EXPLORING THE EXPERIENCES OF ADULT OFFENDERS LIVING WITH HIV ON PRE-ANTIRETROVIRAL THERAPY PROGRAM AT THE LOSPERFONTEIN CORRECTIONAL CENTRE

by

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Declaration

I, Gloria Lekubu (student number 6901875), declare that EXPLORING THE EXPERIENCES OF ADULT OFFENDERS LIVING WITH HIV ON THE PRE-ANTIRETROVIRAL THERAPY PROGRAM IN LOSPERFONTEIN CORRECTIONAL CENTRE IN SOUTH AFRICA DURING THE YEARS 2012-2013 is my own work and all resources that I used and quotes have been indicated and acknowledged by means of complete references.

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GSS LEKUBU
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Dedication

This dissertation is dedicated to the following people:

Participants in the study
Offenders appointed as HIV peer educators with added responsibility of facilitating support groups in correctional centres

Study site leadership
The passionate and very committed HIV partners working in Correctional Services
The health care providers (psychologist, social workers, spiritual care workers, professional nurses, doctors, pharmacists, nutritionists) within correctional centres
Abstract

The aim of the study was to explore the experiences of adult offenders living with HIV (OLWHIV) not qualifying for antiretroviral therapy (ART). Such offenders are put on the pre-antiretroviral therapy (pre-ART) program after HIV diagnosis. Follow up of OLWHIV is done every six months to ensure prompt treatment. Research objectives include exploration of experiences of OLWHIV on the pre-ART program, the accessibility of the program and the challenges thereof. An exploratory, qualitative study with face-to-face interviews was conducted. Purposive sampling of the eight participants was done to conduct the study.

Seven out of eight participants accessed the pre-ART program well but had little knowledge of the pre-ART program. Furthermore, participants experienced little support from partners and health care workers. The study showed institutional constraints such as poor diet, shortage of staff and humiliation from Correctional officers. Participants portrayed commitment in the support group irrespective of the challenges experienced. The study further showed that the self-care theory could enhance the pre-ART program but that institutional constraints deterred the progress. Participants made recommendations such as strengthening of partnerships for support groups, good diet, and an increase of staff capacity. Overall study recommendations include implementation of universal test and treat and mixed methods for future studies.
Acronyms

a) ART: Antiretroviral treatment  
b) DCS: Department of Correctional Services in South Africa  
c) HCT: HIV Counselling and Testing  
d) IACT: integrated access to care and treatment  
e) ILO: International Labour Law  
f) LTF: Loss to follow  
g) MDG: Millennium Development Goals  
h) NDP: National Development Plan  
i) NSP: National Strategic Plan  
j) OLWHIV: Offender living with HIV  
k) PHC: Primary health care  
l) PLHIV: People living with HIV  
m) PMC: Participant management committee  
n) Pre-ART: The period between being infected with HIV and the introduction of antiretroviral therapy (ART) to the individual  
o) SANAC: South African National AIDS Council  
p) STI: Sexually transmitted infections  
q) TB: Tuberculosis  
r) UNAIDS: The joint United Nations Programme on HIV and AIDS  
s) UNODC: United Nations  
t) UNDP: United Nations Development Programme  
u) WHO: World Health Organization
CHAPTER 1: INTRODUCTION

1.1 Introduction

The study explored the experiences of sentenced adult offenders living with HIV (OLWHIV) in the Losperfontein Correctional Centre on the pre-ART program during the years 2012 and 2013. A qualitative research methodology with face-to-face interviews was done with the aim of exploring strategies on how to improve the pre-ART program. Eight participants were purposively sampled for the study as elaborated in chapter 3.

The World Health Organization (WHO; 2012:2) describes the pre-ART program as an intervention between being tested HIV positive and the introduction of antiretroviral therapy (ART) to the individual. The period of pre-antiretroviral therapy among others involves counselling for psychosocial support; giving of vitamin tablets to boost the immune system of the individual and six monthly health screening with every encounter with the health practitioner (South Africa, Dept. of Health 2013:24).

WHO (2011:3) notes that studies show poor retention of PLHIV in care services, hence the pre-antiretroviral therapy program aims at ensuring and sustaining the wellness of PLHIV prior to the introduction of antiretroviral treatment. Studies show that 50% of the people tested for HIV and infected with HIV in sub-Saharan Africa are lost between HIV testing and being assessed for antiretroviral treatment eligibility (WHO 2013:10). Research reveals that shorter waiting times in care services, free cotrimoxazole tablets, regular assessment in care for eligibility for ART and counselling improve retention of PLHIV on the pre-ART program (WHO 2013:16). Furthermore, transfers of offenders between correctional centres, newly admitted offenders, and released or discharged offenders contribute to poor retention of PLHIV in care services (South Africa, Dept. of Health 2013:29-30).

President J. Zuma of South Africa launched antiretroviral (ART) policy guidelines during the commemoration of International AIDS Day on 1st December 2010 in Pretoria (South Africa, Dept. of Health 2013). The aim of the guidelines is to diagnose HIV earlier; prevent the progression of HIV infection; avert AIDS related
deaths; and retain people living with HIV in lifelong treatment (South Africa, Dept. of Health 2013:4).

Offenders have the right to receive health care equivalent to that provided for South African communities according to the Constitution of South Africa (No 108 1996). Offenders are classified as key populations or vulnerable people to HIV (South African National AIDS Council [SANAC] 2008:5). The Department of Correctional Services in South Africa (DCS) took a positive step by crafting a policy on HIV, TB and sexually transmitted infections (STI) in partnership with the Department of Health (DoH). The crafted policy highlighted continuity of care after HIV testing and it was endorsed by the Minister of Health, Dr A. Motsoaledi in 2013 (South Africa, Dept. of Health 2013:13-17).

1.2 Background

SANAC adopted the 20 year vision of the three zeros from WHO; namely, zero new HIV and tuberculosis (TB) infections; zero preventable deaths associated with HIV and TB; and zero discrimination associated with HIV and TB (SANAC 2011:12). SANAC crafted and endorsed the National Strategic Plan on HIV, TB and STIs (2012-2016) based on the vision of the WHO on HIV, TB and STIs.

Benator (2014:613) mentions that currently half of the 21000 offenders in South Africa are on ART. With the 2013 ART guidelines whereby PLHIV with the CD4 count of 500 will commence ART, more OLWHIV will need more treatment and monitoring on the pre-ART program. This demands more financial and other resources (the joint United Nations programme on HIV and AIDS [UNAIDS] 2014). Currently, the greatest challenge for the DCS is the financial support to respond to the strategic needs including access to care of OLWHIV (DCS 2012:13).

The pre-antiretroviral therapy program is a new concept globally and requires PLHIV to be screened for illnesses such as TB immediately after being diagnosed with HIV. The health practitioner is expected to discover the individual’s progress in terms of coping mechanisms of his or her HIV status and support system. The individual should be encouraged to mention any minor physical ailments such as chest pain and flu-like symptoms at every visit. Furthermore, psychosocial assessment should be done to ensure the optimal good health of the individual (South Africa, Dept. of
Health 2013:24). The Department of Health emphasises that PLHIV should receive counselling to alleviate fears, myths and misconceptions with the support of health practitioners, families, and friends.

Because of the above-mentioned demands concerning the pre-ART program in South Africa, the Department of Health implemented the integrated access to care and treatment (I ACT) strategy in 2009 with the aim of giving support and education to PLHIV on basic HIV information, psychotherapy, nutrition, HIV risk reduction, treatment literacy and prevention of opportunistic diseases such as diarrheal disease that also form part of the pre-ART program interventions. Life style adaptations such as exercise are the key areas for discussion in the support group sessions.

The White Paper on Corrections in South Africa (2005:12) acknowledges HIV as a challenge in correctional centres and stipulates that the DCS will mitigate the impact of HIV by focusing on program implementation to reduce these impacts. Furthermore, the Department of Health mentions that program implementation will ensure that inmates leave the system as healthy as possible.

The White Paper for the Transformation of Health Systems in South Africa (No 667 of 1997) dictates that the provincial Departments of Health should integrate health care services for offenders but unfortunately it has never been implemented. Bulbulia and Berger (2008:22) identify major challenges faced by correctional facilities in Africa, which include overcrowding and HIV which make it difficult to implement programs.

This study was undertaken in South Africa at the Losperfontein Correctional Centre. This correctional centre is based in Brits in Northwest province. Losperfontein Correctional Centre was identified as a study site because of its initiative in implementing the HIV program in the province within the DCS. The study site had a population of 988 sentenced male offenders with 138 OLWHIV on the pre-ART program (DCS 2013).

The Pre-ART program is the precursor of treatment and forms an integral part in the continuum of care in all settings of care to reach the target of zero new HIV infections, zero discrimination and zero deaths related to HIV. Psychologists, social
workers and spiritual workers play a critical role in ensuring the implementation of the psychosocial aspects of the pre-ART program.

1.3 Research problem

WHO (2014:XIX) mentions that prisoners are classified as one of the key populations because of the high incarceration of prisoners, high risk behaviour related to HIV and lack of HIV services in correctional centres. Motala and McQuoid-Mason (2013:40) also note that South Africa has the highest incarceration of prisoners in the world. The Population Council (2014) further mentions that “key populations have the highest risk of contracting and transmitting HIV infection as compared to the general population”.

The joint United Nations Programme on HIV and AIDS (UNAIDS) (2014:149) considers that the HIV burden in prisons is 50 times higher than that in the population in the community but countries give little support for program implementation. Offenders are at risk of violence and that contributes to the disruption of HIV prevention, treatment and support programmes (UNAIDS 2014). Two thirds of HIV programmes implemented for the key populations are dependent on international resources irrespective of country availability of budget (UNAIDS 2014:96). The study under scrutiny focused on experiences and challenges related to the pre-ART program to ensure that the study site created an environment that protected and promoted the human rights of offenders. SANAC (2014:2) mentioned that the national development plan (NDP) aims for an AIDS free generation by 2030. Furthermore the National Strategic Plan (NSP) aims to reduce HIV related deaths by 50%, and to start 80% of eligible PLHIV on ART with 70% still alive five years after the initiation of the program (SANAC 2014:2). This study aimed to support the goals of the NSP as mentioned.

UNAIDS (2011:54) mentioned that the distribution of relevant policies on HIV counselling and testing (HCT) is noted but few studies report the level of interventions such as the pre-ART program in the correctional centres. The NDP vision mentioned cannot be reached without this knowledge.

Du Toit, Van Schalkwyk, Dunbar, Jennings, Yang, Coetzee and Beyers (2014:1) reveal that few studies evaluate access to and retention of the pre-ART program in
the community of Cape Town and further emphasise that reasons for poor retention need to be explored. Correctional centres depend on the Department of Health for guidance and leadership with regard to HIV related issues; hence gaps mentioned by the researchers in the community impact correctional centres negatively. The notion encouraged the researcher to explore access to services and experiences in terms of the pre-ART program.

People living with HIV in the pre-ART program are asymptomatic and fear the stigma that follows being recognised at the clinic with repeated visits (Rosen & Fox 2011). This situation contributes to loss to follow (LTF) in health care. These researchers further mention that only 18% of PLHIV remain in the pre-ART program after HIV testing. The study also shows that little research has been done, and none to track PLHIV for loss to follow. Patients that present late for pre-ART with low CD4 count contribute to the high mortality rate in the first year of ART commencement. Research reveals the need to explore the experiences of PLHIV on pre-ART care, and reasons for LTF are crucial. No documented research has been done in Africa and globally in correctional centres. Hence this study concentrated on experiences in the pre-ART program.

The United Nations requires that the quality of health care in correctional centres be equal to that of the general population of that country. This means that offenders should not be discriminated against regarding health care in any country including South Africa (Todrys & Amon 2012:1). Furthermore, the South African Constitution (No 108 of 1996) protects people’s rights to bodily and psychological integrity; but with extreme overcrowding in correctional centres, these freedoms are very difficult to secure for offenders. Overcrowding makes it difficult for offenders to access treatment because of the limited space that compromises privacy and perpetuates stigma and discrimination related to HIV.

The shortage of health care professionals and inadequate facilities for the management of HIV in South African correctional centres pose a threat to the offenders and the community at large (Todrys & Amon 2012:1). The facilities of correctional centres built to house offenders for security but not for health issues are inadequate. This situation is exacerbated by the HIV prevalence of 19.8% in
correctional centres compared with 16.3% in the country (South Africa, Dept. of Health 2013: XI).

Motshabi, Pengpid and Peltzer (2011) researched access to HIV counselling and testing (HCT) at the study site under scrutiny and mentioned that the study showed 50% access to HCT. These researchers related this outcome to poor health education on HIV and concluded that Losperfontein Correctional Centre had a poor health system. HCT being the entry point to the pre-ART program prompted the author of the present study to make a contribution to the goals of NSP 2012-2016 by exploring the experiences and challenges of the pre-ART program. Furthermore it determined the access level thereof and made the necessary recommendations to mitigate deterrents of the program implementation. Because studies on the topic do not show participants’ suggestions, the researcher highly considered participants’ solutions to problems discussed in the topic to ensure that they contributed to their health outcomes.

1.4 **Aim of the study**

The aim of the study was to explore the experiences of adult OLWHIV on a pre-ART program while they were still in the preparatory phase of using ART. The study also aimed to explore the level of participants’ access to the pre-ART program with the intention of starting 80% eligible OLWHIV on ART and improving the life expectancy of 70% of OLWHIV beyond five years after the inception of ART (SANAC 2014:2). The study further aimed to gain knowledge of the challenges experienced by the study participants and their recommendations, with the ultimate aim of making overall recommendations that would inform the implementation strategy of the pre-ART program at the study site.

1.5 **Research objectives**

The objectives of the study were:

- To explore the experiences of offenders living with HIV on the pre-ART program in Losperfontein Correctional Centre.
To explore the level of accessibility to the pre-ART program for the adult offenders living with HIV
To explore challenges experienced by adult offenders on the pre-ART program
To explore recommendations on how to enhance the pre-ART program within Losperfontein Correctional Centre.

1.6 Research questions

- How do adult offenders living with HIV experience the pre-ART program?
- How do adult offenders living with HIV access the pre-ART program?
- What are the challenges experienced by adult offenders who are living with HIV and are on the pre-ART program?
- What are the recommendations to enhance the pre-ART program in Losperfontein Correctional Service Centre?

1.7 Assumptions of the study

1. Adult offenders living with HIV in Losperfontein Correctional Centre experience the Pre-ART program positively.

2. Adult offenders living with HIV in the Losperfontein Correctional Centre adhere to the pre-ART program.

3. The Losperfontein Correctional Centre environment is humane for the offenders on the pre-ART program.

1.8 Operational definitions

a) Awareness of experiences in the study: consciously and subconsciously always striving to make sense of surroundings

b) Pre-ART program: The interventions between being infected with HIV and the initiation of ART to the individual (WHO 2012:2). The interventions involve counselling for psychosocial support; support group participation; provision of
vitamin tablets and nutrition; risk reduction; health screening such as CD4 count with every six monthly encounter with the health practitioner (South Africa, Dept. of Health 2013:24). The pre-ART phase is the period between being infected with HIV and the introduction of antiretroviral therapy (ART) to the individual.

c) Loss to follow of patients (LTF) in this study refers to people living with HIV not accounted for or not traceable owing to reasons beyond control.

d) Adult offenders in this study, refers to any person incarcerated and above the age of 21.

e) Offender means convicted person sentenced to incarceration (Correctional Service Act 2011)

f) Correctional centre (prisons): means “any place or building established for the reception, detention, confinement, training or treatment of persons liable to detention in custody …” (Correctional Service Act No. 25 of 2008).

