralising or buffering stigma and discrimination has been highlighted by several studies as a pivotal platform to reduce stigma among PLHIV (Mannell, Cornish and Russell, 2014; Zanolini *et al.*, 2018; Id *et al.*, 2019). The implementation of DCMs has the potential to give opportunities to confront legal and structural barriers that prevent patients to freely access ART services (Grimsrud *et al.*, 2016).

Emotional support from peers

According to NHI (2013), emotional support from peers is an important component in healthcare service provision. Our study unveiled that peer-to-peer social support including emotional support amongst patients in DCMs constitutes an important part in ART treatment and care. Good, tangible group and peer-to-peer support and excellent group interaction and good relationship with club facilitators enhance social support amongst patients in FACs and CACs. According to Goemaere (2016), the role of peer-to-peer social support is in models such as FAC and CAC that accommodate group interaction, facilitates a community-based treatment social support network, which empowers patients to continue taking their treatment. Their study findings suggested that peer-to-peer relationships spilled outside of the club session creating bigger community relationships.

Other studies have found that the psychosocial aspect of the ART group models provided patient support and improved adherence to treatment (Ware *et al.*, 2009; Agaba *et al.*, 2018). Social support including emotional support has been found to empower patients to self-manage their disease (MSF, 2014; Mukumbang *et al.*, 2019). It has been identified that, club members in group-based ART models establish a positive group dynamic, which renders much-needed peer support for adherence to lifelong treatment (Mannell, Cornish and Russell, 2014). We found that group-based DCMs are a mechanism for bringing individuals together for peer support, which is crucial for navigating the treatment journey.

QPUP patients varied however in their experience of group support as they mostly picked their medication individually and not in a group setting although they were also encouraged on the benefits of peer-to-peer support.

Involvement of family and friends

Our study uncovered that the involvement of family and friends as one of the NHI principles of effective healthcare provision was of relevance to the treatment journey of PLHIV. The opportunity provided by DCMs for families and friends to pick up medication on behalf of the patients is an important way that DCMs enhance the involvement of families and friends. The South African department of health states that PLHIV share common problems and concerns but simultaneously experience unique challenges, therefore, involving family and friends in their treatment journey provides and contributes to positive support outcomes and overall wellbeing (DOH, 2015).

Furthermore, the participation and involvement of family and friends was viewed as a strength and support structure by DCM patients in this study. Clinical and empirical findings suggest that strategies meant to improve and strengthen family support and care for PLHIV is paramount to positive health outcomes (Belsey, 2005; Xu *et al.*, 2017). This notion is highlighted in the UN general Assembly special session of HIV/AIDS (UNAIDS, 2016) recognising the importance of prevention, care and support provided by families in reducing vulnerability and increasing coping capabilities on the impact of the disease to PLHIV. Families and friends in this study provided safety nets for patients in DCMs by providing practical support.

Transition and continuity

Our findings indicated that the healthcare system has measures in place to support and ensure patients in DCMs provide continued access to care. There are modalities put in place within each model to support patient adherence so that they remain in DCMs. To support continued access to care, the DCM have a health practitioner allocated to support the clinical aspect of the DCMs as patients have their viral load (VL) monitored on an annual basis through a comprehensive clinical consultation. Continued VL monitoring is paramount in the global response to HIV/AIDS epidemic as it improves the quality of service provision and assesses individual health outcomes (UNAIDS, 2016; Tsondai *et al.*, 2017; Flämig *et al.*, 2019).

To ensure continued access to ART, DCMs in this study provide patients with four months' supply of medication during the festive season to accommodate migrating patients. Longer supply of medication during the festive season allows patients to have ART supply and facilities their mobility during the holidays. Numerous studies have highlighted the importance of reduced frequency of pick up appointments and longer supply of medication to stable ART patients in reducing the burden on both the health system and the patients (Khabala *et al.*, 2015; Eliya *et al.*, 2017). The frequency of patients coming bi-monthly for their pick up and given four months of medication during the festive season contributed to the improved retention in care of patients in DCMs in this study (MSF, 2014; Mesic *et al.*, 2017).

