

**THE MANAGEMENT OF CHRONIC PAIN IN HIV BY TRADITIONAL
COMPLEMENTARY ALTERNATIVE MEDICINE PRACTITIONERS: GUIDELINES
FOR TREATMENT AND MANAGEMENT**

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Declaration

This is to certify that the work is entirely my own and not of any other person, unless explicitly acknowledged (including citation of published and unpublished sources). The work has not previously been submitted in any form to the Durban University of Technology or to any other institution for assessment or for any other purpose.

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ABSTRACT

Background

Chronic pain is a common clinical complaint and comorbidity that negatively affects the health-related quality of life of people with HIV across the world. The prevalence of chronic pain in HIV is high, with estimates that range from 25% to 85% of people. Chronic pain (CP) in HIV often results in impaired physical ability, a sequelae of clinical complaints and associated mental health problems. People with CP in HIV commonly seek alternative therapy parallel to their conventional therapy, such as opioid analgesics, to manage their pain. One such therapy is traditional complementary alternative medicine therapies (TCAM). Although widely utilised for CP in HIV, TCAM healthcare practices are understudied due to the limited knowledge of the efficacy and safety of these therapies in this field of healthcare.

Aim

The aim of this study was to explore the treatment and management practices for chronic pain in HIV by selected traditional alternative medicine therapies practitioners and to develop TCAM practitioner guidelines for CP management in HIV.

Methodology

A qualitative, explorative, descriptive contextual design, within an interpretivist paradigm, was employed to guide this study. Data were collected from 13 traditional complementary alternative medicine practitioners in the eThekweni Municipality, KwaZulu-Natal, South Africa, utilising purposive and snowball sampling strategies, respectively. These TCAM practitioners consisted of chiropractors, homeopaths, and traditional health practitioners. Semi-structured, face-to-face interviews were employed to collect data. Data were transcribed verbatim and analysed using Tesch's eight steps of thematic analysis.

Findings

It emerged that TCAM practitioners are actively treating and managing chronic pain in HIV, through their various disciplines. The THPs prescribed various traditional herbs either orally or topically. The THPs also relied on ancestral intervention for treating chronic pain in HIV. The chiropractors utilised various manual techniques in their management of chronic pain, whilst the homeopaths made use of remedies, herbs, minerals and vitamins in their treatment protocols. Although referrals amongst and between the TCAM practitioners were common there were no active referral patterns between mainstream healthcare professionals and TCAM practitioners for chronic pain in HIV, which emerged as a barrier in the care for HIV patients suffering with chronic pain.

Keywords: Chronic pain, HIV, management, TCAM, treatment.

DEDICATION

Praise be to my Almighty Creator, who has bestowed upon me the ability to complete this study. Alhamdulillah. This dissertation is dedicated to my children, Ahyaan and Azhar, and my husband, Raees. Thank you for being my inspiration, my hope and my strength. Thank you for allowing me to pursue my dreams without any inhibitions and for the sacrifices made in order for me to achieve my goal.

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“Seek knowledge from the cradle to the grave.” – Prophet Muhammad (SAW)

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TABLE OF CONTENTS

	Page
DECLARATION	i
ABSTRACT	iii
DEDICATION	v
ACKNOWLEDGEMENTS	iv
TABLE OF CONTENTS	ix
LIST OF TABLES	xvii
LIST OF FIGURES	xviii
LIST OF APPENDICES	xix
GLOSSARY OF TERMS	xx
LIST OF ABBREVIATIONS	XXII
CHAPTER 1: OVERVIEW OF THE STUDY	1
1.1 INTRODUCTION AND BACKGROUND OF THE STUDY	1
1.2 PROBLEM STATEMENT	1
1.3 AIM OF THE STUDY	2
1.4 OBJECTIVES OF THE STUDY	2
1.5 SIGNIFICANCE OF THE STUDY	3
1.6 STRUCTURE OF THE THESIS	4
1.7 SUMMARY OF THE CHAPTER	5
CHAPTER 2: LITERATURE REVIEW	6
2.1 INTRODUCTION	6
2.2 HUMAN IMMUNODEFICIENCY VIRUS	6
2.2.1 UNDERSTANDING HUMAN IMMUNODEFICIENCY VIRUS	6
2.2.2 PREVALENCE OF HIV	7
2.2.3 TRANSMISSION OF HIV	8
2.2.4 THE IMMUNE RESPONSE TO HIV	8
2.2.5 TREATMENT AND MANAGEMENT OF HIV	10