1.9 Conclusion

Chapter one (1) stated the research topic and gave a background of the complexities and contextual dimensions of HIV in correctional centres. The little documented research on the topic shows that offenders have been categorised as key populations owing to their high vulnerability to HIV. Irrespective of that situation, UNAIDS (2014) mentions that access to HIV prevention interventions, treatment and support for offenders is lacking tremendously. This study aimed to explore the level of accessibility of the pre-ART program for the participants and further explored participants’ experiences and challenges on the pre-ART program. Research objectives and questions gave direction in terms of the expected outcome of the study.

Structure of the chapters

Chapter 2: Literature review to identify research gap and theory related to the study

Chapter 3: Research design of the study
Chapter 4: Study key findings

Chapter 5: Summary and recommendations
CHAPTER 2: LITERATURE REVIEW AND THEORY

2.1 Introduction

The literature review on the topic deals with sub-Saharan Africa in public communities including the South African Department of Correctional Services. The literature review discussed in this chapter determines the latest developments and the knowledge gap on the experiences and the challenges faced by adult offenders living with HIV (OLWHIV) on the pre-ART program. It further determines the accessibility level of the pre-ART program for OLWHIV (Jesson, Matheson & Lacey 2011:10). The chapter also provides an overview of the policy and legal framework governing correctional centres in South Africa and Africa and the theoretical framework to contextualise the study.

2.2 Literature review

2.2.1 HIV within public health sector: Africa and South Africa

The Global Fund (2015) states that there are 37 million people living with HIV (PLHIV) globally whereas 19 million people don’t know their HIV status. Furthermore, sub-Saharan Africa has the largest number of PLHIV with 70% new HIV infections. The Joint United Nations programme on HIV and AIDS (UNAIDS 2014:34) mentions that new HIV infections increased from 1.02 % in 2001 to 1.98% in 2012 in this region. It notes that 10 million PLHIV access antiretroviral therapy (ART) and 6.6 million people`s lives have been saved with ART. UNAIDS further mentions that even though there is scaling up of ART globally, treatment programs are not reaching key populations such as offenders. AIDSinfo (2016) reports that the global panel on ART guidelines recommended in 2012 that PLHIV should receive ART irrespective of the HIV staging to prevent HIV transmission.

Statistics South Africa (Statssa) (2016) showed that 6.19 million people were living with HIV in South Africa in 2015. Furthermore, the life expectancy of men was 60.6
years and that of women, 64.3 years. The average life expectancy improved from 57 in 2014 to 62.32 in 2015 with the escalation of antiretroviral treatment (ART) in the country. HIV prevalence declined from 12.2% in 2012 to 11.2% in 2015 (Statssa 2015; Human Science Research Council (HSRC) 2014).

Pieterse (2011:57) mentions that the criminalisation of HIV transmission in Africa fuels the HIV stigma and violates the rights of individuals. Policies such as limited access to HIV education and no condoms to marginalised groups such as prisoners in most African countries violate the human rights of such individuals (Pieterse 2011:66). Pieterse further maintains that the solution to HIV prevention and management is systemic not individualistic and that exercising human rights in Africa brings positive results in the fight against HIV and AIDS.

The Constitution of South Africa (No 108 of 1996) emphasises that everyone has the right to access health care services and be in an environment harmless to his or her wellbeing. Access to the pre-ART program for offenders is important for promoting their health. UNAIDS (2010:124) maintains that 57% of sub-Saharan African countries have laws that create obstacles to effective HIV prevention, treatment, care and support for key populations. UNAIDS (2010) continues that a quarter of these countries do not include key populations in their programs. Many countries will fail to reach the Millennium Development Goal (MDG) number six (6) irrespective of the massive progress in interventions to curb HIV in sub-Saharan Africa (UNAIDS 2010:10). MDG 6 focuses on the management and eradication of HIV, among other diseases.

Statssa (2014:2) reported that life expectancy improved tremendously from 57 to 60 years of age with the intervention of ART. HIV prevalence was at 10.2% and PLHIV numbered 5.51 million (Statssa 2014). SANAC (2016:2) aimed to have 70% of PLHIV on ART five years after the start of ART and 80% of the qualifying PLHIV placed on ART. These SANAC objectives needed the pre-ART program as a driver to achieve these outcomes.

Kardas-Nelson (2013:5) mentions that South Africa indicates patients on ART but not those that are not attending care services. Furthermore, only one fifth to one third of PLHIV remains in continuous care from the time they are tested positive for HIV to the time they are placed on ART. Kardas-Nelson (2013) argues that the paper-based
system to collect data for monitoring purposes gives poor quality of data. Because South Africans migrate highly between towns and different health centres, there is difficulty in tracking patients (Kardas-Nelson 2013:5). Furthermore, as the health system is not yet integrated, it is difficult to track patients, and informal housing also makes it difficult. Kardas-Nelson (2013:5) quotes Francis Venter, Deputy Executive Director at the University of the Witwatersrand’s Reproductive Health & HIV Institute, as saying that half of the PLHIV are lost from the HIV testing point to starting ART. Francis Venter also cautions that poor retention in care is a human psychology problem, health system problem and an international problem (Kardas-Nelson 2013:5).

The present study aims to determine the level of accessibility of OLWHIV on the pre-ART program with the intention of promoting their life expectancy and mitigating the challenges related to the program.

2.2.2 AIDS pandemic in correctional centres: Africa and South Africa

There is high HIV infection in correctional centres compared with that of the general community (UNAIDS 2014:150; Scheibe, Brown, Duby & Bekker 2011:8; SANAC 2012:4). HIV prevalence in South African correctional centres is 19.8% compared with 16.3% of the national population (South Africa, Dept. of Health 2013: XI). This implies that the HIV risk is higher in correctional centres than in the general population. Motala and McQuoid-Mason (2013:44) mention that access to health services is not guaranteed for all people as written in the South African Constitution especially within correctional centres. The fact prompts the need for intensive interventions on HIV prevention, treatment and support programs in these facilities. Condoms are distributed in South African correctional centres but HIV prevalence still remains high (Scheibe et al 2011:8-9; SANAC 2012:5). Furthermore, condom distribution is done without lubricants and this puts offenders at risk of sexually transmitted infection (STI) including HIV. Condom collection is monitored but the usage thereof is difficult. Condom usage is one of the risk reduction interventions in the pre-ART program.
Todrys and Amon (2012:3) observe that Zambia banned condoms in correctional centres and that made HIV prevention very difficult. These researchers furthermore mention that correctional centres use Global Funds for irrelevant issues such as new computers when there is no capacity for interventions such as condom distribution and HCT. Todrys and Amon (2012) also maintain that studies show that all correctional facilities in sub-Saharan African countries such as Kenya, Mali, Uganda and Zambia are over 200% of capacity and under-resourced for rendering health and HIV services. This situation is aggravated by the overcrowding in these facilities.

WHO classifies offenders as key populations owing to their high risk nature related to HIV and related challenges (SANAC 2012:2). HIV mitigating strategies for the key populations are prioritised in South Africa to curb HIV infection (SANAC 2015:24). Prevention strategies such as condoms and HCT, early treatment and support have been instituted in correctional centres (SANAC 2015:24). The notion that emphasises that national HIV policy implementation needs support and cooperation at all levels of governance is also supported by UNAIDS (2006:33).

Sifunda, Reddy, Braithwaite, Stephens, Bengu, Ruiter and Van den Borne (2007:807) mention that the period offenders spend in correctional centres gives them the opportunity to acquire skills and knowledge about HIV infection. Motala and McQuoid-Mason (2013:44) emphasise as well that HIV education, peer counselling and access to support groups overcome some of the challenges experienced by offenders. Bulbulia and Berger (2008:23) mention that access to health care in correctional centres is often deterred by non-supportive non-medical staff locking up offenders. The correctional officers hurry to do head counts of offenders and ignore their health care needs. These researchers also note that offenders should be educated regarding disclosure of appropriate medical information to ensure that officials take the necessary measures when health care is needed. Furthermore, these correctional officers should be trained in HIV including confidentiality issues.

UNAIDS (2014:150), in support, mentions that lack of capacity limits health service delivery in correctional facilities. Motala and McQuoid-Mason (2013:42) observe that another challenge that deters health service delivery in correctional centres is the frequent movement of offenders from one correctional centre to another or to an external health facility. These offender movements impact negatively on adherence to treatment because treatment is taken at irregular times.
2.2.3 Pre-ART program in South Africa and sub-Saharan Africa

2.2.3.1 Overview of the pre-ART program

Lykketoft (2015) launched the “Mandela Rules” as the Standard Minimum Rules on the treatment of offenders on 12 October 2015. The Standard Minimum Rules include the right to access health care that is equivalent to that of the community without any discrimination. The Department of Correctional Services (2012) (DCS2012) emphasises that “prisoners are entitled, without discrimination, to a standard of health care equivalent to that available in the outside community, including preventive measures”. WHO (2014) warns strongly that failure to provide adequate HIV services to key populations such as offenders will deter global progress of the HIV prevention response.

The pre-ART program involves health care interventions for PLHIV who do not qualify for ART (WHO 2013:15). Furthermore, interventions in the pre-ART program aim to improve program outcomes and involve counselling, provision of co-trimoxazole prophylaxis free of charge, regular assessment for readiness to commence ART and shorter waiting times at clinics (WHO 2013). HCT is of paramount importance as the entry point to the pre-ART program and support groups are the drivers to sustain it.

HIV support groups included in the pre-ART program aim to provide mutual support and assistance as people with the same problem convene to share their experiences (Ussher, Kirsten, Butow & Sandoval 2005:2567). This grouping provides a forum that promotes safety, hope and the demystification of the unknown and a different space for participants. (Ussher et al 2005:2566). Haslam and Reicher (2012) suggest that members of low status groups such as offenders bond together through a sense of shared social identity, effective leadership and organisation which enable them to minimise stress and secure support in the most extreme situations. The benefits in this grouping also include promotion of social change. These researchers further mention that in-house pre-ART programs might benefit offenders in terms of support groups and treatment adherence. As HIV support groups are the backbone of pre-
ART programs, they were included in the interview guide of this research to explore participants’ experiences of it.

Muhamadi, Marrone, Kadobera, Tumwesigye, Mangen, Ekstrom, Peterson and Pariyo (2011:1) did a study in Uganda on access to HIV services and concluded that new PLHIV in sub-Saharan Africa within public health sectors do not understand the importance of regular pre-ART care because most were counselled by staff members who lacked basic counselling skills. The researchers emphasised that regular pre-ART care is rightfully discussed during counselling immediately after HIV testing and with continued counselling. Furthermore, the study results showed inadequate pre-ART services.

2.2.3.2 Policy implications

Muhamadi, Ekstrom, Mangen, Nsebagasani, Tumwesigye, Peterson & Pariyo (2010:187) observed policy challenges on the initiation of antiretroviral therapy (ART) early in Uganda. Their study focuses on ARV drugs stock outs, and HIV stigma related in Uganda health clinics. The study further shows inadequate pre-ART services and silence on pre-ART policy. These researchers mention that the situation was exacerbated by limited confidentiality of staff and by misconceptions about treatment such as that HIV treatment is designed to kill, and to cause impotence. In-depth interviews were conducted in the study and one of the participants mentioned that he regretted not having attended the pre-ART program because people that attended the program early started ART on time and looked good whereas he was still sick in spite of ART (Muhamadi et al 2010:190). This notion motivated the researcher of the present research to do a qualitative study to identify the core of the situation.

In South Africa, the DCS (2012:5) emphasises that evidence-based interventions are critically important and, furthermore, that the development of policy and programs should be based on empirical evidence on HIV risk reduction and quality improvement of the health of offenders. Motala and McQuoid-Mason (2013:41) mention that politicians and DCS management should commit themselves in dealing with challenges related to effective HIV treatment, care and support strategies in correctional centres. Du Toit, Van Schalkwyk, Dunbar, Jennings, Yang, Coetzee,
and Beyers (2014:4) accentuate the fact that clear policy on pre-ART care would give good outcomes on the program and improve the life expectancy of PLHIV including offenders. These researchers emphasise that integration of services within primary health care would promote pre-ART care retention.

The Correctional Services Act (No. 111 of 1998) emphasises that offenders must be screened for communicable diseases on admission to a correctional centre. The greatest challenge is that although HCT and ART are included in the NSP on HIV, TB and STI (2012-2013) for correctional services to comply with the Department of Health guidelines, the pre-ART program is not specifically outlined and emphasised.

The notions discussed thus far provided guidance concerning the selection of the topic of this study and its research objectives, research design and Interview guide.

2.2.4 Challenges related to the pre-ART program in correctional centres

Challenges are categorised into subsections such as access to the pre-ART program including treatment; loss to follow; diet and physical health; psychosocial issues; experiences of offenders; overcrowding; and limited resources.

2.2.4.1. Access to pre-ART program including treatment

Offenders depend largely on correctional officers to move from one point to the other in a correctional centre, such as accessing clinics (UNAIDS 2006:26). The situation prompted the researcher to explore the accessibility of the pre-ART program in the Losperfontein Correctional Centre and challenges that hindered the program. Further deliberations such as those mentioned below influenced the study.

Bulbulia and Berger (2008:23) argue that accessing health care is often limited by non-medical staff in correctional centres because of lockup times, lack of transport to public health facilities, and limited escorts. These situations make it difficult to sustain pre-ART care and they impact negatively on the timely commencement of ART. The conditions indirectly contribute to HIV related complications and deaths. The United Nations Organization on Drugs and Crime (UNODC), the International Labour Organization (ILO), the United Nations Development Program (UNDP), WHO
and UNAIDS (2012) support these reasons and mention that there is lack of access to HIV care in correctional centres.

Todrys, Amon, Malembeka and Clayton (2011:1) note that the structural barriers of correctional centres in sub-Saharan Africa such as poor infrastructure, inadequate health equipment and limited numbers of health practitioners impede HIV treatment and that there is significantly poor access to health care in Zambian correctional centres owing to overcrowding. These researchers (2011:1) further note that this situation violates the human rights of the offenders and poses a threat to their health. In spite of these challenges, these researchers indicate that little research has been done on HIV prevention and treatment in correctional centres in sub-Saharan Africa (Todrys et al. 2011:1).

Motshabi et al. (2011) also conducted a study on access to HIV counselling and testing (HCT) at the study site (Losperfontein Correctional Centre) and mentioned that the study showed 50% access to services. These researchers related these results to poor health education and health promotion. The study concluded that this correctional centre had a poor health system.

The above-mentioned information prompted the researcher to choose the Losperfontein Correctional Centre for the study. Accessibility to the pre-ART program was included in the research questions and a qualitative research design was chosen.

2.2.4.2 Loss to follow (LTF) vs. retention on Pre-ART program

WHO (2011:4) mentions that 80% of patients diagnosed with HIV infection may be lost or missing between testing and initiation of ART. WHO, UNICEF and UNAIDS (2013:16) also emphasise that many patients are lost between HIV testing and the starting of ART but mention that approaches such as shorter waiting times in the clinics and free prophylaxis have positive outcomes. Scott, Zweigenthal and Jennings (2011:1389-1390) support the notion and mention that HIV care is neglected, and that priority is given to the scaling up of HCT and ART with little guidance on how to deal with the period between HCT and ART initiation.
WHO (2012) reports that many PLHIV remain undiagnosed and start ART late and die early after commencement of ART. The situation signifies poor retention in the pre-ART program. HIV care is explained as a continuous engagement from HIV diagnosis with prevention, treatment, support and care services (WHO 2012:4). The prerequisite of keeping patients that tested positive with HIV until initiation of ART is the determination and understanding of where and when they are lost in the health care system.