Access to Care

Our study revealed that DCMs provide flexibility to patients to navigate taking their treatment and continue with their daily commitments. Being in the DCM allows for easy access to medication, which facilitates timely medication pick-up to meet up with other commitments. The QPUP model allows patients to pick up their medication on their way from work. Flexibility in terms of time for medication pick-up allows patients to schedule their daily work activities around their ART appointment times. The flexibility of DCMs increases their appeal to patients and allows the patients to choose where and when they want to access care (Sharer *et al.*, 2019).

CAC were designed to take ART services closer to patients' homes to address distance and transport costs barriers while FAC and QPUP take place in the facility. Although some patients travelled walkable distances to their ART collection venues, others required taking taxies to the clinics. Easy access to ART is a vital component in improving health outcomes (Duncombe *et al.*, 2015; Goemaere, 2016). Studies have found long distances from the facility and spending transport costs as barriers to accessing HIV services (Agaba *et al.*, 2018; Eshun-Wilson *et al.*, 2019). Consequently, increased availability of community-based ART services options can address these barriers. Patients in our study highlighted easy accessibility to ART collection venues and did not have to spend on transportation.

5.3 Limitations

Only two groups per DCM were included in the study, which is not representative of the ART cohort in the facility.

Interviews were conducted once off; therefore, the researcher could not explore the patients' experiences prospectively, which should have been important as individuals' experiences and perceptions change.

CHAPTER SIX

Conclusions and recommendations

6.1 Conclusions

Evidence from this study indicated that DCMs for the most part address the needs and support the self-management for healthy and stable patients on ART. Patient-centred approaches such as the DCMs presented in this study highlight the importance of models that address patients' challenges in accessing healthcare services as key facilitators to continued care. The findings in this study highlight that patients found DCMs easily accessible and convenient and overall had positive experiences in relation to the NHI patients experience principles. DCMs, especially FACs and CAC address the attributes of patient-centeredness as prescribed by the NHI. We found that the QPUP model fell short on some of the attributes of patient-centeredness such as coordination and integration of care; Information, communication and education; and emotional support. While QPUPs do not completely align with the NHI's patient-centeredness attributes, considered as a full package to improve retention in care and adherence to medication for PLHIV, DCMs fulfil the NHI patients experience principles.

6.2 Recommendations

In an effort to motivate adherence and retention in care, strategies such as the DCMs are vital programmatically. Thus, strengthening these is critical to HIV treatment outcomes. Experiences of patients in DCMs and patient centred approaches should be central in any innovative process to allow them to address the exact needs of the population. It is paramount, therefore, to promote differentiated delivery of services that speak to the needs of the clients thereby protecting them from the effects of stigma and discrimination.

As highlighted in the study, patients in QPUP rarely received any interaction with the health service providers other than picking up their medication and during their blood draw and clinical consultation dates. The use of text messaging to provide health information and promotion may be a supporting system to enhance continued patient interactions. The use of mHealth in an ever-changing technological environment is vital in equipping the health system to reach closer to patients. This will allow patients to constantly have increased knowledge and control of their care and treatment.

Once a year, patients in the DCMs have their blood draws for monitoring their VL and comprehensive clinical consultation check-up. Patients in CAC who meet in the community need to come back to the facility to access these services. A recommendation in this regard is to provide a conducive environment and clear process flow to have a clinician visit the CACs and offer the service in the comfort of their community venue. This may require systems put in place to support the initiative. Integration of such services may drastically reduce any facility visit for CAC patients.

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APPENDIX 1 : CONSENT FORM

CONSENT FORM

Title of Research Project:	**Comparison of patient experiences in three Differentiated Antiretroviral Delivery Models in a Public Health Care facility**

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Participant's name………………………..

Participant's signature……………………………….