2.2.6 THE CLINICAL SEQUELAE OF HIV INFECTION	11
2.3 CHRONIC PAIN	12
2.3.1 AETIOLOGY OF CHRONIC PAIN	12
2.3.2 PREVALENCE OF CHRONIC PAIN	12
2.4 CHRONIC PAIN IN HIV	13
2.4.1 AETIOLOGY OF CHRONIC PAIN IN HIV	13
2.4.2 PREVALENCE OF CHRONIC PAIN IN HIV	14
2.4.3 CLINICAL SYMPTOMATOLOGY OF CHRONIC PAIN IN HIV	15
2.4.4 IMPACT OF CHRONIC PAIN IN HIV	15
2.4.5 TREATMENT AND MANAGEMENT OF CHRONIC PAIN IN HIV	17
2.5 TRADITIONAL COMPLEMENTARY ALTERNATIVE MEDICINE	19
2.5.1 GLOBAL VIEW ON TRADITIONAL COMPLEMENTARY ALTERNATIVE MEDICINE TREATMENT AND MANAGEMENT FOR CHRONIC PAIN IN HIV	20
2.5.2 AFRICAN VIEW ON TRADITIONAL COMPLEMENTARY ALTERNATIVE MEDICINE TREATMENT AND MANAGEMENT FOR CHRONIC PAIN IN HIV	21
2.5.3 SOUTH AFRICAN VIEW ON TRADITIONAL COMPLEMENTARY ALTERNATIVE MEDICINE TREATMENT AND MANAGEMENT FOR CHRONIC PAIN IN HIV	22
2.6 THE USE OF TRADITIONAL COMPLEMENTARY ALTERNATIVE MEDICINE FOR CHRONIC PAIN IN HIV IN SOUTH AFRICA	23
2.7 TREATMENT AND MANAGEMENT OF CHRONIC PAIN IN HIV BY CHIROPRACTORS	23
2.8 TREATMENT AND MANAGEMENT OF CHRONIC PAIN IN HIV BY HOMEOPATHS	25
2.9 TREATMENT AND MANAGEMENT OF CHRONIC PAIN IN HIV BY TRADITIONAL HEALTH PRACTITIONERS	27
2.10 SUMMARY OF THE REVIEWED LITERATURE	29
2.11 SUMMARY OF THE CHAPTER	31
CHAPTER 3: THEORETICAL FRAMEWORK	32
3.1 INTRODUCTION	32
3.2 CONCEPTUAL FRAMEWORK TO GUIDE THE STUDY	32
3.3 SELECTION OF CONCEPTUAL FRAMEWORK FOR THE STUDY	33
3.4 APPLICATION OF CONCEPTUAL FRAMEWORK FOR THE STUDY	34
3.5 SUMMARY OF THE CHAPTER	36

CHAPTER 4: RESEARCH DESIGN AND METHODOLOGY	37
4.1 INTRODUCTION	37
4.2 RESEARCH DESIGN	37
4.2.1 QUALITATIVE RESEARCH	38
4.2.2 EXPLORATIVE RESEARCH	39
4.2.3 DESCRIPTIVE RESEARCH	39
4.2.4 INTERPRETIVIST PARADIGM	40
4.3 STUDY SETTING	40
4.4 STUDY POPULATION	41
4.5 SAMPLING PROCESS	42
4.5.1 SAMPLE SIZE	43
4.5.2 INCLUSION CRITERIA	43
4.5.3 EXCLUSION CRITERIA	44
4.6 RECRUITMENT PROCESS	44
4.7 DATA COLLECTION PROCESS	44
4.8 DATA ANALYSIS	45
4.9 DEVELOPMENT OF TCAM TREATMENT AND MANAGEMENT PRACTITIONER GUIDELINES FOR CHRONIC PAIN MANAGEMENT IN HIV	46
4.9.1 IDENTIFYING AND REFINING SUBJECT AREA	47
4.9.2 TRANSLATING EVIDENCE INTO A CLINICAL PRACTICE GUIDELINE	47
4.9.3 EXTERNAL REVIEW OF THE GUIDELINE	47
4.10 RESEARCH TRUSTWORTHINESS	48
4.10.1 CREDIBILITY	48
4.10.2 DEPENDABILITY	48
4.10.3 CONFIRMABILITY	49
4.10.4 TRANSFERABILITY	49
4.11 ETHICAL CONSIDERATIONS	50
4.11.1 AUTONOMY	50
4.11.2 NON MALEFICENCE	50