This notion motivated the researcher to decide on the topic and explore the experiences of OLWHIV on the pre-ART program as explained in chapter 1.

Rosen, Larson and Fox (2012:1235-1237) conducted a systematic review of pre-ART retention in health care in Africa. The study shows that less than one third of people tested as infected with HIV are retained in pre-ART programs continuously. These researchers mention that countries have one or two studies on the topic. Half of the studies qualifying for the review are from South Africa. The study also shows the lack of standard definitions such as “wellness program” versus “pre-ART program”. These researchers observe that lack of standard definitions is one of the limitations of the study. Rosen et al (2012:1237) reveal that 41% of PLHIV in the community are not accounted for in pre-ART programs and that mobility of PLHIV could contribute to LTF. Furthermore, long waiting times at health facilities, long distances and limited transport to clinics are some of the contributors to LTF.

Rosen et al (2012) recommend proper health information systems to track patients at every level of the pre-ART program. A unique patient identifier is also recommended for the tracking of patients from the HIV testing point and that it should be used at every clinic visit. The system could determine reasons for LTF and detect early LTF offenders. Interventions could be instituted to curb the problem. The system should also link OLWHIV on admission to a correctional centre with care services, during their transfer to other correctional centres or with offender release to the community. This is important for the continuity of care.

As a linkage to care study is currently underway in correctional centres, the researcher did not consider the topic.
Robi (2013:4) conducted a study in rural Ethiopia on factors associated with LTF of PLHIV on pre-ART programs. The researcher mentions that 38.2% of PLHIV are retained in a year on pre-ART care and 50% of LTF occurs within six months. The researcher shows that there is no distinct pre-ART package or guideline. Furthermore, Robi (2013:4) mentions that mistrust of PLHIV in pre-ART care, fear of discrimination and stigma, and limited transport to the clinic contribute to LTF. Robi (2013) recommends reduction on long waiting time at the clinic and non-frequency of return dates to achieve quality pre-ART program. Patients should not have to wait too long at clinics and return dates should not be too frequent unless there is a dire need. This factor also prompted the researcher to decide on the present research topic and to determine the application of the self-care theory to the topic.

Govindasamy, Meghij, Negussi, Baggaley, Ford and Kranzer (2014:7) note that few studies have been done on pre-ART programs in low and middle income countries. They also report that some PLHIV are not retained in pre-ART care but attend health facilities for other medical conditions. They recommend integration of pre-ART care into primary health care. The research of Govindasamy et al (2014) further shows low patient uptake and low sustainability of the pre-ART program. The writers argue that the quality of pre-ART care studies done so far is low and suggest a higher quality of research on the key population groups such as offenders because of their high risk and vulnerability to HIV (2014).

Du Toit et al (2014:1-6) conducted a study to assess reasons for non-retention in pre-ART care in the community of Cape Town. These researchers support other researchers and cite that very few studies focus on pre-ART programs irrespective of the challenges experienced by PLHIV. The study shows retention in the pre-ART program of between 26% and 45%. Furthermore, the study reveals that many PLHIV start ART with a CD4 count of 111 cells/mm³ and 124 cells/mm³, males and female respectively. Late starters on ART reflect poor retention on the pre-ART program whereas they could have commenced treatment earlier with CD4 counts of 200 cells/mm³. These researchers recommend a qualitative study to explore the reasons for the LTF of patients; suggest decentralisation and integration of pre-ART services with primary health care; and provision of incentives such as free vitamin
tablets and counselling services. Du Toit et al (2014) also recommend awareness campaigns on HIV with emphasis on pre-ART care and support groups.

The researcher of this study included support groups in the interview to determine their effectiveness in pre-ART care.

The Department of Health (2014:36) acknowledges these shortfalls mentioned by the researchers and notes that irrespective of progress on ART, retaining HIV patients in care is a challenge. Furthermore, high risk patients such as offenders need to be targeted at all stages from health screening, HCT, on-going counselling and retention in care to treatment. Weschler and Manby (1994:127) note progress made in South Africa as offenders are allowed and encouraged to do physical exercise daily for an hour irrespective of these challenges. Davies and Karstaedt (2012:1) point out that the reasons for loss to follow up (LTFU) in correctional centres include inter correctional facility transfers and releases of offenders. These researchers (2012:1) suggest that priorities of care should include HIV testing and counselling, timely ART commencement and linking to care of all transferred and released offenders on HIV treatment and care programs.

### 2.2.4.3 Diet and physical health

Motala and McQuoid-Mason (2013:42) observe that customisation of diets makes it difficult to cater for the nutritional needs of the offenders owing to systematic problems such as varying times of serving food. The situation poses a threat to the health condition of OLWHIV and the correctional centre population as a whole. OLWHIV are generally immune-compromised and a proper diet is critically important. Routine multivitamins are prescribed for OLWHIV to boost immune systems. United Nations (2014) mentions that nutritional failure is not only related to poor access to food but has negative implications on health conditions and diseases such as HIV.

Poor nutrition including scarcity of food drives offenders to exchange food for sex in correctional centres (UNODC; UNAIDS & World Bank 2006:25). The researcher as an employee of the Department of Correctional Services knows of reported incidents
of high protein diet good food sold or exchanged for any favours including sexual favours in the correctional centres.

Offenders having both HIV and TB infections need a good healthy meal because they manifest anorexia, weight loss and nutritional deficiencies (DoH 2013:27). “Meals at the Correctional Centres must be nutritionally well-balanced and the menu should consist of breakfast, lunch and supper with one hot meal per day approved by a qualified dietician” (South Africa, Dept. of Health 2013:27).

Goyer, Salojee, Richter and Hardy (2005: 7-8) note the lack of proper nutrition for offenders in South Africa. The notion is supported by Carrabine (2012:896) who reveals incidents of intimidation, bullying, assault and robbery of any kind including food in the everyday life of prisoners. Carrabine (2012:896) also states that daily victimisation has a tremendous impact on the development of prisoners at these correctional centres. This situation has a negative impact on the pre-ART program because it interferes with education, training and HIV support groups. Security is strengthened in correctional centres and that threatens the operation of support groups as well.

Bulbulia and Berger (2008:26) also mention that meal times may be a major barrier to adherence to treatment because treatment requires ingestion of fluids with meals. The routine of the correctional centre may make treatment adherence very complicated.

2.2.4.4 Psychosocial issue experiences of offenders in correctional centres

Pieterse (2011:62) acknowledges that feelings of guilt, fear and hopelessness prevent marginalised people such as offenders from seeking HIV testing, information and treatment. This situation gives a skewed number of PLHIV and has a negative impact on national planning and the allocation of resources for treatment, care and support for PLHIV. The situation limits and compromises entry to pre-ART care.

This notion motivated the researcher to decide on the topic to explore the attitudes, and emotions related to pre-ART care.

Francis (2014:64) comments that an individual experiences low self-esteem and self-blame when he or she lives in an environment of negative messages and images.
The individual ultimately accepts the situation and thinks that he or she deserved such degrading treatment. Francis (2014:62) also notes that such stereotypes are linked to HIV related stigma and prejudices and that this stigma is underpinned by sexual conduct and drug use but not based on facts. The implication is that HIV related stigma encroaches on the social life of the individual’s free human rights. Francis (2014) further mentions that negative messages could be related to institutional discrimination and exclusion at schools and hospitals. Ultimately, many PLHIV are oppressed and live as second class citizens owing to the prevalence of stigma (Francis 2014). These issues mentioned by Francis relate to the study under discussion because participants live with HIV while incarcerated.

Todrys and Amon (2012:36-38) mention that research shows that people who know their HIV status are more likely to change behaviour but violence, coercive sex and sex traded for food in sub-Saharan correctional centres deter HIV care. Condom usage is not easily negotiated in a violent situation and has negative spinoffs for pre-ART programs. What aggravates the impact of these social ills is that health care workers in these centres are often put in a difficult ethical position with conflicting loyalties to the patient and the authority of their superiors. An example of such conflicting loyalties is in the case of doctors disregarding the torture of the late Steve Biko who needed treatment (Bulbulia & Berger, 2008:23). These researchers recommend access to health care in correctional centres. This also prompted the researcher to explore the access to pre-ART programs and the challenges and solutions involved.

**2.2.4.5 Lack of resources and health systems**

Scott, Zweigenthal and Jennings (2011:1389) mention that pre-ART care is neglected by leadership and researchers who focus only on the scaling up of HCT and ART. Resources are not allocated and supportive counselling is not prioritised vigorously for PLHIV between HIV testing and ART (Scott et al 2011:1390). Johnstone-Robertson, Lawn, Welte, Bekker and Wood (2011:809) also reveal that shortage of staff in the Department of Correctional Services exacerbates the AIDS pandemic. Additionally, the limited number of health care workers means reliance on offenders to report minor ailments at every encounter with health professionals. It is
not easy for offenders to verbalise minor ailments on admission because of fears of HIV stigma and discrimination. South Africa, White paper on Corrections (2005:79) encourages offenders to seek health care solutions that are appropriate and attainable within a correctional centre environment.

Benator (2014:613) explains that although fewer than 25% of 800 professional nurses in the DCS have primary health care (PHC) qualifications, they are the only ones allowed to prescribe ART. This situation causes a delay in service delivery. Todrys and Amon (2012:3) suggest additional human resource for the HIV program in Uganda Correctional Centres. Scheibe et al (2011:9) also note that quality and HIV service delivery are compromised by the shortage of doctors and other health professionals within correctional centres. These researchers further argue that the situation is exacerbated by the limited funding for HIV interventions within these centres.

Faure (2014:32) mentions that most of the clinics in correctional centres experience large numbers of offender consultations daily and this puts a strain on staff that is already limited. The contributing factor of the strain in many instances is based on the daily provision of treatment for HIV and chronic care. Faure (2014) also notes that the distance of the supplying pharmacies from Losperfontein Correctional Centre is problematic. The situation delays the medical scripts and often reaches pharmacies a day later. The process contributes to delays in HIV care treatment.

Faure (2014:16) further mentions that the patient develops dependency on the health care team when daily treatment is availed. Daily treatment is important for difficult HIV care regimen patients to improve adherence to treatment. The challenge is that offenders given daily treatment tend to know only the colour, shape of the tablets but not the name of treatment. This situation has a negative impact on their self-care when they are released from the correctional centre.

Research questions on challenges related to the topic were included in the present study to determine the core of the situation.
2.2.4.6 Overcrowding in correctional centres

UNAIDS (2006:27) indicates that poor supervision and compromised safety of offenders as a result of overcrowding predisposes offenders to gangsterism, violence, sexual abuse and HIV. These social ills promote exchange of food, sex and medicines which impacts negatively on the wellbeing of OLWHIV. Medicines are also snatched or destroyed during violent attacks. Wellness and risk reduction are paramount areas of the pre-ART program.

Offenders in South Africa are frequently housed in overcrowded communal cells with floor space less than 1.4 square metres (m²) per inmate (Johnstone-Robertson et al. 2011:809). These researchers mention that regulations in South Africa stipulate a minimum of 3.34 m² of floor space in communal cells whereas the international agencies recommend a minimum floor space per offender of 5.4 m². The South African Department of Correctional Services (1997:15) argues that 3.5 m² floor spaces were allocated during the era prior to 1994 when offenders slept on floors but at the new correctional centres such as that at Vanrhynsdorp, 2.5m² bed occupancy space is provided.

Overcrowding interferes with the privacy and confidentiality of offenders because sometimes they are pressured to hide treatment from fellow offenders and correctional officers (Motala & McQuoid-Mason 2013:43). Brown, Weschler and Manby (1994:127) mention that offenders in South Africa are allowed and encouraged to do physical exercise daily for an hour to promote health irrespective of the overcrowding that persists. This activity promotes pre-ART care for OLWHIV.

The information on physical care related to pre-ART programs was included in the interview guide of the present study.

High volumes of offenders and inadequate health care systems contribute to late HIV diagnosis and late commencement of pre-ART care for OLWHIV (DCS 2013:9). The greatest threat in the overcrowded correctional centres is that 50 to 60% of PLHIV develop active TB. The situation complicates pre-ART care and prompts the elevation of care to ART programs.
2.2.4.7. Uncoordinated movement of offenders

Motala and McQuoid-Mason (2013:42) argue that the movements of offenders and recidivism impact negatively on the continuity of care for offenders with resulting poor adherence to treatment. The researcher’s experience in DCS supports the findings of these authors as she knows of incidents of offenders giving wrong names and addresses for fear of further criminal charges but unfortunately this impact negatively on health outcomes. Continuity of care is also compromised by correctional officers who ridicule offenders who ultimately become reluctant to report a need for care (Motala & McQuoid-Mason 2013:43).

All the above-mentioned challenges had an influence on the crafting of the present research topic and the determination of the research questions as elaborated in chapter 1.

2.3. Theoretical point of departure

2.3.1 Major tenets of the self-care theory

Comley (1994:756) mentions that developmental self-care requisites are derived from the health condition, such as adjustments in the life of PLHIV and learning of new skills to cope with the condition that contributes to their developmental needs. Furthermore, modification of life style such as diet and physical exercise is important for health reasons.

Taylor and Renpenning (2011:22) also note that universal self-care requisites include human development within social groups such as support groups according to human potential and human desire to be normal. Self-care is a self-initiated, deliberate and purposeful activity in the interest of one’s life and wellbeing (Fernandez, Johnson, Tran & Miranda 2012:413; Taylor & Renpenning 2011:29; Parissopoulos & Kotzabassaki 2004:1)

Comley (1994:756) mentions that health deviation self-care requisites relate to being aware and living with the effects of a discomforting physical condition as do PLHIV
who know their status and live with an opportunistic disease such as TB. Self-care further relates to the seeking of medical assistance for the illness at clinics for a period of six months as determined by the responsible health practitioner.

The DCS model of health care includes primary (basic) care, secondary (partially dependent care) and tertiary care (complicated care). The focus of the study under discussion is on primary and secondary care in primary health care. HIV testing and counselling (HCT) is done during primary care and pre-ART care during both primary and secondary care. While PLHIV carry out other activities for themselves, interventions such as health screening and counselling are done by the health team. Self-care includes all levels of care.

Comley (1994:755) points out that Dorothea Orem developed a model based on this theory. She further mentions that when an individual experiences limitations in terms of health issues, nursing care augments or provides the care needed. Taylor and Renpenning (2011:4) indicate that self-care deficits in nursing theory comprise of four areas such as nursing systems, self-care, self-care deficit, and dependent care. Self-care and self-care deficit concepts are discussed below because of their relevance to the study. OLWHIV take responsibility for their self-care by describing their experiences on pre-ART programs, and how they access the programs to improve or sustain their health. Furthermore, OLWHIV apply self-care by taking the opportunity of expressing verbally the challenges and solutions related to the pre-ART program.

The self-care theory refers to the requirements and capabilities of the person who provides the care. The theory of self-care expresses the notion that human beings attend to and deal with their problems themselves; the individual is the one acting and acted upon (Taylor & Renpenning 2011:23). “Self-care deficit is the imbalance between the required self care and the ability to perform the care” (Taylor & Renpenning 2011:4; Godfrey, Harrison, Lysaght, Lamb, Graham & Oakley 2011:3). The latter authors argue that self-care differs from person to person and depends on what motivates the self-care behaviour and the extent to which health care professionals are involved.