Date………………………

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ISIVUMELWANO SEMFIHLELO SAMALUNGU EQEMBU

Isihloko soluphando : ***Ukuthelekisa Izimvo Zezigulane kumacandelo Empilo Yasekuhlaleni***

Olu phando lucaciswe kum ngolwimi endIlivayo. Imibuzo yam malunga noluphando iphenduliwe. Ndiyayiqonda into yokuba inxaxheba yam izokubandakanyeka ntoni na kwaye isivumelwano ngomphefuml'okhululekileyo nodlamkileyo. Ndiyaqonda ukuba iinkcukacha zam aziyi kudluliswa ngaphandle kwemvume yam. Ndiyayivisisa into yokuba ndingakwazi ukurhoxa koluphando ngaphandle kokunika izizathu yaye ngaphandle loloyiko lwezimvo endizakuzifumana. Ndiyavisisa ukuba ikukhuseleka kwam koluphando kuxhomekeke kwamanye amalungu oluphando.

Ndiyazinikela ukugcina lonke uluvo oluzathethwa koluphando kum andinga thethi nabani na malunga namanye amalungu oluphando ngaphandle kweli qela.

Igama lomthathi nxaxheba……………………………………………..

Isiginetsha somthathi nxaxheba…………………………………..

Date………………………

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

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APPENDIX 2: INFORMATION SHEET

INFORMATION SHEET

Project Title:

Comparison of patient experiences in three Differentiated Antiretroviral Delivery Models in a Public Health Care facility

What is this study about?

This is a research project being conducted by **SIBUSISO NDLOVU** at the University of the Western Cape. We are inviting you to participate in this research project because you are part of the anti-retroviral therapy Differentiated model of care (facility club, community club, Quick pick up group) that the facility offers. The purpose of this research project is to compare the experiences of patients in three DCMs in a Community Health Care Facility and explore their different experiences and perceptions in the different models of care.

What will I be asked to do if I agree to participate?

You will be asked to participate in the focus group discussions, which will take place in the facility at a venue appropriate for you. You will do these interviews on your already scheduled clinic appointment date. You will also be asked to participate in the individual interviews as requested by the researcher. The individual interviews will be between 30 minutes to an hour. Focus Group Discussion will take place between 1 hour and 2 hours. The following are the questions, which will be asked:

In accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities information that comes to our attention concerning child abuse or neglect or potential harm to you or others. In this event, we will inform you that we have to break confidentiality to fulfil our legal responsibility to report to the designated authorities.

This study will use focus groups, therefore, the extent to which your identity will remain confidential is dependent on participants' in the Focus Group maintaining confidentiality.

What are the risks of this research?

There may be some risks from participating in this research study.

All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about the ART Differentiated Models of Care and how health services meet the expectations of the patients. We hope that, in the future, other people might benefit from this study through improved understanding of ART Differentiated Models of Care and their input in helping patients stay in care but still continue with their normal lives.

Understanding the experiences of patients using DCMs could improve our understanding of how DMCs promote self-management among PLHIV (or not) and some of the challenges faced by the patients using these care models. This understanding could inform strategies to tailor ART delivery services that suit the patients' needs and enhance them to achieve the objective of retention in care and viral suppression.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by ***SIBUSISO NDLOVU from the School of Public Health*** at the University of the Western Cape. If you have any questions about the research study itself, please contact SIBUSISO NDLOVU at: University of the Western Cape, Phone number 0843993141, email 3610379@myuwc.ac.za

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Prof Uta Lehmann

School of Public Health

Head of Department

University of the Western Cape

Private Bag X17

Bellville 7535

soph-comm@uwc.ac.za

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Prof Anthea Rhoda

Dean of the Faculty of Community and Health Sciences

University of the Western Cape

Private Bag X17

Bellville 7535

chs-deansoffice@uwc.ac.za

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

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This research has been approved by the University of the Western Cape's Research Ethics Committee. (REFERENCE NUMBER: *BM 19/1/18*)

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IPHEPHA LENCUKACA

Isihloko soluphando: Ukuthelekisa Izimvo Zezigulane kumacandelo Empilo Yasekuhlaleni

Oluphando Lungantoni?