4.11.3 BENEFICENCE	51
4.11.4 JUSTICE	51
4.12 SUMMARY OF CHAPTER	51
CHAPTER 5: PRESENTATION OF FINDINGS	53
5.1 INTRODUCTION	53
5.2 DESCRIPTION OF THE PARTICIPANTS OF THE STUDY	53
5.2.1 DEMOGRAPHIC DATA OF THE PARTICIPANTS	53
5.3 CONCEPTUALISATION OF THE THEMES OF THE STUDY	54
5.4 DESCRIPTION OF THE THEMES	56
5.4.1 THEME 1: KNOWLEDGE AND UNDERSTANDING OF HIV DISEASE	56
5.4.1.1 SUB-THEME 1: UNDERSTANDING HIV AS AN INDIVIDUALISED EXPERIENCE	56
5.4.1.2 SUB-THEME 2: UNDERSTANDING THE PROCESS OF CHRONIC PAIN IN HIV	57
5.4.1.3 SUB-THEME 3: INVOLVEMENT OF ARVS IN CHRONIC PAIN DEVELOPMENT	58
5.4.2 THEME 2: THE PRINCIPLES AND PRACTICE OF TREATMENT OF CHRONIC PAIN IN HIV	59
5.4.2.1 SUB-THEME 1: DIAGNOSIS OF CHRONIC PAIN IN HIV	60
5.4.2.2 SUB-THEME 2: TREATMENT PRACTICES AND METHODS FOR CHRONIC PAIN IN HIV	63
5.4.3 THEME 3: THE MANAGEMENT OF CHRONIC PAIN IN HIV	73
5.4.3.1 SUB-THEME 1: EVALUATION OF TREATMENT	73
5.4.3.2 SUB-THEME 2: REFERRAL PATTERNS	76
5.4.4 THEME 4: CHALLENGES AND BARRIERS IN THE TREATMENT AND MANAGEMENT OF CHRONIC PAIN IN HIV	78
5.4.4.1 SUB-THEME 1: THE PATIENT	78
5.4.4.2 SUB-THEME 2: LACK OF COLLABORATIVE PRACTICE WITH MAINSTREAM HEALTHCARE	79
5.4.4.3 SUB-THEME 3: LACK OF KNOWLEDGE OF TCAM PRACTICES	80
5.5 REFLEXIVITY	81
5.6 SUMMARY OF THE CHAPTER	83
CHAPTER 6: DISCUSSION OF FINDINGS	84
6.1 INTRODUCTION	84

6.2 OVERVIEW OF THE RESEARCH STUDY DISCUSSION	84
6.3 DEMOGRAPHIC PROFILE OF THE TCAM PRACTITIONERS WHO TREATED CHRONIC PAIN IN HIV	85
6.3.1 CHIROPRACTORS	85
6.3.2 HOMEOPATHS	86
6.3.3 TRADITIONAL HEALTH PRACTITIONERS	86
6.4. THEME 1: KNOWLEDGE AND UNDERSTANDING OF HIV DISEASE	86
6.4.1 SUB THEME 1: UNDERSTANDING HIV AS AN INDIVIDUAL EXPERIENCE	87
6.4.2 SUB THEME 2: UNDERSTANDING THE PROCESS OF CP IN HIV	87
6.4.3 SUB THEME 3: INVOLVEMENT OF ARV DRUGS IN CHRONIC PAIN DEVELOPMENT	88
6.5 THEME 2: THE PRINCIPLES AND PRACTICE OF TREATMENT OF CHRONIC PAIN IN HIV	89
6.5.1 SUB THEME 1: DIAGNOSIS OF CP IN HIV	89
6.5.1.1 DIAGNOSIS OF CHRONIC PAIN IN HIV BY CHIROPRACTORS	90
6.5.1.2 DIAGNOSIS OF CHRONIC PAIN IN HIV BY HOMEOPATHS	91
6.5.1.3 DIAGNOSIS OF CHRONIC PAIN IN HIV BY THPS	91
6.5.2 SUBTHEME 2: TREATMENT METHODS AND PRACTICES FOR CHRONIC PAIN IN HIV	92
6.5.2.1 PRIMARY AREAS OF COMPLAINT	92
6.5.2.2 TREATMENT METHODS UTILISED BY CHIROPRACTORS FOR CHRONIC PAIN IN HIV	93
6.5.2.3 TREATMENT METHODS UTILISED BY HOMEOPATHS FOR CHRONIC PAIN IN HIV	93
6.5.2.4 TREATMENT METHODS UTILISED BY THPS FOR CHRONIC PAIN IN HIV	94
6.6 THEME 3: THE MANAGEMENT OF CHRONIC PAIN IN HIV	95
6.6.1 SUB THEME 1: EVALUATION OF TREATMENT	95
6.6.2 SUBTHEME 2: REFERRAL PATTERNS	95
6.7 THEME 4: CHALLENGES AND BARRIERS IN THE TREATMENT AND MANAGEMENT OF CP IN HIV	97
6.7.1 SUB THEME 1: THE PATIENT	97
6.7.2 SUB THEME 2: LACK OF COLLABORATIVE PRACTICE WITH MAINSTREAM HEALTHCARE	98
6.7.3 SUB THEME 3: LACK OF KNOWLEDGE ON TCAM HEALTHCARE PRACTICES	99