Godfrey et al (2011:6) further state that WHO describes self-care as happening at three levels such as individually, in family, and community. An example of an
individual level refers to the person “exercising to maintain physical fitness and good mental health, eating well, self-medicating, practicing good hygiene and avoiding health hazards such as smoking, prevention of injuries, early detection of disabilities, and compliance to a professionally prescribed medication”. PLHIV in the pre-ART program are usually healthy and active hence the use of the self-care theory. Community level refers to the self-care group which creates an environment conducive for the person who needs care such as support groups (Godfrey et al 2011:6). Because participants should be able to access support groups, the present study explored the level of accessibility of the pre-ART program regarding support groups.

These interventions are included in pre-ART programs, and the current study explored how the participants experienced all these areas.

2.3.2 Self-care concept

The theory of self-care expresses the view of human beings attending to and dealing with their problems themselves (Taylor & Renpenning 2011:23). Furthermore, the individual is the one acting and one acted upon, such as an offender taking an initiative to attend a support group while the counsellors encourage the offender by motivating and counselling him or her (Taylor & Renpenning 2011:23). The individual offender is the agent of self-care.

Taylor & Renpenning (2011:23) argue that the self-care concept reflects people dealing with their own care. Comley (1994:756) describes self-care behaviour as a learned behaviour from birth which is continuous in adult life, initiated and performed to maintain life, health and wellbeing. OLWHIV should be able to display self-care behaviour through participating in pre-ART programs. Comley (1994) adds that there are three categories of self-care requisites such as universal, developmental and health deviation. Universal self-care requisites include environmental variables such as air and food ingestion.

Developmental self-care requisites are derived from the health condition, such as a newly diagnosed OLWHIV makes adjustments to his or her life that contributes to his or her developmental need. The individual learns new skills to cope with the condition through counselling and teaching. Health deviation self-care requisites are
related to being aware of and living with the effects of the discomforting medical condition. They further relate to the seeking of medical assistance for the illness such as when the patient seeks treatment for diarrhoeal diseases. The taking of treatment prescribed by health practitioners is one of the requisites. Comley (1994:756) defines therapeutic self-care demand as “the total self-care action needed to meet self-care requisites”. When therapeutic self-care demands exceed individual self-care, then the intervention of the health care team is legitimate. Health care teams include practitioners dealing with psychosocial matters such as social workers and priests who participate in the counselling aspect of pre-ART programs.

2.3.3 Self-care deficit concept

Desbiens, Gagnon and Fillion (2011:2115) mention that self-care deficit has a concept of self-care as a core of the model, which relates to the health activities performed by individuals on their own to maintain life, health and wellbeing. Comley (1994:755) also supports the view that self-care is a learned behaviour which acts to regulate human structural integrity, functioning and development. She furthermore mentions that when there is a self-care deficit such as how to take tablets, the health practitioner guides, teaches, supports, and gives personal development for future demands for the OLWHIV. Godfrey et al (2011:3) support this notion and mention that as the patient initiates or engages in self-care, the health practitioner provides support.

Taylor and Renpenning (2011:9) note that an individual cannot be separated from his or her environment. But factors between the environment and the individual can be identified and explained. The researchers (2011) further mention that the environment conditions the individual’s self-care needs, the activities he or she does to meet the self-care needs, and the opportunity to engage in self-care activities. The conditioning also determines restrictions or interferences as he or she pursues self-care. Because the participants are incarcerated, they can verbalise their needs but their movements are restricted and, therefore, self-care activities are limited.
Study participants’ experiences on pre-ART care which include treatment of minor ailments were explored by the researcher. This aim included the accessibility level of the services, challenges thereof and solutions.

2.4 Application of self-care deficit theory

The self-care agency is the health care team that supports the patient to meet self-care requisites or demands. Taylor and Renpenning (2011) point out that the self-care theory acknowledges self-maintenance of the individual according to his or her capability. The health team intervenes when the person does not have the capacity or capability to care for him- or herself. Rosenbaum (1986:410) mentions that self-care encompasses all disciplines in social sciences such as psychology, social work, spiritual care and professional nursing. OLWHIV should report any deviation of health including that caused by stress.

Baquedano, Dos Santos, Teixeira, Martins and Zanetti (2010:1014) reiterate that WHO recommends self-care education to prevent and treat chronic diseases, and to improve the development of self-care skills. Furthermore, the interventions promote good health and acclimatisation with contracted illness such as HIV. Riegel and Dickson (2008:190) emphasise that self-care involves routine symptom recognition, treatment adherence, monitoring and evaluation. The present study needed to determine the experiences of adult male OLWHIV on pre-ART programs, whether they were able to access care services and able to initiate contact with a team of health practitioners every six months or when the need arose (South Africa, Dept. of Health 2013:7). Many people on a pre-ART program are well while living with HIV hence the present researcher used the self-care theory to determine the relevance and applicability in a correctional setting. OLWHIV are expected to participate in their care plan while using health care systems in the correctional centres.

2.5 Conclusion

The literature review discussed in this chapter explored previous studies on the experiences of adult offenders living with HIV on pre-antiretroviral therapy at correctional centres in sub-Saharan Africa. The review showed that
little to nothing was done regarding the topic in correctional centres and researchers identified the topic as a research gap in the public settings.

The problem in correctional centres is exacerbated by overcrowding, gangsterism and sexual abuse. Furthermore, high HIV co-infection, poor food supply, limited human resources across the board. High movements of offenders due to transfers and releases escalate such problems as well. Policy and legal issues were discussed at national and international level. Irrespective of the existing challenges, the offenders have the right to HIV care and significant efforts have been made to improve the situation (SANAC 2012). WHO (2014) also warns countries that fail to provide adequate HIV services for key population groups such as offenders that they threaten global progress on the HIV response. The self-care theory was discussed in relation to the topic.

Chapter 3 discusses the research design of the study, outlines research sampling, data gathering, data analysis and the ethical issues of the study.
CHAPTER 3: RESEARCH DESIGN

3.1 Introduction

This chapter presents the research method of the study. The profile of the study site; population; the sampling of the participants; research design; and data collection methods are outlined. Data analysis, ethical issues and validity of the study are also elaborated in this chapter. The background of the study; problem statement; and the rationale of the study were detailed in chapter 1.

3.2 Research design and methods

Because the literature review showed that no study was documented on the topic under discussion, the researcher opted to do a qualitative study to explore the feelings, attitudes and perceptions of eight offenders living with HIV. This method would assist to tap into the core issues of the topic. The research design lays out how the study observations and analysis will be done (Babbie 2010:91; Hofstee 2011:107).

A qualitative, exploratory research design was utilised. A qualitative approach focuses on human behaviour experiences and examines social research without the use of numerical data or conversion (Babbie 2010:394; Welman, Kruger & Mitchell 2009:7-34). Facts and observation should be used during inductive processes of the study (Welman et al/ 2009:34). Furthermore, the theoretical statement provides an explanation of the observations and facts in the study.

3.3 Research sampling and procedures

An exploratory research design was chosen because a pre-ART program study was new at the Losperfontein Correctional Centre and because it was the first time such a study had been conducted in a correctional centre in Africa as a whole. Exploratory
study provides a deeper understanding of a new interest in research; hence this design was used to explore the variables as mentioned in chapter 1 (Babbie 2010:92).

Sampled participants were on pre-ART during the period of 01 April 2012 to 31 March 2013. As offenders could be transferred, or even released from the correctional centre back to the community, sampling was done purposively on the day of data collection. The sample was inclusive of offenders on antiretroviral treatment who were on a pre-ART program during April 2012 to March 2013. Only OLWHIV who were keen to disclose their HIV status to the researcher and the officials that assisted with the study and were willing to participate in the study were sampled.

Study exclusion criteria ensure that more focused and appropriate data collection is done. Exclusion criteria entailed OLWHIV already on ART before 01 April 2012 and offenders that were diagnosed with HIV after March 2013. Paroled offenders were also excluded from the study. OLWHIV that refused to participate and those that left the correctional centre on the day of data collection were excluded from the sampling. Inclusion criteria included OLWHIV who were on a pre-ART program on 1 April 2012 to 31 March 2013. OLWHIV who commenced ART in the period 2012 to 2013 were also included in the sampling. The sampled participants voluntarily participated in the face-to-face interviews and were given the option of using the indigenous languages of Zulu and Setswana to ensure clear understanding and comfort during the interviews. Pseudo names were used to protect the vulnerable participants’ identities and they were also used to summarise the main findings as presented in the next chapter (UNISA 2007:15). Below is the profile of the participants sampled.

3.3.1. Participants’ profiles

The target population for the study was eight adult sentenced OLWHIV in Losperfontein Correctional Centre as explained in chapter 1. The pseudo names were as follows: John, Joseph, Peter, Esau, Moses, Khadija, Keorapetse and Tlotlo. The ages ranged from 24 to 46 years. Open ended questions in the interview guide were used to ensure that the study was focused and that the interviewing time was
well managed. Individual face-to-face interviews of participants were done in a private room with the assistance of professional nurses.

**Joseph**

He was diagnosed in 2009 with HIV but was not yet on ART. He was incarcerated in 2007.

**John**

He was diagnosed with HIV in 2011 and not yet on ART. He was incarcerated in 1999 in a correctional facility.

**Esau**

He was diagnosed in 2010 for HIV and was not yet on ART. He was incarcerated in 2005.

**Peter**

He was diagnosed with HIV in 2012 and commenced ART only in 2014. He was incarcerated in 2010.

**Khadija**

He was diagnosed with HIV in 2010 and started ART in 2014. He was incarcerated in 2005.

**Moses**

He was diagnosed with HIV in 2007 and started ART in 2014. He was incarcerated in 2005.

**Keorapetse**

He was diagnosed with HIV in 2006 and started ART in 2014. He was incarcerated in 2003.

**Tlotlo**

He was diagnosed with HIV in 2012 and was not yet on ART. He was incarcerated in 2010.
The researcher presented to the management of Losperfontein Correctional Centre a proposal approved by the Department of Correctional Services’ Research Committee and UNISA ethics committees. The date and time of implementation were set over three weeks and the study site professional nurses communicated the rationale of the study and the selection criteria as elaborated in 3.3. Exclusion and inclusion criteria were emphasised by professional health practitioners as mentioned in 3.3 to comply with the study.

The leadership of the offender support group was informed by the Losperfontein Correctional Centre HIV/AIDS coordinator about the study three weeks before data collection. This facilitated the marketing of the study in the support groups. The counsellors and professional nurses also promoted the study at every encounter with OLWHIV. The interested and suitable OLWHIV were expected to inform the correctional centre’s HIV/AIDS coordinator two weeks before the data collection. The coordinator verified participants’ details in terms of the criteria a week before data collection. He confirmed with participants through the HIV coordinator the day before data collection to ensure the success of the study.

3.4 Data gathering

The arrangements regarding date, time and venue were confirmed with the Losperfontein Correctional Centre head a week prior to the interviews. Telephonic confirmation of the appointment with the study site was done the day before the data collection. Data collection was carried out in 2014 and verification of the report with participants was done in 2015 on completion of the dissertation.

Participants voluntarily signed the informed written consent to participate in the study and at every interview session. The researcher introduced herself to each participant as he came into the private room allocated for the study, and explained her role in the study. She approached the data collection as mentioned above as a student, neutral and not as an employee of the Department of Correctional Services, to ensure that participants were at ease when answering questions. Neutrality was crucial because offenders might tense up or exaggerate narrations with the
knowledge of the researcher being a correctional officer. The researcher further ascertained that the procedure of recruitment and sampling had been handled correctly by asking each participant to elaborate how recruitment had been done by the correctional centre. Ethical issues such as confidentiality, no harm, benefits of the study and written consent were accentuated. Written consent was obtained from participants, signed and witnessed by the coordinator. Furthermore, confidentiality and privacy were adhered to during the face-to-face interviews with the use of an audio digital recorder using open ended questions. The importance of debriefing after the study was also emphasised. Interview guides included lists of topics and aspects thereof that had a bearing on the specific theme (Welman et al 2009:166).

Security measures were instituted at the study site throughout the contact with participants. Correctional officers were outside the room during the interviews, but secluded from listening to details. The coordinator arranged the participants and brought them into the private room for the interview and vice versa on completion of the interview. The researcher assured the participants that the interview was confidential and encouraged them to have cold drink and biscuits as refreshments she had brought in to help create a relaxed atmosphere. A panic button was given as a security procedure for all internal and external health teams. To ensure confidentiality, each participant was interviewed separately in a private room in a clinic setting of the study site. Data was collected until it reached saturation, that is, when probing of questions reached the same answer repeatedly.

Notes on the participants were written by the researcher at every interview. Probing and paraphrasing were used during the interview to gain more in-depth information and facts. Gestures, mannerisms were observed to assess the depth and sensitivity of the interview. This assisted the researcher’s interview technique to prevent harm to participants. None of the participants were referred for emergency psychotherapy.

Each participant was observed for non-verbal communication on entrance to the interview, during, and immediately after completion of the interview. These observations including the time started and completion were noted by the researcher. An average of twenty minutes was spent with each participant. The correctional centre did not restrict time for the study but participants were conditioned that from 12:00 to 13:00 lunch was served. The correctional centre locks
up after the head count is done and movement of offenders is strictly limited. Institutional policy of daily head count of all offenders at 14:00 could have impacted negatively on the time of interview. The correctness of data was verified with participants on completion of the report to ensure maximum accuracy of data reported.

The participants were encouraged to disclose their feelings after the interview to determine the status quo. Counselling arrangement was done with management beforehand to assist those who needed help after the interview. Each participant's counselling referral letter was written with the support of the HIV coordinator for debriefing purposes on completion of the study. The importance of debriefing was emphasised to participants.

3.5 Data analysis

All Interviews were recorded on an audio digital recorder and transcribed on paper to conduct thematic coding and verification. Welman *et al* (2009:211) emphasise that preparation of transcripts from the voice recordings should be done to convert notes into written information that can be read and edited. Data analysis was conducted immediately after the interviews so as to determine saturation of data. Mason (2010) mentions that saturation is achieved when new data does not add value to the topic under investigation. Categories were coded in the interview guide to ensure that all areas of the research objectives were included and to have interviews that were focused on the correctional centre setting, which is where the daily programme was structured. Content analysis was used whereby interviews were repeatedly listened to with the aim of identifying codes or themes based on the interview guide and then re-coded repeatedly until saturation was reached. Welman *et al* (2009:222) describe content analysis as the repeated, systematic examination of the content of the sources with the aim of recording the frequency of the themes and how these themes are portrayed.

Interviews were continually transcribed verbatim and translated from indigenous languages into English without editing the narrations. Field notes, emotions or expressions of interviewees were integrated into the thematic coding to ensure that
the analysis and the interpretation of the findings were valid. On completion of the study report, only five participants of the eight were still in the correctional centre to verify the report. The other three participants had been released to the community.

Transcriptions were sorted according to common themes; this assisted in identifying interrelated themes and new emerging ones for further descriptions. Common themes were placed together to provide meaning while the new themes or subthemes were separated for comparison with the common themes. The procedure was repeated until no new theme could be coded so as to ensure that data flowed into key findings.

The supervisor provided guidance and support in terms of the research methodology and inputs were completed as recommended. Axial coding was utilised to identify different themes and subthemes. Hsieh and Shannon (2005:1277) mention that summative content analysis involves counting and comparisons of content followed by interpretation of the underlying contents. Babbie (2010:394) supports the process and notes that “data collection, analysis and theory are intimately intertwined”.