Oluphando lwenziwa ngu **SIBUSISO NDLOVU** osuka kwi Univesiti yeNtshona Koloni. Siyakumema ukuba uthathe inxaxheba koluphando olumalunga nezimvo zezigulane ezifumana ukunyangwa kumacandelo empilo yasekuhlaleni (facility club, community club, Quick pick up group).

Yintoni ezakubuzwa xa uzathi uvume ukuthatha inxaxheba koluphando?

Uzakucelwa ukuba uthathe inxaxheba kumaqembu eclubini nakwi QPUP kulekliniki uhamba kuyo. Uzakuphendula imibuzo ngalamini xa kulusuku lwaho lokuza eclubini/QPUP. Uzakucelwa ukuba uthathe inxaxheba ekuphenduleni imibuzo ezakubuzwa ngumthathi ncukacha. Ixesha lolululphando luzakuthatha amayure amabini noma amathathu. Uphando sisemaqinjini angathat ixesha elisuka kumayure amathathu kusiya kwamane. Elandelayo yimibuzo ezakubuzwa koluphando:

Ingaba ukuba yinxalenye kwam koluphando lingagcine luyimfihlelo?

Lilungelo labaphandi ukukugcina kuyimfihlo ngokuncedisa ukwakha koluphando ukuqiniseka ukungaziwa, unikwe elinye igama elingelo lakho. Olulwazi aluzukuchaza ukuba lusuka kuwe. Ngumphandi yedwa ozakunikisa olilwazi kwabanye abantu. Ukuqiniseka ukuba luyimfihlo, umphathi uzakugcina iRecorder ezakusetyenziwa ekuqokeleleni ulwazi olubhale aluthixele kundawo ekhuselekileyo alugcine nalo kwi computer enepassword. Ukuba sibhala ingxelo okanye iphephandaba malunga noluphando, wena uzokhuseleka.

Ngokunxumelene nemfuno zomthetho nemiqathango, sizakuchaza kubo bonke abntu nazebaselungelweni yonke ingxelo ne nkcazelo eza kuthi malunga noxhatshazwanokungahoyeki kwabantwana okanye nantoni na enokubangela ukuhlukumezeka nakwabanye abantu, kukho konke okhu, sizakukwazisa ukuba kufuneka siqhawule iimfihlelo ukufezekisa uxanduva lwethu lomthetho lokuchazela wonke amalungu amiselweyo

Oluphando luzasebenzisa amaqembu abantu ukufuna olulwazi ngapho ukukhuseleka kwakho kuxhomekeke emalungwini amanye azothatha inxaxheba koluphando.

Buyini ubungozi boluphando?

Bungakhona ubungozi ngokuba yinxalenye koluphando. Bonke abantu abanganegalelo kanye nokuthetha ngeziqu zabo okanyesingazama ukunciphisa obungozi onokuthi ubufumane ngokwasengqondweni nokungakhululeki xa sesisenzauphando. Sizakuthumela kubantu abanolwazi oluphangaleleyo bakucebise bangenelele.

Yintoni inzuzo ngoluphando?

Oluphando alokhelwanga ukunceda wena wedwa, kodwa luzokwazi ukukunceda ngophando nokufunda kabanzi nge ARTs nokukhathala ngokwahlukana kwe ART. Noba uncedo lwezempilo lungalindele ntoni kubaguli. Sinethemba lokuba ebomini abanye abantu bazozuza koluphando bakhulise ulwazi lwabo nokukhathala ngokwehlukeneyo nge ART. Izokunceda abaguli bahlale bezikhathalele baqhubekeke ngobomi babo.

Ndiphoqelelekile ukuba koluphando njalo ndingayeka ukuthatha inxaxheba nanini na?

Oluphando uthatha inxaxheba kulo ngokuzithandela. Ungazikhethela ukuthatha inxaxheba koluphando kodwa uba ungafuni ukuqhubekekeka ungayeka noma nini. Xa ungakhetha ukungathathi inxaxheba koluphando, noba uyeke esiphakathini, awuzungafumani lokho obukuthenjisiwe ukuba uzakufumana ekuqaleni koluphando.