6.8 RESULTS IN RELATION TO THE OBJECTIVES OF THE STUDY	100
6.9 SUMMARY OF THE CHAPTER	100
CHAPTER 7: TREATMENT AND MANAGEMENT PRACTITIONER GUIDELINES ON CHRONIC PAIN MANAGEMENT IN HIV INFECTED INDIVIDUALS	102
7.1 INTRODUCTION	102
7.2 PROCESS OF DEVELOPING GUIDELINES	102
7.3 APPLICATION OF THE CONCEPTUAL FRAMEWORK TO THE DEVELOPMENT OF THE GUIDELINES	103
7.4 PURPOSE OF THE DEVELOPED GUIDELINES	103
7.5 RATIONALE FOR THE DEVELOPED GUIDELINES	104
7.6 SCOPE OF THE DEVELOPED GUIDELINES	105
7.7 RECOMMENDATIONS FOR DEVELOPMENT OF GUIDELINES FOR STAKEHOLDERS	105
7.7.1 RECOMMENDATION FOR DEVELOPMENT OF GUIDELINES FOR TCAM PRACTITIONERS	105
7.7.2 RECOMMENDATION FOR DEVELOPMENT OF GUIDELINES FOR POLICY MAKERS AT NATIONAL DEPARTMENT OF HEALTH	106
7.7.3 RECOMMENDATION FOR DEVELOPMENT OF GUIDELINES FOR POLICY MAKERS AT NATIONAL DEPARTMENT OF EDUCATION	106
7.8 DEVELOPED GUIDELINES	107
7.8.1 GUIDELINE A: GUIDELINES FOR TCAM PRACTITIONERS	107
7.8.2 GUIDELINE B: GUIDELINES FOR POLICY MAKERS AT NATIONAL DEPARTMENT OF HEALTH	111
7.8.3 GUIDELINE C: GUIDELINES FOR POLICY MAKERS AT NATIONAL DEPARTMENT OF HIGHER EDUCATION	112
7.9 ANALYSIS AND EVALUATION OF THE GUIDELINES	113
7.9.1 VALIDITY	114
7.9.2 CLARITY	114
7.9.3 APPLICABILITY	114
7.9.4 FLEXIBILITY	114
7.9.5 CREDIBILITY	115
7.10 DISSEMINATION OF DEVELOPED GUIDELINES	115
7.11 SUMMARY OF THE CHAPTER	115
CHAPTER 8: SUMMARY, LIMITATIONS, RECOMMENDATIONS AND CONCLUSION OF THE STUDY	116
8.1 INTRODUCTION	116

8.2 SUMMARY OF THE STUDY	116
8.3 REALISATION OF THE STUDY AIM	116
8.4 REALISATION OF STUDY OBJECTIVES	117
8.5 RECOMMENDATIONS	117
8.6 RECOMMENDATIONS FOR FUTURE RESEARCH	118
8.7 CONTRIBUTION OF THE RESEARCH STUDY TO THE BODY OF KNOWLEDGE	119
8.8 LIMITATIONS OF THE STUDY	120
8.9 CONCLUSION OF THE STUDY	120
REFERENCES	122
APPENDICES	153

LIST OF TABLES

List of Tables	Page
Table 3.1: Conceptual Framework for the study	34
Table 5.1: Demographic data of the participants	54
Table 5.2: Main themes and sub themes that emerged from interviews With TCAM practitioners	55
Table 7.1: Developed Guidelines	107

LIST OF FIGURES

List of Figures	Page
Figure 1.1: Structure of Thesis	5
Figure 4.1 Map of eThekwinini	41
Figure 5.1 Main themes that emerged from the study	55

List of appendices

Appendix	Page
Appendix 1: University Ethics Clearance	153
Appendix 2a: Letter of Information for Interview Participants (English)	154
Isithasiselo Sesi-2b: Incwadi Yolwazi Yalabo Abazobe Behlonywa Imibuzo	156
Appendix 3a: Consent	159
Isithasiselo Sesi-3b: Isivumelwano Esicatshangisiwe	160
Appendix 4a: Demographic Data of the Participants (English)	161
Isithasiselo Sesi-4b: Imininingwane Yabantu Okanye Ye-Demografiksi Yabahlanganyeli/ Yababambiqhaza	162
Appendix 5: Interview Guide for Chiropractors	163
Appendix 6: Interview Guide for Homoeopaths	164
Appendix 7a: Interview Guide for Traditional Health Practitioners (English)	165
Isithasiselo Sesi-7b: Umhlahlandlela Wokuxoxisana Nabalaphi Bendabuko/ Bamakhambi	166
Appendix 8: Sample of a Transcript	167
Appendix 9: Letter from the Professional Editor	171
Appendix 10: Turnitin Report	172

GLOSSARY OF TERMS

Chronic Pain

Chronic pain is pain that is ongoing and usually lasts longer than six months. This type of pain can continue even after the injury or illness that caused it has healed or gone away. Pain signals may remain active in the nervous system for weeks, months or years (International Association for the Study of Pain).

HIV

HIV (human immunodeficiency virus) is a virus that attacks the body's immune system. If HIV is not treated, it can lead to AIDS (acquired immunodeficiency syndrome) (Wang *et al* 2016).

Guideline

A guideline is a noun that refers to a general rule, principle, or piece of advice. In this study, a guideline is defined as a developed and recommended referral guide to be used by stakeholders for the treatment and management of chronic pain in HIV (Hunter *et al* 2017).