A theme is an umbrella construct identified by the researcher before, during and after the data collection (Welman et al 2009:211). The themes were identified after the transcription of the interviews and the analysis of the narrations. Findings and interpretation were done by way of comparing the data collected with the theoretical framework and literature review to ensure validity of the study. The analysis of the data and the summary of the findings were done by observing meaningful patterns and repetition of themes to draw conclusions from the data.

3.6 Pre-test of the interview guide

The testing of a data collection tool is important to ensure coherence, quality data collection and to determine the speed of the tool. Indigenous languages were included in the development of the interview guide. Welman et al (2009:166) describe an interview guide as the list of topics that has a bearing on the given theme and that the interviewer uses to raise questions. The Interview guide should befit the participants’ social background such as literacy level and furthermore tally with the allocated time of the interview (Welman et al 2009:166). This is important in
a correctional setting because offenders have a daily structured program with allocated times.

The pilot of the interview guide was done with one colleague to ensure the validity of the study and the applicability of the tool a week before the interviews. A timer was used to determine the possible time that would be spent on each interview. The Interview guide was used to ask every question and gestures were observed during a pre-test. On completion of the pre-test interview, the participant was asked to give an honest opinion of how he felt about the procedure, the interview guide and the sensitivity and practicality of the interview. The interview lasted for fifteen minutes and he recommended rephrasing a question on access to the pre-ART program.

3.7 Validity of the study

Validity is the measure that accurately shows the concept it is intended to measure (Babbie 2010:153). Furthermore, validity means that we are measuring accurately what is intended to be measured. Validity also reflects the level at which the research findings accurately represent the real situation in the environment (Welman et al 2009:166). Shenton (2004: 63) and Polit and Hungler (1997:304) emphasise the establishment of the trustworthiness of a study. Trustworthiness was assessed by applying the two methods of validity: credibility and authenticity.

Credibility

Credibility means a true picture under scrutiny is presented or rather there is confidence in the truth of the data (Polit & Hungler 1997:304; Shenton 2004:63). The researcher sampled purposively on the day of data collection to ensure confidence in the truth of the study. Furthermore, research questions were aligned to the topic to ascertain that the study measured what it intended to measure as mentioned in chapter 1 (Shenton 2004:64).

The interview guide was tested for appropriateness. The researcher invested sufficient time with individual participants at an average of twenty minutes to ensure that sufficient data was collected. Noble and Smith (2015:35) point out that the credibility of a study should be proved during the research design and
implementation of the study. Key findings were validated by the literature review and theoretical framework to ensure credibility. The researcher verified the narrations with the participants to ensure that the information was representative.

Authenticity

Interactions should be authentic in research (Milner 2005). The face-to-face interviews were done with a digital audio recorder to ensure authenticity of the study as participants’ real life experiences were recorded. Participants’ direct quotes were included in the key findings and coded to enhance theoretical assumptions from the self-care theory as discussed in chapter 2. Milner (2005) observes that authenticity ensures that study data is faithful and fair to the participants.

The detailed analysis of the conversations including emotional expressions was done by identifying patterns and key quotations to ensure authenticity. The faithfulness and fairness of the study was also demonstrated by a pre-test of the interview guide to ensure that appropriate, relevant questions were used to record the exact experiences of the participants (Edmunds & Scudder 2009). Paraphrasing and verification of data ensured originality of experiences of participants.

3.8 Ethical considerations

Offenders are classified as a vulnerable group in research hence ethical issues were strictly adhered to at all times (UNISA 2007:13). The HIV Correctional Centre Coordinator signed the departmental secrecy and confidentiality form. Ethical issues are deliberated below.

3.8.1 Gatekeepers’ approval

Permission from the Department of Correctional Services Research Committee was granted following the approval of the UNISA High Degree Committee of the study as per Annexure C. Approval letters were sent to the regional leadership and Losperfontein Head of Correctional Centre. The management team of Losperfontein were briefed about the study to motivate for their support. The offender-support group and professional nurses promoted the study as mentioned in 3.3. Approval
received from gatekeepers did not substitute for the consent of the participants (UNISA 2007:14). Furthermore, names of participants were not known prior to the interviews.

3.8.2 Informed consent

According to the Constitution of the Republic of South Africa (1996), participants should give consent before they participate in any research study. All study participants were above eighteen years of age and could legitimately give individual informed written consent. Informed written consent as per Annexure A was received from participants after the study processes were explained as above. Consent was obtained at every interview irrespective of the previous consent received (UNISA 2007:14). Pseudo names were used to ensure anonymity.

3.8.3 Voluntary participation

The research study was advocated by the offender support group at the correctional centre and the professional nurses two weeks before data collection. The interested parties reported to the professional nurses. Criteria for study participants were considered and adhered to. The criteria for selecting the participants were utilised as discussed in 3.3. The researcher confirmed the sample for the study with the head of the correctional centre. Voluntary participation was emphasised by the researcher before the study participants agreed and signed the informed consent. Language preference was considered for the participants before interviews were conducted. UNISA (2007:13) notes that participants should be informed that if they feel uncomfortable with the study, they have the right to withdraw with no penalty or prejudice. Furthermore, they are free to refuse to answer certain questions or the use of data-gathering tools, for example, a camera (UNISA, 2007:13). The DCS ethical committee completely disallowed the use of a camera in the study.

3.8.4 Confidentiality and privacy

Pseudo names were used in the study and the names of participants were not known prior to the interviews to ensure privacy. All data transcribed was kept safely to ensure confidentiality. Transcriptions were coded to ensure anonymity. Identity
and contact details of the researcher and approving bodies were provided on all correspondence to facilitate communication and allay anxieties. The identity of participants within the scope of the study was not divulged to outsiders to ensure confidentiality. Publication of the study findings will only be done with the consent of UNISA and the Department of Correctional Services. Publication will be done in such a way that the privacy of participants and institutions involved is protected. (UNISA, 2007:16).

3.8.5 Potential and psychological harm

The study participants were informed by the researcher before the interview that they should participate voluntarily and had the right to withdraw from the study with no penalty if they felt uncomfortable with the study (UNISA 2007:13. Welman et al (2009:181) and Babbie (2010:65-66) also emphasise that researchers should not reveal any study information that might embarrass the participants. The researcher avoided questions on participants’ behaviour or predisposing issues on their HIV status because the judicial system had already classified them as offenders. Participants’ daily structured programs for rehabilitation purposes were considered prior to the interviews. Interviews were conducted in the middle of the week when most staff members were available to avoid compromising service delivery. Because of the high risk nature of correctional centres, security measures were instituted to prevent harm to the researcher.

3.8.6 Debriefing of participants

Babbie (2010:70) describes debriefing as an interview with a participant to determine any problems experienced by the participant during the interview. The aim of debriefing is to identify and correct any emotional problems experienced. There may be psychological harm to the participants from the research interviews; hence debriefing of participants was necessary and was done by the counsellors within the correctional centre on completion of the study. The researcher was sensitive to any harm to participants, and considered possible precautions. Each participant was observed during question time for any emotional problems, and asked after the interview how he felt. Debriefing was done immediately by the local social workers. Participants were informed about the debriefing arrangements prior to signing the
consent form. Participants were also free to refuse to answer certain questions or the use of data gathering tools (UNISA 2007:13). All eight participants managed to participate in the study actively and with ease.

3.9 Insider/outsider view

The researcher as a senior officer and a regional coordinator HIV/AIDS in the Department of Correctional Services had to deal with the pre-conceived ideas of and challenges with regard to the topic and was compelled to do the study with an open mind in a different region from the one in which she is employed. All arrangements were made by means of the researcher’s private cell phone and she wore private clothes during interviews instead of uniform to avoid imposing authority. This arrangement helped participants to relax and communicate their experiences openly. Furthermore, the aim was to ensure that offenders received support from the relevant correctional centre officers to the designated area for the interviews. No departmental status report was obtained on the topic to ensure an open mind. For those officers that identified the researcher’s portfolio, her role at that time and the importance of neutrality were emphasised for the benefit of the study.

3.10 Conclusion

This chapter detailed the methodology of the research study. A qualitative, exploratory research design was used. The population, sampling method, data collection tools and data analysis were outlined. Ethical considerations and validity of the study were also discussed. The research findings and interpretation are discussed in the next chapter.
CHAPTER 4: KEY FINDINGS

4.1. Introduction

Chapter 4 presents the research findings and interpretation of the study based on the purpose and objectives of the study as explained in chapter 1. Of the eight participants, only five were still in the correctional centre to verify narrations on completion of the research report; the other three had been released to the community. Face-to-face interviews were conducted as described in chapter 3.

The research objectives include exploration of the experiences of offenders living with HIV (OLWHIV) on the pre-ART program as mentioned in chapter 1. Other objectives include gaining knowledge of and insights into the accessibility level of the pre-ART program for OLWHIV; the challenges experienced; and solutions suggested by participants. The overall recommendations aimed to enhance interventions in the pre-ART program. Participants preferred to use their indigenous languages during the interviews. Direct quotes are reflected below without editing.

4.2 Key findings

4.2.1 Participants’ experiences on the pre-ART program

The interview guide (Annexure E) outlines the research questions to ensure focused and prompt discussion. Participants’ experiences of the pre-ART program were the main questions. Participants responded immediately and strongly with food and nutrition problems. Other research questions requested that they explain the term “pre-ART”, their participation in the pre-ART program and the benefits they had experienced. Participants generally did not understand the term “pre-ART program” until the researcher gave a description of the program such as the support group, taking of vitamin tablets and consulting health practitioners every six months to tap into their knowledge. Below are the narrations based on the research questions.
4.2.1.1 Knowing the term: Pre-ART

John, Joseph, Tlotlo, Esau:

What? Pre-ART program? I do not know what it is. Is it a new service?

Peter:

I think I heard about it with an advert of your research study, is it a new service you are introducing to help us?

Khadija:

I saw the word on HIV and AIDS pamphlets, but I do not really know what it means.

Moses:

There is a poster at the clinic written that word, but I really don’t know what it means. Please explain to me.

Keorapetse:

Pre-ART program is a fourteen (14) day period of preparation before ARV treatment is started. Keorapetse emphasised further, tablets are given and CD4 count should be at 200 before antiretroviral therapy is started.

In summary, participants could not explain the term “pre-ART” but could only mention some activities related to the programme such as support group and periodic checking of bloods at the clinic. Most of the participants had never heard of the term even though there is a pre-ART poster at the clinic. This could mean that there are competing posters or the poster is not obvious enough. The narrations also signify that the participants do not know the latest developments in the program. Motshabi, Pengpid and Peltzer (2011) support this notion and mention that poor HIV education contributes to 50% access to HIV counselling and testing (HCT) at the Losperfontein Correctional Centre.
Ba quedano, Dos Santos, Teixeira, Martins and Zanetti (2010:1014) observe that WHO recommends self-care education to prevent and treat illnesses, and to improve the development of self-care skills.

4.2.1.2. Food and nutrition at the correctional centre

Food and nutrition were the issues strongly emphasised with reference to the question on experiences of the pre-ART program. All participants mentioned that a special diet was prescribed to boost their immune system but complained about the bad food given at the correctional centre. Offenders suffering from both HIV and TB infections need good healthy meals because they manifest anorexia, weight loss and nutritional deficiencies (DoH 2013:27). Diet and nutrition are interventions essential in the pre-ART program. A few comments follow:

One of the participants, Keorapetse, vehemently said:

*Bribery and smuggling of good food in the correctional centre is rife. You (researcher) have a right to come and see for yourself how food is served, surely! The situation is bad. You will be shocked about the situation.*

Poor food and nutrition including scarcity of food drives offenders to exchange food for sex in correctional centres (UNODC, UNAIDS & World Bank 2006:25). The researcher, as an employee of the Department of Correctional Services, knows of reported incidents of high protein diet for OLWHIV sold or exchanged for any favours at correctional centres. A high protein diet is prescribed by the medical profession for OLWHIV in the pre-ART program to boost immunity and prevent nutritional deficiencies (DoH 2013:27). The UN (2014) mentions that nutritional failure is not only related to poor access to food to appease hunger, but also has negative implications for health conditions of PLHIV. More comments are provided below.

Khadija:
Ga re mo ‘five star hotel’, maphodisa a re bolelela jalo fa re bua ka dijo tse dimpe. Re a itse, fela bophelo ba rona bo tla pele. [The correctional officers tell us that we are not in a five star hotel when we complain about the bad food they give us, we all know that we are not in a five star hotel but our health is of paramount importance].

Peter:

*Ba si nika isinkwa ngo buningi, futhi ngi ya lithanda iphalishi* [They give us a lot of bread and I really prefer and like stiff porridge. Bread would never appease hunger. We want stiff porridge].

Keorapetse:

*The quality of food these days is poor; the fruit stays long in the fridge hence we are given the spoilt ones. Milk is also terrible in this place; I heard that it is diluted with water. It tastes terrible madam!*?

Tlotlo also complained:

*The food in this place is bad; I really miss the food of “Sun City” prison [Johannesburg prison]. Selling of food and bribery is also a problem. Sun City used to give us three meals per day, with fruit, vegetables and good meat. In this place food is served twice a day and it is not even palatable.*

The narrations support Goyer, Salojee, Richter and Hardy’s (2005: 7-8) belief that there is lack of proper nutrition for offenders. Carrabine (2012:896) supports the information and mentions that there are incidents of robberies and assaults related to food in the everyday lives of offenders.

Moses:

*Correctional officers give us diluted milk and very old apples many a time. Sometimes the food is dry and we are given food twice a day. Breakfast is served at 06:30 and lunch is at 15:00. It is not fair because by then we are extremely hungry and what is frustrating is that tablets give us appetite whereas food is served late.*
Francis (2014:62) notes that negative messages could be related to institutional discrimination and exclusion in areas such as correctional centres. The researcher concluded that many PLHIV are oppressed and live as second class citizens. Institutional discrimination is experienced because participants are living with HIV while incarcerated.

Motala and McQuoid-Mason (2013:42) mention that customisation of diets makes it difficult to cater for the nutritional needs of offenders owing to systematic problems such as varying times of serving food. The situation poses a threat to the health condition of OLWHIV because they are generally immuno-compromised and proper diet is important. Bulbulia and Berger (2008:26) also observe that meal times may be a major barrier to adherence to treatment of OLWHIV because treatment requires ingestion of both food and fluids. These researchers also allude to the fact that the routines in correctional centres may make treatment adherence very complicated.

4.2.1.3 How the participants involved themselves in the pre-ART program

The self-care theory dictates that people participate in their care programs. It was important that participants described their experiences in the program as they participated in it. Participants’ narrations are as follows;

Khadija:

Ke e mela go bitswa ke baoki ka nako e ba e beileng, nna ke iketla fela. Ke nwa dithare tsa me sentle`: [I rely on professional nurses to call me for check-up at the clinic. I am normally at ease and wait on them. I take my own treatment].-

He further explained:

I participated in the training of HIV in the centre as the HIV peer educator, so I know about the disease. The knowledge I acquired assist me in the discussions during the support group meeting. Remember that we are on our own in this support groups.

The theory of self-care expresses the views of human beings attending to and dealing with their problems themselves (Taylor & Renpenning 2011:23).
Furthermore, the individual is the one acting and the one acted upon as Khadija explained.