Kuzathini xa ndinemibuzo?

Oluphando lwenziwa ngu ***SIBUSISO NDLOVU osuka kwi School se Public Health kwi Univesiti yeNtshona Koloni***. Xa unemibuzo malunga noluphando, ungadibana noSIBUSISO NDLOVU wase: Univesiti yase Ntshona Koloni kwinumber foni 0843993141, email 3610379@myuwc.ac.za

Ukuba unako okunye ofuna ukwazi ngoluphando okanye ufuna ukuchaza izinto ezingakuphathanga kakuhle koluphando, wamkelekile ukufownela u:

Prof Uta Lehmann

School of Public Health

Head of Department

University of the Western Cape

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APPENDIX 3: FOCUS GROUP CONFIDENTIALITY BINDING FORM

Title of Research Project: ***Comparison of patient experiences in three Differentiated Antiretroviral Delivery Models in a Public Health Care facility.***

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone by the researchers. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits. I understand that confidentiality is dependent on participants' in the Focus Group maintaining confidentiality.

I hereby agree to uphold the confidentiality of the discussions in the focus group by not disclosing the identity of other participants or any aspects of their contributions to members outside of the group.

Participant's name……………………………………….

Participant's signature…………………………………..

Date………………………

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Isihloko soluphando : Ukuthelekisa Izimvo Zezigulane kumacandelo Empilo Yasekuhlaleni

Olu phando lucaciswe kum ngolwimi endIlivayo. Imibuzo yam malunga noluphando iphenduliwe. Ndiyayiqonda into yokuba inxaxheba yam izokubandakanyeka ntoni na kwaye isivumelwano ngomphefuml'okhululekileyo nodlamkileyo. Ndiyaqonda ukuba iinkcukacha zam aziyi kudluliswa ngaphandle kwemvume yam. Ndiyayivisisa into yokuba ndingakwazi ukurhoxa koluphando ngaphandle kokunika izizathu yaye ngaphandle loloyiko lwezimvo endizakuzifumana. Ndiyavisisa ukuba ikukhuseleka kwam koluphando kuxhomekeke kwamanye amalungu oluphando.

Ndiyazinikela ukugcina lonke uluvo oluzathethwa koluphando kum andinga thethi nabani na malunga namanye amalungu oluphando ngaphandle kweli qela.

Igama lomthathi nxaxheba……………………………………………..

Isiginetsha somthathi nxaxheba…………………………………….

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APPENDIX 4: **INDIVIDUAL INTERVIEW GUIDE**

1. Respect for patient-centred values, preferences and expressed need

What do you think about the model of care you are in? How do you find the service in the model (CC, FC, QPUP)? What can be done to better the service in the model? What would you prefer to happen in the model of care you are in and why?

2. Coordination and integration of care

Apart from receiving your medication from the club (for example), are there other services that you receive? If yes, what are they? If not what can be provided?

3. Information communication and education

What happened in the model of care you are in? Is there any kind of information (general, health related, community related) you get when attending the club/QPUP? Is it what you expected when you joined the model of care you are in? If not, how would you like information to be delivered and what kind of information would you prefer?

4. Physical comfort

Where do you access care (or receive your medication?).How did you get to find yourself in accessing care in the particular venue? How do you find the venue to be like? How is the place convenient (or not) for your access of care?

5. Emotional support

Do you know on average how many people attend in the model of care you are in? Do you receive any peer support from the other attendees? How can you describe the peer support you get in this care? Do you have any kind of your relationship do you with your facilitator? How would you describe your relationship with the other group members? Do you have any contacts outside your club space? If so how is the relationship and support?

6. Welcoming the involvement of family and friends

What are your thoughts around people close to you being involved in your life as you walk this journey? How has their involvement been like in terms of support? In the club/QPUP, are you allowed to send someone to collect your medication? Do you have anyone whom you can say is your support in the group/family/ buddy? How are they supporting you?

7. Transition and continuity

How long have you been in the facility before you joined the club/QPUP? When did you join this care? What made you join the club/ QPUP? *Would you have preferred another model of care?*

What do you like in a club/QPUP? What do you think needs to be improved?