TCAM

Traditional, complementary, and alternative medicine (TCAM) refers to a set of healthcare practices (indigenous or imported) that are delivered outside of the mainstream healthcare system (James *et al* 2018).

THP

A traditional health practitioner is a person who is registered under the Traditional Healers Act 2007, of South Africa, in one or more of the categories of traditional health practitioners. The categories of traditional health practitioners include diviners, herbalists, traditional birth attendants, and traditional surgeons (Tshehla 2015).

Chiropractor

A chiropractor is a healthcare professional focused on the diagnosis and treatment of neuromuscular disorders, with an emphasis on treatment through manual adjustment and/or manipulation of the spine and joints (Dagenais and Haldeman 2008)

Homeopath

A homeopath is an alternative medicine practitioner who bases treatment on the theory of treating 'like with like'. Homeopathy claims to stimulate healing responses to diseases by administering substances that mimic the symptoms of those diseases in healthy people (Gupta and Mittal 2018).

eThekwini Municipality

eThekwini Metropolitan Municipality is a metropolitan municipality created in 2000, that includes the city of Durban, South Africa, and surrounding towns. eThekwini is one of the 11 districts of the province of KwaZulu-Natal in South Africa. The majority of its 3,442,361 people speak isiZulu (www.durban.gov.za).

LIST OF ABBREVIATIONS

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
CAM	Complementary alternative medicine
CP	Chronic pain
HIV	Human immunodeficiency virus
IASP	International Association for the Study of Pain
KZN	KwaZulu-Natal
UNAIDS	Joint United Nations Programme on HIV/AIDS
TCAM	Traditional complementary alternative medicine
WHO	World Health Organisation

CHAPTER 1 OVERVIEW OF THE STUDY

1.1 INTRODUCTION AND BACKGROUND OF THE STUDY

Chronic pain (CP) is a major health problem (Treede *et al.* 2019; Veehof *et al.* 2011), and is defined as pain that persists for longer than three months, with an average of more than one pain site (Gaikwad *et al.* 2017). CP is prevalent in 85% of individuals with HIV infection (Lerner, Eisinger and Fauci 2020; Merlin *et al.* 2015a; Parker, Stein and Jelsma 2014; Del Borgo *et al.* 2001) and classically includes syndromes of HIV neuropathy (Scott *et al.* 2020; Balderson *et al.* 2013; Swendeman, Ingram and Rotheram-Borus 2009) and widespread musculoskeletal pain (Miaskowski *et al.* 2011).

Due to the substantial functional impairment of CP in HIV (Kole, Roy and Kole 2013), literature has revealed that HIV infected individuals seek both allopathic and non-allopathic interventions for their management of pain. The most commonly used non-allopathic treatment methods in the world include a host of traditional complementary and alternative medicine therapies (TCAM) (Peltzer and Pengpid 2018; Littlewood and Vanable 2008; Peltzer *et al.* 2008). Although TCAM is widely utilised, there is limited evidence of its safety and efficacy (Bauer *et al.* 2016). This field of healthcare is not a new concept in South Africa (SA) (James *et al.* 2018).

Multiple HIV positive individuals in SA seek treatment from TCAM practitioners, primarily for pain associated with the disease (Peltzer and Pengpid 2018; Mbutho, Gqaleni and Korporaal 2012; Peltzer 2009; Gqaleni *et al.* 2007). Therefore, the aim of this study has been to investigate the various TCAM treatment and management practices for CP in HIV, understand their benefits, and develop treatment and management guidelines for TCAM practitioners to assist in HIV holistic care.

1.2 PROBLEM STATEMENT

The use of TCAM is widespread in many countries of the world, specifically amongst patients with chronic or long-term illnesses (James *et al.* 2018; Chitindingu, George and

Gow 2014; Lee and Raja 2011). Research has revealed that as many as two-thirds of people with HIV have used TCAM (Gurmu, Teni and Tadesse 2017; Nlooto and Panjasaram Naidoo 2014; Mbutho, Gqaleni and Korporaal 2012; Peltzer *et al.* 2011; Coulter and Willis 2004) and most commonly for CP associated with the disease (James *et al.* 2018; Parker, Stein and Jelsma 2014; Littlewood and Vanable 2008). James *et al.* (2018) revealed that despite this evidence of increased usage, challenges exist amongst both practitioners and patients. The evidence surrounding TCAM benefits and efficacy is limited and questioned. This could be due to a lack of knowledge on the treatment practices in this field of medicine and, therefore, warranting such an investigation.

1.3 AIM OF THE STUDY

The aim of the study was to explore the treatment and management practices for CP in HIV by selected TCAM practitioners and to develop TCAM practitioner guidelines for CP management in HIV.