Tlotlo:

*I take my tablets on my own and I check bloods for CD4 count when requested to do so. There is nothing more one can do. That’s is all.*

Keorapetse:

*I represent fellow offenders through participants’ management committee (PMC); PMC operate in the correctional centre whereby management of the correctional centre with the six offender representatives meet on quarterly basis of the year to discuss the operational problems encountered in the correctional centre. They plan jointly to improve the situation. Unfortunately meetings were postponed repeatedly recently. I am always keen to participate to represent my fellow offenders. I also take my medicines and attend counselling sessions as required.*

Desbiens, Gagnon and Fillion (2011:2115) note that self-care deficit has a concept of self-care as a core of the model, which relates to the health activities performed by the individuals on their own to maintain life, health and wellbeing.

Moses:

*Even though there is little support from correctional officers in the centre regarding the support group, offenders meet every Friday and offender peer educators facilitate the support program effectively. It is really better than nothing.*

Haslam and Reicher (2012:154) suggest that when members of low status groups such as offenders bond together through a sense of shared social identity, effective leadership and organisation enable them to minimise stress, secure support, and promote social change in the most extreme situations. This notion emphasises the active involvement of participants in the support groups to alleviate stress, and take responsibility for their wellbeing by taking the vitamins prescribed by health practitioners. All these activities are interventions in the pre-ART program (WHO 2012: 2).
Peter:

I really could not do anything for myself during the early days of my sickness, because I could not walk, bath on my own, let alone feed myself. I was really sick. My wife and family visited me frequently during those difficult times. Professional nurses and sometimes my family bathed and fed me. It was difficult but I now can do all things for myself.

Moses:

I drink my tablets daily, and do monthly check ups at the clinic. I also come to the clinic when I am sick with flu, or when I am stressed. He further said I am doing exercise and read booklets on HIV/AIDS to get a good understanding. The books are received from Department of Health from time to time.

When therapeutic self-care demands exceed individual self-care, then the intervention of the health care team is legitimate (Comley 1994:756). The health care team includes practitioners dealing with psychosocial issues such as social workers, psychologists and priests (Comley 1994:756). Moses made an effort to seek treatment for a common cold, and furthermore took treatment as directed by the health team. The study shows participants’ active participation and interest in their health in spite of hindrances that persist. There was dependency on follow-up visits at the clinic but no clinic card was mentioned.

4.2.1.4 Pre-ART program benefits experienced by participants

Participants were requested to comment on how they benefited from or valued the program. Attitudes to and perceptions of the pre-ART program were raised with narrations in this subsection. All participants including Moses and Keorapetse mentioned the positive aspects of the program. Below are a few comments:

Keorapetse:

Dikgothatso tse di molemo di thusitse. Modiriloago, mme Motaung o thusitse ka dikgothatso, e bile o ne o ka re ke mme wa me. [I benefited
from counselling done by the social worker, Mrs Motaung. She helped me so much, and she was more like a mother to me].

Keorapetse:

_I also appreciate that I am called in by nurses for check-up when it is necessary. This kind of treatment cannot be found anywhere. Furthermore, I am able to take my treatment well as instructed at the clinic._

Moses:

_There are good benefits once you tested positive with HIV. Benefits include the diet is changed from ordinary to special diet, immediate counselling, CD4 testing after every 3 months to check the progression of the disease. Those are very critical for me._

John:

_Ke leboga dithuto ka kokwana- tlhoko ya HIV mo dikopanelong tsa batshwarwa, di siame, ga go na mathata [I appreciate support group teachings on HIV; they are good and there are no problems]._

Tlotlo added:

_Ke mo tlotlo e bile ke leboga gore re ne wa di pilisi tsa koketso ya mmele, nna ke ne ke le moketa ruri. Go nale di `support group`, e bile baoki le di `NGOs` ba re ruta ka bolwetse ba mafatlha le `HIV`. Tota re a leboga. [I really appreciate that vitamin tablets are given. I was really emaciated arriving here. A support group is also available in the correctional centre to help us with stress. Education on HIV and TB is conducted by nurses or the NGO. It is really appreciated]._

Motala and McQuoid-Mason (2013) mention that peer counselling and access to support groups overcome stigma experienced by key population groups such as offenders. Participants were keen to disclose their HIV status to the researcher. Stigma did not emerge as a problem as more offenders wanted to participate but the researcher was limited to the first volunteers.
Taylor and Renpenning (2011), Comley (1994) and Fernandez et al (2012) support the self-care theory stipulation that the health team should intervene when the individual is limited; such supportive education in self-care is important. Participants appreciated the pre-ART program and mentioned benefits such as counselling; support group existence; teachings at the support groups; the availability of vitamin pills; and that they were seen by health practitioners from time to time to monitor the status of their health. Furthermore, participants acknowledged that a high protein diet was prescribed once an offender tested HIV positive. One could see the way they beamed to show appreciation when this was mentioned.

4.2.2 Accessibility of the pre-ART services

The Constitution of the Republic of South Africa (No 108 of 1996), as the supreme law of the land, dictates that prisoners should have access to health care. The DCS (2012:5) emphasises that prisoners are entitled, without discrimination, to a standard of health care equivalent to that available in the community, including preventive measures. The participants were asked to describe how they accessed pre-ART services, what measures they put in place to overcome challenges related to accessibility of the pre-ART program and how often they attended the clinic. Participants also deliberated on accessibility to counselling services, physical health and services by stakeholders.

4.2.2.1. Description of how the clinic is accessed

All participants, except Moses, mentioned that they registered a need to go to the correctional centre clinic in the morning between 07:30 and 8:30 with the correctional officers daily. They registered health problems such as stress or sickness to be seen by a practitioner such as the social worker or a professional nurse. Comley (1994:756) notes that health deviation self-care relates to the seeking of medical assistance when one is ill as participants did. Participants’ narrations are as follows:
Moses:

The hospital section (clinic) opens on Monday until Wednesday whereas Thursday is doctor’s appointment day. It means nurses cannot see other patients on Thursdays. I am not really sure about the availability of the clinic services on Fridays. Weekends, only emergencies are prioritised. Maybe administrative work is done on Fridays.

All participants mentioned that they were summoned for clinic consultation after 09:00 by the correctional officer who escorted them to the clinic. Almost all the participants supported the notion that sentenced offenders had 100% access to health care services (DoH 2013:11). Motshabi, Pengpid and Peltzer (2011), however, observe that this study site has only 50% access to HIV care services including HIV counselling and testing. These researchers relate this to poor HIV education and health promotion. They conclude that the correctional centre has a poor health system.

4.2.2.2 Frequency of pre-ART clinic attendance

All participants commented that they depended on the clinic to call them for follow up unless there was an urgent health need. None of them had clinic appointment cards.

Moses, Keorapetse, Khadija and Tlotlo mentioned that follow-ups were done every three months. Esau mentioned six months whereas Peter said he was not sure because he was too sick to remember details. Faure (2014:16) notes that when access to daily treatment is available, it is unfortunate if the patient develops dependency on the health care team. Daily treatment is important for a difficult HIV care regimen to improve adherence to treatment. Most of the patients knew only the colour of the tablet, shape and size and could not remember the name of the treatment itself (Faure 2014:16).

Only one participant knew that the pre-ART clinic is attended every six months. All other participants did not know the follow-up period. The researcher observed that they were hesitant when mentioning a three-month period as they were not sure.
4.2.2.3 Mitigation of challenges related to accessibility to clinic

Only Moses of all the participants experienced challenges related to accessibility to the clinic. The following are his opinions:

Moses:

*It is really frustrating ma’am. We are taken to outside hospital by escorting officials when we cannot get assistance in the correctional centres. These complaints were raised to IVP through the complaints register at the correctional centre. IVP is an independent body that have our interest at heart and they assist us with any problem. We also have participant management committee (PMC) which also assist in such situations. This committee comprises of six offenders and management of the correctional centre and meet every 3 month or if necessary. Currently these meetings were postponed repeatedly. Maybe we don’t make more efforts as offenders.*

Moses further commented:

*Actually the situation is not as bad as 3 years ago; all this structures really helped to a certain extent but it not perfect as yet*

Francis (2014:64) points out that for oppression to be effective, it is necessary to involve the oppressed in the process. The oppressed individual would experience low self-esteem and self-blame. Frances mentions that the individual will ultimately accept the situation and think that he deserves such degrading treatment.

The study shows that there are structures to mitigate the challenges in this correctional centre. It further shows that few of the participants had problems with accessing the pre-ART program.

4.2.2.4. Access counselling services and support groups in the correctional centre

Moses, Joseph, Tlotlo, Esau and Peter mentioned that they accessed counselling sometimes with the social worker and other times with the HIV support group every
Friday. They explained that sometimes NGOs assisted with the facilitation of discussions in the support groups or offender peer educators did that. Taylor and Renpenning (2011:23) explain that the self-care theory acknowledges self-maintenance of the individual according to his or her capability. The researcher of this study also observed that the participants were at peace with the mentioned arrangements, but three participants stated additionally:

Keorapetse:

*I attend the support group every Friday in the correctional centre. I was very depressed when I was diagnosed with HIV but the social worker Mrs Motaung gave me counselling. She was like a mother to me. Presently there is no officer responsible for support group on full time basis, but I still attend because we benefit something as a group. We also talk about things that stress us, so it really helps.*

The narration supports the notion that self-care is a self-initiated, deliberate and purposeful activity in the interest of one`s life and wellbeing (Fernandez, Johnson, Tran & Miranda 2012:413; Taylor & Renpenning 2011:29; Parissopoulos & Kotzabassaki 2004:1). Self-care helps an individual to self-actualise through patience, honesty, trust and humility (Fernandez et al 2012:413). Taylor and Renpenning (2011:29) further support Keorapetse`s view and mention that capabilities of individuals are developed over time with the support and experience of social groups. Once the individual accesses a support group, it provides a forum that promotes a sense of belonging, socialisation, reduces anxiety, improves coping mechanisms and demystifies the unknown for the participants (Herron 2005:14)

Khadija:

*I don’t attend support groups in the correctional centre often because they are facilitated by fellow offenders. I rely on HIV/AIDS booklets, and moreover I was trained on the HIV in 2007. I don’t think offenders have more knowledge on the matter. I mean basically they are behind bars; there is no easy access to such knowledge. Accessing counselling is another story; no one is available to assist. Literally there are no social workers and psychologist; there is only one social worker for almost two*
hundred of us. It is tough ma`m because we need counselling. I continue with counselling in an external hospital. Presently we just support one another as offenders because it is not easy

Peter:

I was very sick for a very long time, most of the time sleeping and I never attended services of the social worker or a priest but my wife and family were very supportive. They came to check on me repeatedly and managed this year to celebrate family day with me in the correctional centre. Ijo! It was really nice.

Peter added:

Ngi jabulile nga umndeni wami [I am happy with my family]. They really took care of me when I needed them. I was really sick, I could not do anything, feeding myself, and bathing even the walking was so difficult. I really thank God I now can do things for myself.

Godfrey et al (2011:6) mention that WHO describes self-care at three levels: namely, individual, family and community levels. They further mention that family levels of self-care are instituted when a family member needs help with his care. Peter was supported and assisted by family when he was sick.

Participants realised the need for counselling and support groups hence they continued to attend services even though there was little support. The study shows lack of support in sustaining support groups, and limited counselling services. Only one social worker was available according to participants and that impacted negatively on counselling services. The narrations show that the success of the HIV program in South Africa depends on the availability and accessibility of intensive counselling and treatment literacy (Karim, Churchyard, Karim & Lawn 2009:931).
4.2.2.5 Access to clinic for vitamins and routine blood taking (HIV wellness) and physical fitness

Joseph and John mentioned that they had their vitamin treatment with no problems and did physical exercises well because they participated in the indoor games arranged by the correctional centre from time to time

Moses explained:

Vitamin tablets and special diet were given daily immediately after I was diagnosed with HIV. I also did exercises to keep myself healthy and fit. You can see my body yourself. I am very fit.

Moses added:

The nurses check the treatment plastic pockets for tablets to verify that I took them every time I go for clinic check-up. The issue kept me on my toes that I should not forget to take my treatment. The nurses really showed me that they care. I also do exercises daily as advised by the nurses

Weschler and Manby (1994:127) confirm Moses’ comments and mention that offenders in South Africa are allowed and encouraged to do physical exercise daily for an hour to promote their health. Physical exercise maintains physical fitness and good mental health. Furthermore, adherence to professionally prescribed medication maintains good health (Godfrey et al 2011:6). Riegel and Dickson (2008:190) also point out that self-care involves accessing treatment with the ultimate outcome of treatment adherence and monitoring of the health status at every clinic visit.

Esau explained:

I am taking vitamin tablets to prevent diseases like TB and flu. The clinic staffs verify whether I completed the tablets every time with my check-up. I also do physical exercises to keep myself fit. We were informed at the support group by the nongovernmental organisation that was volunteering to teach us on HIV/AIDS the beginning of this year that it is important.
Khadija remarked:

*Professional nurses are really taking care of us, I have my vitamin tablets, and they call me for check-up if necessary. I am well, I really don’t have problems. There are a lot of activities in the Centre, physical exercises in this place is really galore.*

Taylor and Renpenning (2011:23) point out that the self-care theory acknowledges self-maintenance of the individual according to his or her capability. The health team intervenes when the person does not have the capacity or capability to care for him or herself. The researchers further emphasise that the individual is the one acting and the one acted upon in his care.

Keorapetse also said:

*I don’t have a problem with professional nurses, the problem is that sometimes. At times we don’t get enough treatment because they are not coping with work. As far as physical exercises, there’s no problem. We do exercises.*

Francis (2014:64) mentions that the individual experiences low self-esteem and self-blame when he lives in an environment of negative messages and images. The individual ultimately accepts the situation and thinks that he deserves such degrading treatment. Francis (2014) noted that such stereotypes are linked to HIV related stigma and prejudices. Keorapetse portrayed the notion mentioned by the researcher. Keorapetse`s scenario impacts negatively on the self-care theory because he accepted not receiving treatment and had no intention of making any effort to change the status quo.

Peter also explained:

*I am drinking many pills at the clinic, but I don’t know their names. I only know the colour and shape. Presently I stay full time at the ‘hospital section’ that is the reason I don’t really bother myself with the names of my tablets. Ijo, remember they can be difficult to memorise. I am ok, and happy that I don’t have body pains or anything bothering me now. The tablets nurses give really work.*
Faure (2014:16) notes that most of the offenders are dependent on the staff for treatment and know only the colour of their tablet shape and size but cannot remember the name of the treatment itself. The self-care theory mentions that when the person is incapable, the health team assists with care. Peter was very sick and dependent on the health team for his self-care, but his condition improved. The situation prompts him to make an effort for his own care.

Tlotlo, however, commented:

*I don’t want to drink vitamin tablets anymore because I will be released from the correctional centre in a week’s time. Vitamins give appetite but with poverty out there, it is difficult to survive. I am not sure whether I will cope financially to support myself and family when I get released. I know all the tablets by heart; I know which ones to exclude because really I am now well. I am going to tell the nurses to stop them before I go home.*

All the participants except Keorapetse accessed the clinic services. Keorapetse complained that sometimes professional nurses could not assist them because of shortage of staff. Most of the participants did not complain outright about access to services for wellness and physical exercise.

### 4.2.2.6 How services of partnerships are accessed

The White Paper on Corrections in South Africa (2005:12) acknowledges HIV as a challenge in correctional centres and mentions that correction is a societal responsibility. This situation prompts the establishment of partnership with stakeholders on HIV programs in the correctional centres. Offenders should be able to access these services rendered by stakeholders. Participants commented as follows:

Moses:

*There are other non-governmental organisations that come from sometimes to help us with the support group; they teach us how to cope with stress and how to live in a healthy manner. The main challenge is that the escorting correctional officers are not always available. It is very*
difficult because sometimes you end up not attending because there is no one to escort. The situation is really frustrating.