8. Access to care

How often do you get to meet? Do you walk, get a taxi/train or drive to come to the group? Comparing to the clinic care, how can you rate getting treatment in QPUP/Club? What do you think could be done to improve the way the services are provided in the model?

IMIBUZO EZAKUBUZWA UMTHATHINXAXHEBA

1.Ulungalelaniso nokudibanisa kwenkathalo nentlonipho

Ucinga ntoni ngokuba seclubini/ QPUP?Sinjani isiphatho okanye indlela okuqhutywa ngazo izinto apha? Yintoni enokwenzeka ukuze nifumane uncedo olubhetele?Ngaphandle kokufumana amayeza ngendlela yeclub (umzekelo) , ingaba zikhona ezinye iindlela othi uncedwe ngazo. Ukuba zikhona , ingaba ziintoni?

2. Indlela yokunika umnyango wezempilo odibene neminye iminyako kahulumeni?

Ingaba zikhona ezinye iindlela onokuthanda uncedwa ngazo ? Nika imizekelo .

3. Ulwazi lonxibelelwano nemfundo.

Kwenzeka ntoni eclubini/QPUP? Ingaba lukhona ulwazi oluphangaleleyo othi ulifumane xa uthe waya kwi club/QPUP?Lulwazi olunjani othi ulifumane?Lulwazi olucinga luphangalele? Xa lungenelanga, chaza ukuba ufuna lubenjani?

4. Uphatheka kakuhle ngokufumana uncedo

Uze eclubini/QPUP ngantoni?Ulufumanela ndawoni uncedo (ekliniki, ekuhlaleni)?Ungene kanjani eclubini/QPUP uze ube lapha? Kunjani ukufumana uncedo eclubini/QPUP

5.Olu lwazi lunikezwa njani

Nibangaphi eclubini/QPUP? Uyalufumana uncedo kumalungu amanye? Bunjani ubudlelwano benu?Bunjani ubudlelwano bakho no facilitator? Bunjani ubudlelwano bakho namanye amalungu eclub/QPUP?Niyadibana okanye nithethe ekuhlaleni ngaphandle kokuba nibonane eclubini/QPUP?

6. Ukwamukela ukubandanyeka kosapho/nabahlobo?

Ukhona umntu owaziyo ukuba uthatha amayeza ekliniki xa uthatha oluhambo?Ukunceda kanjani?Eclubini/QPUP, ingaba uvumelekile ukuthumela umntu azekuthathela amayeza? Ukhona umntu othembileyo oya umthume azekuthathela amayeza?ukhona umntu ongumhlobo onothi uluncedo apha kuwe? Luncedo luni akunika lona?

7. Ukuqhubekeka kwezempilo

Unexesha elingakanani usitya lamachiza? Uqale nini ukuba seclubini/QPUP? Yintoni eyakwenza wangena iclub/QPUP?Uyafisa ukuba ufumane uncedo ngezinye indlela ngaphendle kweclub/QPUP?Yintoni oyithandayo/onagyithandiyo nge club? Kungaphuculwa njani oku?

8. Ukufumana komnyango wezempilo

Nidibana eclubini/QPUP kangaphi? Uza ngantoni xa usiza eclubini/QPUP?Uhamba ngetaxie, bhasi okanye uza ngenyawo? Uthelekisa ne kliniki, ingaba impatho yaseclubini/QPUP injani?I ngaphuculwa kanjani?

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APPENDIX 5: FOCUS GROUP INTERVIEW GUIDE

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Ingaba zikhona ezinye iindlela onokuthanda uncedwa ngazo ? Nika imizekelo .

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8. Ukufumana komnyango wezempilo

Nidibana eclubini/QPUP kangaphi? Uza ngantoni xa usiza eclubini/QPUP?Uhamba ngetaxie, bhasi okanye uza ngenyawo? Uthelekisa ne kliniki, ingaba impatho yaseclubini/QPUP injani?I ngaphuculwa kanjani?