1.4 OBJECTIVES OF THE STUDY

The objectives of the study were to:

- Identify and describe the specific treatment regimens used for CP in an HIV positive patient by the selected TCAM practitioner.
- Explore and describe the management protocols used for CP in an HIV positive patient by the selected TCAM practitioner.
- Assess barriers and challenges experienced by the selected TCAM practitioner in the treatment and management of CP in an HIV positive patient.
- Determine the implications of the barriers on the treatment and management of CP in HIV positive patients.
- Develop treatment and management practitioner guidelines on CP management in HIV infected individuals.

1.5 SIGNIFICANCE OF THE STUDY

The World Health Organization (WHO) defines TCAM as “including diverse health practices, approaches, knowledge and beliefs incorporating plant, animal, and/or mineral based medicines, spiritual therapies, manual techniques and exercises applied singularly or in combination to maintain well-being, as well as to treat, diagnose or prevent illness” (WHO 2015).

CP is a common condition and, due to its unique neurobiological basis and impact on physical function, quality of life, and health outcomes, it has been conceptualised as a chronic disease (Merlin *et al.* 2015a). CP in HIV is more complex due to the multi-faceted components of the pain and the stigma associated with the condition (Ruddere and Craig 2016). CP is prevalent in 85% of individuals with HIV infection (Davis *et al.* 2011; Merlin *et al.* 2015) and remains a common problem that often results in debilitation (Lawson *et al.* 2015). The pain comprises of widespread neuropathic, musculoskeletal, and psychogenic aetiologies (Lawson *et al.* 2015; Merlin *et al.* 2015b).

The treatment and management of CP in HIV is varied due to the pain experienced being highly subjective, which can be challenging for practitioners (Merlin *et al.* 2016). The optimal approach is to assume that all patients who report having CP suffer from CP. Infected individuals explore both pharmacological and non-pharmacological interventions for CP in HIV, with opioid analgesics, being the most common pharmacological choice that is utilised (Isenberg *et al.* 2017).

An exploration into the literature has revealed that pharmacological interventions in HIV infected individuals have been widely researched, but the treatment outcomes remain mixed (Isenberg *et al.* 2017; Merlin 2015). Non-pharmacological intervention usage is often self-reported in infected HIV individuals with the most common practice being an array of TCAM therapies.

South Africa is a heterogenous and multi-cultural society and has been aptly referred to as the ‘rainbow nation’ (Carstens 2020). Due to its diversity, various forms of TCAM practices are utilised. In 2003, the WHO reported 75% of HIV-infected patients take some remedies, from complementary to African traditional medicine, in South Africa.

Peltzer *et al.* (2008) further supported this by highlighting that 87% of TCAM usage in HIV individuals in KwaZulu-Natal (KZN) alone was mainly for pain relief.

Although studies have revealed the use and practice of TCAM therapies by HIV infected individuals for CP in South Africa (Merlin *et al.* 2016; Mbutho, Gqaleni and Korporaal 2012; Peltzer *et al.* 2008; Babb *et al.* 2007), several important gaps in the HIV CP literature exist that require investigation (Merlin *et al.* 2016). One such gap is that of TCAM practices.

Due to the limited evidence of TCAM's safety and efficacy (Fischer *et al.* 2014), the effectiveness and usage of the system is often challenged in mainstream healthcare. This could be due to a disjuncture that exists from the public's perceptions, and lack of knowledge on TCAM's practice methods by both the public and by allopathic practitioners. In addition, a lack of communication between mainstream healthcare workers (HCWs) and patients, as well as between HCWs and TCAM practitioners, has been identified as one of the challenges that may adversely affect treatment of HIV and AIDS patients (Mbutho, Gqaleni and Korporaal 2012).

An investigation into the practices, treatment and management protocols for CP is necessary in this selected group, to provide an insight on alternative treatment methods explored by these patients. This model of treatment could be beneficial in establishing multidisciplinary approaches in the management of CP in HIV and fostering guidelines in the healthcare system. An investigation into the TCAM model for CP in HIV is required, as the potential outcomes of this study may reveal that pain should be an important consideration in HIV primary care, since its prevalence is rife.

1.6 STRUCTURE OF THE THESIS

This thesis is presented in eight chapters. The orientation and overview of the study is covered in Chapter 1. The literature related to the study is reviewed in Chapter 2; and in Chapter 3 the theoretical framework which guided the study is discussed. The research design is outlined in Chapter 4; in Chapter 5, the findings are presented; and the results of the study are discussed in Chapter 6. In Chapter 7, the researcher advocates guidelines to TCAM treatment and management of chronic pain in HIV; and in Chapter 8

recommendations, limitations and conclusions are outlined. Chapter 9 provides a list of references that guided the study.

Figure 1.1 below illustrates a synopsis on the structure of the thesis.