Khadija:

The support group in the centre is facilitated mainly by fellow offenders hence I prefer to attend the support group and counselling outside the centre at Brits hospital. We have other NGO`s helping with HIV testing, counselling and education. They are not always available; maybe they are busy in other areas. I sometimes attend support group meeting at centre but it is not worth it. We just meet to discuss things that are not beneficial for me.

Keorapetse:

Re rutilwe ka bolwetse jwa HIV ka ngwaga wa 2013. Ke lebetse leina la setlhopha se se neng se re ruta. Maswabi ke gore ga re ise re simolole go ruta. Setlhopha se, se sa le se ile. Nnete ke gore batlhokomedi barona ga ba, na sepe le rona. Ga go thuso epe. Re bone gore re tswelele ka mokgatlho re thusane. [HIV peer educators were trained in 2013 by a certain NGO but implementation is such a struggle. The NGO only came once and disappeared. From the correctional centre staff, no one is keen to assist to ensure that the program kick starts. We are not assisted whatsoever in this matter, but we decided to continue the support group to assist one another].

Sifunda, Reddy, Braithwaite, Stephens, Bengu, Ruiter and Van den Borne (2007:807) mention that the period offenders spend in a correctional centre gives them the opportunity to acquire skills and knowledge about HIV infection. It is for this reason that UNODC (2006:26) recommends that OLWHIV should establish self-help and peer-support groups among fellow offenders to raise issues on HIV/AIDS from their backgrounds.

The participants’ narrations showed that there was access to services rendered by partners but inconsistency was evident because participants mentioned that services were provided sometimes.
4.2.3. Challenges of the pre-ART program

Participants repeated some of the issues discussed above as challenges, and all participants strongly reiterated that food was terrible in the correctional centre. Almost all participants mentioned that professional counsellors were not allocated to facilitate the support groups as expected. They gave the reason of shortage of staff. The participants mentioned that fellow offenders facilitated the support groups and occasionally the non-governmental organisation participated in the support group. Almost half of participants continued to attend the support group irrespective of the situation.

The discussion that follows highlights the main challenges mentioned. John awkwardly said:

\[
\text{I don't have any challenges.}
\]

The researcher observed that John was not interested in commenting on challenges and was in a hurry to complete the interview. When asked whether he wanted to continue with the interview, he mentioned that he was fine to continue but emphasised that he did not have problems.

4.2.3.1. Food and nutrition

Most participants complained about the poor nutritional diet as mentioned above at 4.2.2.4. Moses suggested that the researcher should witness the dishing up of food to observe challenges related to food.

\[
\text{You have the right to see yourself the meals served in the centre. He further emphasised: We are not at a five star hotel but our health come first. Correctional officers keep telling us that we are not at a five star hotel when we complain about the nasty food. It’s not fair.}
\]

The researcher assured Moses that the matter would be raised with the senior staff as soon as possible.
Peter:

The milk that is given in the correctional centre is diluted with water. It really tastes terrible; it’s not fair because all vitamins are gone. I think there is corruption somehow.

Moses:

This milk is smuggled; we can’t be having this type of milk; its really having a bad taste.

Joseph:

Ga e yo ‘high protein diet’ fa! Ga go dithaloso tsa gore go diragalang. Go maswe fa.[There is no high protein diet in this place, nowhere!. No one is explaining what is really happening. The situation is terrible].

Esau:

I used to get high protein diet but now there is no sign of high protein diet in my plate. I even feel I lost some weight; I am really upset; senior authorities should help us.

Tlotlo compared this correctional centre with the previous one he was incarcerated in before and explained:

Sun City prison had good food but this one ‘haai’! [Sigh of despondence]. He shrugged his shoulders.

Keorapetse alleged:

Motlhamongwe o (lephodisa) reetse ke matona a gagwe go re neela dijo tse di maswe jana [Perhaps the correctional officer was instructed by his seniors to give us the disgusting food .Maybe this is some form of punishment.
4.2.3.2 Lack of treatment

Esau remarked:

Sometimes treatment is delayed for days after doctor’s prescription and nurses end up taking other patients’ treatment to close the gap. I think they replace the treatment. I don’t know; the nurses can explain it better.

Moses said:

Treatment gets finished earlier sometimes before doctors’ appointment date at external hospital. I am not sure whether they miscalculate tablets or what is happening. The matter was raised with the responsible people. We lost hope because there is no improvement. People died ma`m as I explained earlier. Investigations should be done urgently.

Peter explained:

Treatment sometimes is short in this place; nurses have a way. But it is not so bad, because we end up getting treatment.

Faure (2014) acknowledges that Losperfontein Correctional Centre is distant from the supplying pharmacies. The situation delays medical scripts which often reach pharmacies very late, or even a day later. The process contributes to delays in HIV care treatment. Participants confirm the delay of treatment mentioned by Faure.

4.2.3.3 Limited support for support groups

All participants mentioned that there was no support for the support group as noted in 4.2.2.4. The following comments strongly emphasised this:

Keorapetse:

Currently, there is no officer responsible for support group on full time basis, but support groups still continues because we benefit something as a group. This relieves stress, there is no other way.
Khadija:

Like I explained earlier, I don’t attend support groups in the correctional centre often because they are facilitated by fellow offenders. I rely on HIV/AIDS booklets. I maintain that offenders have little knowledge on HIV. They really cannot contribute in a professional manner.

Moses:

Support group were formed after training by the NGO, but no one assist us. Fellow offenders assist to facilitate the discussions every Friday. The problem is that the NGOS cannot assist every week. It’s been a long time they assist with the program.

The study shows lack of support for support groups and limited counselling services. A limited number of health professionals such as social workers contribute to this challenge. Scott, Zweigenthal and Jennings (2011:1389-1390) mention that HIV care is neglected, and that priority is given to the scaling up of HCT but counselling and support groups are neglected.

4.2.4 Recommendations by participants to improve the pre-ART program

Participants were requested to give one or two helpful recommendations to curb challenges experienced by the pre-ART program. The following comments were emphasised, with all participants except Tlotlo suggesting that the correctional centre should allocate health professionals to facilitate and account for the support groups.

Tlotlo:

I am just upset with the situation in this place of food; I don’t want to make a suggestion. I cannot wait to go home because I am released next week.

Keorapetse:

Management should deal with the terrible diet urgently and allocate the responsible officer to assist with the support group

Esau and Peter suggested that medicines or rather tablets should be available at all times because sometimes there were shortages. Esau did not really emphasise this as a challenge but made this recommendation. Faure (2014:32) mentions that
medical scripts in North West correctional centres such as Losperfontein are far from pharmacies and often reach pharmacies late; often over a day later. Faure (2014:32) further notes that if a patient is released or transferred, it becomes a problem of unused or wasted tablets.

Moses:

Presently lunch is given around 15:00 whereas it should be served at 12:00. We get hungry; breakfast is at 06:00. Furthermore, there should be more and better vegetables and fruits in the diet.

Keorapetse:

I prefer counselling done externally at a public hospital because they give quality services.

In the community health services, this could be a challenge for the public because offenders are often moved to the front of the queue in a busy public clinic to prevent their escape (Bulbulia & Berger 2008:29). Besides, this mainly shortens the time of guarding while offenders are in the public space and it is not necessarily preferential treatment (Bulbulia & Berger 2008:29).

Joseph and John:

Proper diet should be given three times a day, and treatment be availed at all times.

Khadija:

Involvement of external partners can make me happy to close gaps on HIV care and education on latest HIV issues in support groups.

In summary, participants’ recommendations include proper diet; support groups; education on latest developments on HIV; availability of treatment with an increase in the number of health practitioners; and involvement of external stakeholders in HIV care.
4.3 Personal reflection on the study

The researcher observed uneasiness and tension with the professional nurses at the study site. They seemed uncomfortable about the outcome of a study that might have a negative effect on the reputation of their profession. One of the professional nurses mentioned that the choice of Losperfontein for the study was not fair. She mentioned that the correctional centre was extremely short staffed to assist with the study.

The researcher emphasised the purpose of the study as mentioned in chapter 1 and further mentioned that the study would enhance the programme and that the correctional centre could be one of the best practices. The explanation allayed the anxiety of the professional nurses and their participation contributed to the success of the study.

The researcher as a woman in her late forties with a full figure provided a mother figure to both offenders and health professionals. The stature of the researcher could have been a deterrent in interviewing younger participants who might not have wished to disclose sensitive issues out of respect for her. In African culture, it is taboo to discuss sexual and sensitive issues with elders.

Participants were assured from time to time that the study was for academic reasons to encourage openness. More than eight participants were keen to be interviewed for the study and the first available eight participants were sampled. The researcher observed during the interviews that most of the participants were uneasy about and reluctant to describe the challenges experienced regarding the pre-ART program at the centre. John, one of the participants, mentioned previous gunshot injuries that were incompletely healed and awkwardly said that he did not have any problems.

Open ended structured questions were beneficial and kept the study interviews focused because most of the participants occasionally got derailed and entangled themselves in personal issues such as bail and parole. Additionally, Joseph enquired whether the researcher knew a lawyer who could assist him with his case because he had committed no offence. The researcher was confronted with the task of keeping the participants focused in order to conclude the interviews. An average of fifteen minutes per person was spent on the interviews.
The pre-ART program is scantily implemented; that could be one of the reasons why professional nurses were initially uncomfortable with the study. The participants were more relaxed and keen to continue with interviews longer after the rationale of the study was explained. Correctional centres have a structured program with set times; hence interviews could not be prolonged beyond the arranged time. All questions were answered fully within the time allocated.

Participants spoke well about health professionals but were mum about their relationships with custodian officers. They would only complain about bad food. The researcher’s managerial experience in the Department added value to the study because she knew the social issues in the correctional centres.

4.5. Conclusion

In conclusion, this chapter indicated that the self-care theory at primary and secondary levels is possible in a correctional centre with participants’ initiatives in the care program. Institutional constraints such as staff shortages, poor diet and non-functional participant management committees (PMC) deter self-care. Participants’ commitment in sustaining the support group showcased self-care attributes. The link of HCT to the pre-ART program is notably and extremely important. The pre-ART program does, however, face serious challenges such as participants’ lack of knowledge, and limited capacity for health interventions including the sustainability of support groups. Accessibility to the program is relatively good. These findings are based on the research questions and research objectives.
CHAPTER 5: SUMMARY OF THE FINDINGS AND CONCLUSION

The aim of the study was to explore the experiences of sentenced offenders living with HIV on a pre-antiretroviral therapy program at the Losperfontein Correctional Centre as mentioned in chapter 1. Challenges of and recommendations for the study will hopefully add helpful information and enhance the program at the mentioned Losperfontein Correctional Centre.

5.2 Summary of key findings

5.2.1 Participants’ experience of the pre-ART program

Four areas were deliberated regarding participants’ experience of the pre-ART program: description of the term “pre-ART”; how participants involved themselves in the program; how participants benefited from the program; and issues regarding food. Problems related to food were the major ones. The summary is detailed below:

5.2.1.1 Knowing pre-ART

The study showed that the participants did not know the term “pre-ART program” and could not properly explain it. Offenders mentioned varying periods for the programme intervention; instead of six months, they mentioned periods of a month, three months and twelve months. The participants’ responses indicate that HIV education was poorly executed in the centre. Training was done without mentorship. Furthermore, the participants confused pre-ART with the antiretroviral (ART) program. Taylor and Renpenning (2011:23) mention that the self-care theory acknowledges self-maintenance of the individual according to his or her capability. There is a possibility of self-care but support for OLWHIV in the study was poor. Baquedano, Dos Santos, Teixeira, Martins and Zanetti (2010:1014) note that WHO recommends self-care education to prevent and treat illnesses, and to improve self-
care skills. Lack of mentorship deterred self-care education and skills in the correctional centre.

5.2.1.2 Food and nutrition issues

As mentioned in 5.2.1, participants brought this aspect up immediately when asked the question on pre-ART experiences. The researcher embraced the narrations because nutrition is one of the interventions of the pre-ART program for the wellness of OLWHIV. The study revealed smuggling of food and dilution of milk with water which contributes to poor nutrition. UNODC, UNAIDS, World Bank (2006:25) support this notion and mention that poor food and nutrition including scarcity of food drive offenders to exchange sex for food in correctional centres.

The other revelation was that meals were served twice a day instead of thrice as stipulated by the nutrition policy in the correctional services. The disparity has a bearing on adherence to treatment because often meals must be taken prior to ingestion of treatment. Contrary to what participants said about special diet, routine special diets are not recommended from a medical point of view (South Africa, Dept. of Health 2013:27). Diets are determined by the health status of the individual according to the health practitioner’s assessment.

5.2.1.3 Involvement of participants in the pre-ART program

Participants’ involvement in health matters bore fruit through participant management committee meetings attended by their representatives. The meetings did not have pre-determined dates but there was a representation of six offenders. Other strengths included participants’ interest in their health, cooperation with the health team and keenness to participate in their care. Self-care is a self-initiated, deliberate and purposeful activity in the interest of one’s life and wellbeing (Fernandez, Johnson, Tran & Miranda 2012:413; Taylor & Renpenning 2011:29; Parissopoulos & Kotzabassaki 2004:1). Self-care helps an individual to self-actualise through patience, honesty, trust and humility (Fernandez et al 2012:413). A participant management committee is a precursor of self-care and improves self-care interventions.
5.2.1.4 Benefits of the program

Participants appreciated activities related to the pre-ART program and their faces lit up when narrating the benefits. The benefits were listed as follows:

Counselling assists with coping mechanisms and alleviation of stress. The availability of a support group strengthens group cohesion, and provides a learning opportunity to learn from one another. The prescribed diet gives an opportunity to boost immunity. The availability of treatment for opportunistic diseases and being checked periodically to ensure good health were the mentioned benefits. The benefits mentioned portrayed self-care. Self-care is defined as actions directed by the individual towards him or herself or the individual’s environment in order to regulate his or her functioning in the interest of his or her life and wellbeing (Fernandez et al 2011:29). Participants took deliberate responsibility or action for their wellbeing. Godfrey et al (2011:3) support this notion and mention that not all is done by the health practitioner as the patient initiates or engages in self-care for him- or herself.

5.2.2 Access to pre-ART program

The study indicated that almost all participants accessed the pre-ART program and experienced no challenges. The Department of Health states that all sentenced offenders should access health care services in South Africa (DoH 2013:11). Participants described how they accessed the clinic; they discussed the frequency of clinic visits related to the program, and how they overcame challenges related to access of HIV services. They commented as well on access to counselling services, services by partners, the wellness clinic and physical fitness.

5.2.2.1. Description of how the clinic is accessed

All participants mentioned that they were summoned for clinic consultation after 09:00 by the correctional officer who escorted them to the correctional centre clinic. Almost all the participants supported the notion that sentenced offenders had total access to health care services (DoH 2013:11). This is contrary to the statement by Motshabi, Pengpid and Peltzer (2011) that only half of the population had access to
HIV care services at this study site. These researchers related this to poor HIV education and health promotion.

5.2.2.2. Frequency of clinic attendance

Only Esau knew that pre-ART clinic was attended every six months unless there was an emergency. All the other participants did not know the follow-up period. Other participants’ answers varied from one to a three-month follow-up period for pre-ART care. It was notable that participants confused pre-ART and ART follow-ups.