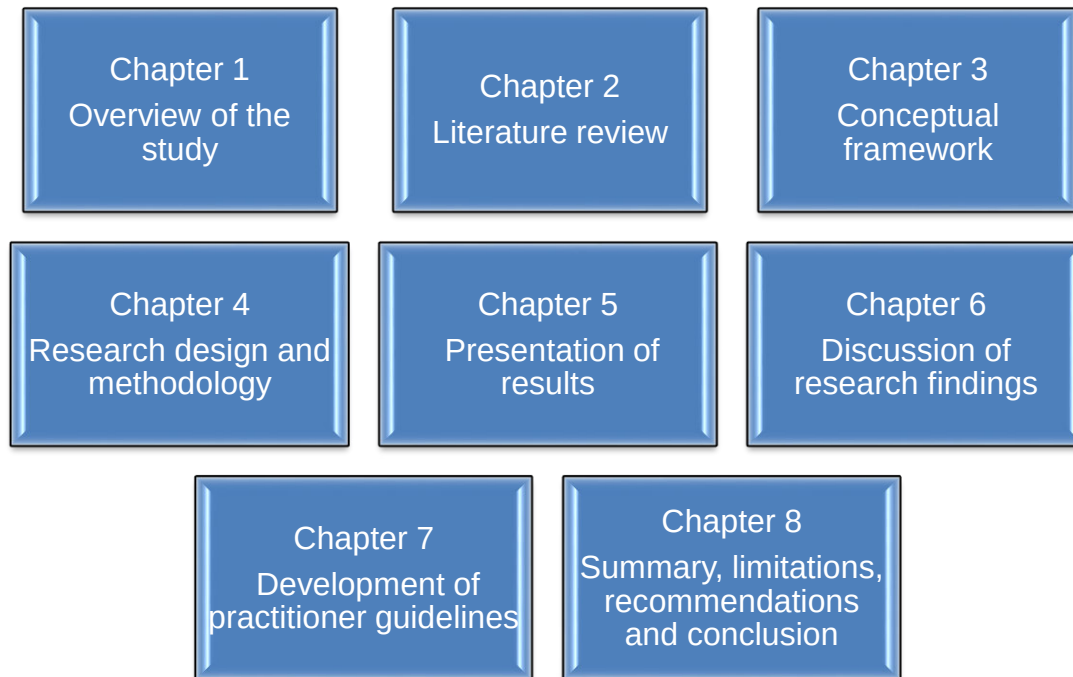


Figure 1.1: Structure of the thesis

1.7 SUMMARY OF THE CHAPTER

This chapter presented the background of the study by highlighting issues pertaining to treatment and management of CP in HIV by TCAM practitioners. The problem statement identifies the gap in the literature in the management of CP in HIV by TCAM practitioners. It highlights the need for further investigation into this domain of healthcare that is widely used in both a global and South African context.

The next chapter will review the literature related to this problem.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter reviews the literature related to the study. The review of the literature on this topic assisted the researcher to identify the gaps in the existing body of knowledge relating to this topic.

Various sources of literature were reviewed using search engines such as Science Direct, Google Scholar, and PubMed. The key words utilised in the search included HIV, CP, and CP in HIV, TCAM, and TCAM usage in HIV.

Peer-reviewed journal articles, abstracts and books were utilised. The relevant literature retrieved from these sources assisted the researcher to identify the existing body of knowledge relating to the TCAM practices for CP in HIV. All information from these resources were collated and grouped according to their sections in the study. Journal articles unavailable in full text form locally were located and obtained through the inter-library loan service.

2.2 HUMAN IMMUNODEFICIENCY VIRUS (HIV)

2.2.1 Understanding Human Immunodeficiency Virus

Human immunodeficiency virus (HIV) is an epidemic, affecting people across the globe, and is a leading cause of death and disease burden (Wang *et al.* 2016; Ortblad, Lozano and Murray 2013). It is a viral infection that is transmitted primarily through blood and genital fluids and via new-born infants from infected mothers (Naif 2013; Simon, Ho and Abdool Karim 2006; Levy 1993). The disease has grown exponentially over the past decades and has emerged as a global crisis (Wang *et al.* 2016; Mondal and Shitan 2013).

HIV primarily affects those in their most productive years; and the majority of infections are in those below the age 25 (Wang *et al.* 2016; Mondal and Shitan 2013; Simon, Ho

and Abdool Karim 2006). Globally, women are more susceptible to HIV and, as a result, are more likely to become infected with HIV than males (Wang *et al.* 2016; Mondal and Shitan 2013). Because of this, women embody greater than half of all people living with HIV globally (Wang *et al.* 2016; Mondal and Shitan 2013).

Although HIV is a viral disease, it not only affects the health of individuals, it impacts households, communities, and the development of economic growth of nations at large (Wang *et al.* 2016; Ortblad, Lozano and Murray 2013).

2.2.2 Prevalence of HIV

According to the WHO, since the beginning of the epidemic, 75 million people have been infected with the HIV virus and about 36.3 million people have died of HIV (WHO 2015). More recently, according to UNAIDS (2021), 37.7 million people are living with HIV globally and 1.5 million people became infected with HIV in 2020 alone. An estimated 0.8% of adults aged 15-49 years worldwide are living with HIV, with the burden of the epidemic continuing to vary considerably between countries (WHO 2015).