5.2.2.3. Mitigating challenges related to accessibility of the pre-ART program

The study showed that there were structures such as a participant management committee that could be utilised to mitigate challenges at this correctional centre. It is unfortunate that these are not fully functional. The use of a complaints register was raised whereby an independent body called Independent Prisoner Visitors (IPV) assists with any problem. IPV mediates if there are problems between prisoners and correctional centre staff. This study showed that almost all participants did not experience challenges related to accessibility to the pre-ART program.

5.2.2.4. Access counselling services and support groups

Participants realised the need for counselling and support groups and they attended these interventions even though there was little support from both internal and external service providers. The study revealed lack of support for sustaining support groups and limited counselling services. Only one social worker was available according to participants and that impacted negatively on access to counselling services. Counselling is important because when therapeutic self-care demands exceed individual self-care, the intervention of the health care team is legitimate (Comley 1994:756). Haslam and Reicher (2012:154) suggest that when members of low status groups such as offenders bond together through a sense of shared social identity, effective leadership and organisation enable them to minimise stress, secure support, and promote social change in the most extreme situations. Innovation and participation of offenders in the support groups showed the relevance of the self-care theory at the study site.
5.2.2.5. Access clinic for wellness and physical fitness

The participants accessed the clinic services with ease except for Keorapetse who mentioned that sometimes professional nurses could not assist them owing to shortage of staff. Treatment was provided for OLWHIV and adherence to treatment was verified by the professional nurses. Furthermore, the study showed that no clinic appointment cards were used for the follow-up of treatment. Participants reported at the clinic when summoned by the health professionals. The situation does not promote offenders taking responsibility for their treatment regimen. Motshabi et al (2011) support this notion and mention that Losperfontein Correctional Centre has a poor health system.

The researcher observed that the policy on comprehensive management of HIV and AIDS in correctional services endorsed in 2005 was silent about the frequency of HIV Care. SANAC (2012:4) mentions that the DCS in South Africa has made positive strides in the implementation of comprehensive HIV and AIDS treatment, but further notes that staff shortages, limited technical support and policy gaps limit DCS SA.

5.2.2.6. Access to interventions by partners

Participants appreciated the partnerships established for support groups because the lessons they received on stress management were beneficial. Furthermore, HIV testing and counselling services and HIV peer education provided by partners were utilised for the implementation of the program and contributed to their development. (Sifunda et al 2007:807).

The study showed that partners provided excellent services even though the services were not always available. Participants mentioned that the greatest challenge was the non-availability of mentors for the support groups and HIV peer education after partners gave services.
5.2.3 Challenges experienced by offenders on the pre-ART program

Challenges mentioned included bad food, limited support for support groups, inadequate treatment, shortage of health professionals and limited services from partners.

5.2.3.1 Food and nutrition

Participants mentioned challenges such as poor nutrition and being ridiculed by correctional officers when they queried the quality of the food. Almost all the participants complained about the diluted milk and poor diet caused by smuggling. They mentioned that adherence to treatment was difficult because of the poor diet. Goyer, Salojee, Richter and Hardy (2005: 7-8) note that there is lack of proper nutrition for offenders. Carrabine (2012:896) also notes that there are incidents of robberies and assaults in the everyday life of offenders. Francis (2014:64) mentions that an individual experiences low self-esteem and self-blame when he or she lives in an environment of negative messages and images. Participants did not intend to make any effort to change the status quo and that impact negatively on self-care.

5.2.3.2 Inadequate treatment

The study showed periodic shortages of treatment and health professionals who periodically resigned. UNAIDS (2014:150) in support mentions that lack of health care capacity such as that provided by doctors and other health professionals within SA DCS limits health service delivery in correctional facilities. The study revealed poor sustenance of the support group as a deterrent of the programme because few participants preferred services at the external public health services. The researcher observed that HIV testing was poorly offered on admission of the offenders. Motshabi et al (2011) also did a study on access to counselling and testing at the study site and concluded that only half of the population accessed HIV counselling and testing services. These researchers concluded that this study site had a poor health system.
5.2.3.3. Limited support for support groups

The study showed that the support group was formed after HIV training by an NGO, but limited support was given to ensure proper implementation. Fellow offenders facilitated the discussions in support groups. This posed a problem of sustainability. Scott et al (2011:1389-1390) mention that HIV care and support groups are neglected, and instead priority was given to the scaling up of HIV counselling and testing. Participants appealed for support group intervention.

5.2.3.4. Shortage of health professionals

Comley (1994:756) mentions that health deviation self-care relates to the seeking of medical assistance when one is ill. It is unfortunate that health care services in correctional centres are compromised by the shortage of doctors and other health professionals (UNAIDS 2011:54). A small number of participants complained about the shortage of health professionals, the greatest challenge being in counselling and sustainability of the support group. However, the researcher realised that participants had sympathetic comments about the health professionals. Participants' involvement in the PMC structure did give them the opportunity to address the shortage of health care professionals.

In summary, challenges experienced by participants included improper diet, the limited number of health professionals, poor support groups and poor supply of treatment. Inconsistencies in stakeholder support added to the problems.

5.2.4 Recommendations by participants to improve the pre-ART program

Participants were requested to provide one or two critical solutions for the challenges experienced in the pre-ART program. These critical solutions are important for the urgent attention of the study site management and for future research.
Participants suggested immediate allocation of professionals to facilitate and account for the support groups. Two participants suggested that counselling be done externally at a public hospital to improve the quality of lives.

Participants further recommended that management should deal with the poor diet issue urgently to improve their immune systems. Unavailability of treatment at all times was also raised as critical.

The other suggestions include orientation and education of offenders on the latest Correctional Services policy guidelines on HIV, TB and STIs to ensure that participants took responsibility for their health. The re-establishment of a Participant Management Committee would ensure that collective voices of offenders were heard and problems could be solved in the early stages. Strengthening partnerships was deemed important to continue with HIV programmes. An additional number of health practitioners were also considered critical to curb the challenges.

5.3. Limitations of the study

Financial constraints: the researcher incurred all the financial burdens of the study and that posed a threat to the success of the research. UNISA Bursary office could not accommodate the researcher’s application. Study payments were made from the researcher’s savings and it was difficult to raise such funds.

Access: only participants who disclosed their HIV status and volunteered to do the study participated. The researcher may have missed the opportunity of vital information from non-participatory offenders.

Time of the study was more than two years and was dependent on time constraints of the researcher. Institutional constraints such as an average time of twenty minutes allocated for the interviews limited even though the correctness of data was verified with participants on completion of the report to ensure maximum accuracy of data reported.

Qualitative study: interpretation of the study findings can be applied to the study site only and cannot be generalised.
5.4 Recommendations of the study

Recommendations are based on the activities and research gap identified in the findings of the study. Participants’ recommendations mentioned in 4.2.4 were considered as well. The recommended activities that follow are structured according to the study research questions as mentioned in chapter 1.

5.4.1. Activities recommended

a. Proper diet should be implemented and meals be adjusted according to the correct standards of three meals per day. Furthermore, investigation of allegations of poor diet by management should be carried out. To prevent future problems, monitoring and evaluation of the nutritional value of meals and diet plans should be implemented.

b. Induction of offenders on the contemporary issues of HIV/AIDS would improve knowledge of the pre-ART program.

c. Improvement of access to treatment services would ensure prompt treatment.

d. Implementation of the universal test and treat policy in this controlled environment would reduce the risk of HIV infection. The universal test and treat policy was proclaimed by the Minister of Health in 2016 for implementation.

e. Allocation and sustainability of a responsible practitioner for support groups and those that would need counselling.

f. Strengthening partnerships on HIV and AIDS programs to improve HIV interventions. A well-structured collaboration between partners using a memorandum of understanding would improve interventions on the pre-ART program.
5.4.2 Research-related recommendations

a. Mixed method of both qualitative and quantitative study would ensure data verification in relation to interviews.

b. The retention level of the pre-ART program in correctional centres is important because offenders move from one centre to the other for various reasons. Continuity of care is critically important and appropriate interventions need to be implemented.

C. Exploring the experiences of offenders regarding HIV testing on admission of the offender to a correctional centre would provide a clear indication of how offenders receive HIV testing on admission.

5.5 Conclusion

In conclusion, participants’ recommendations include proper diet; functional support groups; education on the latest developments in HIV treatment; availability of treatment; and involvement of external stakeholders in HIV care. The self-care theory was utilised to conduct the study in question, and showed applicability and relevance regarding the experiences of offenders living with HIV on the pre-ART program irrespective of the institutional constraints experienced. Most of the participants portrayed attributes of self-care such as physical exercise, importance of good nutrition and adherence to treatment. The recommendations outlined above would enhance the pre-ART program at the Losperfontein Correctional Centre and could add to the body of knowledge for future studies.
6. LIST OF SOURCES


Haslam, SA & Reicher, SD. 2012. When prisoners take over the prison, a social psychology of resistance Sage Journals 16(2):154-79. Available at: www.psr.sagepub.com/content/16/2/154.abstract (Accessed on 15/02/2015).


Robi, Z. 2013. Pre-antiretroviral services in rural Ethiopia: patient retention, factors associated with loss to follow up, and reasons for discontinuation. MA-dissertation, University of South Africa.


Acts, statutes and laws referred to in the text:


7. APPENDICES

7.1 Annexure A: Informed consent for offender participants

I hereby confirm that I have been informed by the researcher about the study exploring the experiences of adult sentenced offenders living with HIV on pre-antiretroviral therapy programme in Losperfontein correctional centre in South Africa during the years 2012-2013.

The benefits thereof, risks, scope of the study. I managed to read the information leaflet and understood the attached written information in Annexure D. The consent is compliant with the current statutory guidelines.

I am aware that my identity, personal details example age, HIV status, prison number, educational level etc. will be completely anonymous in the results of the study. I also understand that the results may be published and I have been assured that my identity would remain confidential. I may at any point without prejudice withdraw my consent and participation in the study. I voluntarily declare myself to participate in the study.

NB: Please print

Participant’s name: ---------------------

Participant’s signature: --------------------- Date: ---------------------

Researcher`s name: ---------------------

Researcher`s signature: --------------------- Date: ---------------------

Witness’s name

Witness’s signature: --------------------- Date: ---------------------
Dear participant

1. Your participation in the research study that aim to explore your knowledge and experiences on the pre-antiretroviral therapy program will be appreciated. The aim of the study further explores experiences of the pre-program and how it can be enhanced.

2. This information letter highlights your benefits and risks in the study.

3. The Departmental Research unit gave the consent for the study to be done based on the letter from the university.

4. Participation will be done with your written consent, and completely voluntarily, there are no obligations to participate in the study mentioned.

5. Pseudo names are allowed for your privacy.

6. You have a right to query or withdraw from the study if you feel uncomfortable. Report to the researcher if there are queries or problems, telephone details of the researcher are provided below.

7. The study is approved by Research Ethics Committee of University of South Africa. Queries can be directed at 012-4296587

8. If you withdraw from the study, please return for a final discussion to terminate the researcher properly.

9. Your participation may be terminated if you are reluctant or fail to follow instructions or when the situation is deterring the study.

10. Your identity will remain anonymous throughout the study but the results of the study may be presented in scientific conferences or publications.

11. The consent developed is compliant with the current statutory guidelines.

Yours sincerely

Gloria Lekubu (Ms)                    Leon Roets
Researcher                              Supervisor
7.3 Annexure C: Approval Letter

Dear Ms Lekubu,

Ms GSS Lekubu
PO Box 95
Morula

RE: FEEDBACK ON THE APPLICATION TO CONDUCT RESEARCH IN THE DEPARTMENT OF CORRECTIONAL SERVICES ON “COMPLIANCE ON THE PRE-Antiretroviral Therapy Program for HIV Positive Adult Offenders Losperfontein Correctional Centre in South Africa during the Years 2012-2013”

It is with pleasure to inform you that your request to conduct research in the Department of Correctional Services on the above mentioned topic has been approved.

Your attention is drawn to the following:

- The relevant Regional and Area Commissioners where the research will be conducted will be informed of your proposed research project.
- Your internal guide will be Acting Director: HIV & AIDS (Ms. Bool). You are requested to contact him at telephone number (012) 307 2310 before the commencement of your research.
- It is your responsibility to make arrangements for your interviewing times.
- Your identity document and this approval letter should be in your possession when visiting.
- You are required to use the terminology used in the White Paper on Corrections in South Africa (February 2005) e.g. offenders not prisoners and Correctional Centres not prisons.
- You are not allowed to use photographic or video equipment during your visits, however the audio recorder is allowed.
- You are required to submit your final report to the Department for approval by the National Commissioner of Correctional Services before publication of the report.
- Should you have any enquiries regarding this process, please contact the Directorate Research for assistance at telephone number 012-307-2770 / 012-305 8554.

Thank you for your application and interest to conduct research in the Department of Correctional Services.

Yours faithfully,

ND SIHLJEZANA
DC: POLICY CO-ORDINATION & RESEARCH
DATE: 17/5/2014
7.4 Annexure D: Interview Guide

1. Explain how you understand and experience pre-ART program?
   1.1 How do you involve yourself in the pre-ART program?
   1.2 How do you benefit from the pre-ART program?
   1.3 How do you feel about the pre-ART program?
   1.4 Explain how you feel about diet matters related to the pre-ART program?

2. Explain how you access the pre-ART clinic?
   2.1 How often do you go to the pre-ART clinic for services?
   2.2 Are there challenges to access pre-ART clinic? If so, explain.
   2.3 If there are challenges to go to the clinic, how do you overcome the challenge thereof?

3. What are the challenges related to pre-ART?
   3.1 What is one biggest challenge for the pre-ART implementation program?

4. What should happen to improve the situation?
7.5. Annexure D 2: Questionnaire in Setswana

1. O ka thalosa jang pre-Art program le bophelo ba yona?
   
   1.1 Pre-ART program e go thusa jang?

   1.2 O tshameka karolo e fe mo pre-ART program?

2. Le fitlha jang mo tliniking go tswa mo seleng?
   
   2.1. O boela ga kae kwa tliniking ya pre-ART program?

   2.2. A go nale mathata a go fitlha mo tliniking? Thalosa mathata a teng.

   2.3. O dira jang go fitlhela mo tliniking fa o nale mathata a go tswa mo seleng? Thalosa

3. Bua mathatha a a le teng
   
   3.1. Bua mathata a magolo ka pre-ART program?

4. Go ka tokafatswa jang maemo a pre-Art program?
7.6. Annexure D3: Questionnaire in Zulu

1. Chaza ukuthi uhlelo lwe pre-ART lusebenza kanjani?

1.1 Wena ungenelele kangakanani ku lelihlelo ye pre-ART?

1.2 Sizo luni olutholakala kulomtholampilo we pre – ART?

1.3 Uzizwa kanjani ngalo uhlelo lwe pre – ART?

1.4 Chaza ukuthi uzizwa kanjani ngohlelo lokudla elihlangeni nohlelo lwe pre – ART?

2. Chaza ukuthi ufinyelela kanjani kulomtholampilo we pre – ART?

2.1 Uwuvakashela kangaki umtholapilo we pre – ART ukuzothola usizo?

2.2 Ngabe zikhona izinkinga mayelana nokuqokwa kwesikhathi sokuvakashela umtholampilo we pre – ART?

2.3 Umangabe zikhona, chaza kafushane Umazikhona izinkinga zokuvakashela umtholampilo, ngabe uzinqoba kanjani lezingkinga?

3. Iyiphi inqinamba ehlangabezwa yilo mtholampilo we pre – ART?

3.1 Iyiphi inqinamba enkulu enihlangabezana nayo ukwethula kwezintlelo zomtholampilo we pre – ART?

3.2 Kunzengziwani ukuthi lesisimo sibengcono?