The African region remains the most severely affected with HIV, with nearly one in every 25 adults (3.9%) living with HIV, thereby accounting for more than two-thirds of the people living with HIV worldwide (WHO 2015). Sub-Saharan Africa remains the region most heavily affected by HIV (Wang *et al.* 2016; Gyasi, Tagoe-Darko and Mensah 2013), with 64% of HIV infected people residing in this region. Southern Africa remains the epicentre of the pandemic and continues to have high rates of new HIV infection (Akullian *et al.* 2021; Simbayi *et al.* 2019; Satoh and Boyer 2019; Simon, Ho and Abdool Karim 2006).

The most recent statistics in South Africa reveal that the estimated overall HIV prevalence rate is approximately 13.7% among the South African population (Stats SA 2021). The total number of people living with HIV (PLWHIV) is estimated at approximately 8.2 million and adults aged 15–49 years, are estimated to make up 19.5% of the population that is HIV positive. KZN still remains the province in South Africa with the highest prevalence of HIV infection of 18.7% (Akullian *et al.* 2021; Stats SA 2021; Simbayi *et al.* 2019).

Despite the high prevalence of HIV in South Africa, statistics have revealed a decrease in the incidence of the disease in the country (Akullian *et al.* 2021; Stats SA 2021; Wang

et al. 2016). The decline in incidence is attested to the large scale expansion of antiretroviral (ARV) drug treatment and HIV prevention models across high burden communities (Akullian *et al.* 2021).

2.2.3 Transmission of HIV

HIV is transmitted via four key mechanisms, which include sexual intercourse, blood transfusion, the sharing of contaminated needles and lastly between mother and infant during pregnancy, childbirth, and breastfeeding (Naif 2013; Simon, Ho and Abdool Karim 2006; Levy 1993). Heterosexual transmission remains the dominant mode of transmission and accounts for about 85% of all HIV infections (Agosto, Uchil and Mothes 2015; Naif 2013; Simon, Ho and Abdool Karim 2006).

The pathogenesis of HIV on a cellular level involves the entry of the virus into various cell types and receptors (Naif 2013; Simon, Ho and Abdool Karim 2006; Levy 1993), but most commonly involves the virus interaction with the CD4+ T cells (Naif 2013). During the entry process, the virus attaches to the cell membrane by first binding to the CD4+ receptor protein on the surface of these cells (Naif 2013). Various intercellular interactions occur and the viral core is then released into the cell cytoplasm. The viral core then disassembles, and the viral genome transcribes into DNA by the virus's own enzymes (Naif 2013; Simon, Ho and Abdool Karim 2006). Within the CD4+ lymphocytes, HIV replication can cause syncytium formation and cell death, leading to a decreased CD4+ cell count, infecting and destroying CD4+ T cells, which in turn leads to immunodeficiency at a later stage of the disease (Naif 2013). In other cells, such as macrophages, persistent infection can occur, creating reservoirs for the virus in many cells and tissues (Simon, Ho and Abdool Karim 2006). HIV strains are highly heterogeneous, and certain biologic and serologic properties determined by specific genetic sequences can be linked to pathogenic pathways and resistance to the immune response (Naif 2013; Simon, Ho and Abdool Karim 2006; Levy 1993).

2.2.4 The Immune Response of HIV infection

HIV infection results in regular activation of the immune system and the presence of persistent inflammation (Agosto, Uchil and Mothes 2015; Ipp and Zemlin 2013). There is

a constant depletion and death of CD4⁺ cells that results in immunosuppression (Ipp and Zemlin 2013). The immune response is linked to the host genetics and existing immunity, viral load and viral replication (Agosto, Uchil and Mothes 2015; Perreau, Levy and Pantaleo 2013). The recurrent chronic inflammation is a result of the infection and the constant activation of the immune system (Ipp and Zemlin 2013). The activation of the immune system results in the release of inflammatory cytokines and this results in further triggering of the immune system (Agosto, Uchil and Mothes 2015).

The immune response of HIV is dependent on the stage of the disease that the host presents with (Perreau, Levy and Pantaleo 2013). In the primary or early stages of the infection, there are no symptoms with slight changes in the immune system (Naif 2013; Perreau, Levy and Pantaleo 2013). This stage spans up to three months after exposure until seroconversion occurs, where HIV specific antibodies can be detected in the infected individuals (Naif 2013; Perreau, Levy and Pantaleo 2013). During this phase, despite being asymptomatic, the disease is actively replicating in the lymph nodes and the blood of the infected individuals (Perreau, Levy and Pantaleo 2013).

Disease progression with clinical symptoms differs between individuals, and often progresses fairly slowly (Perreau, Levy and Pantaleo 2013). It takes several years from the primary infection stage to the development of symptoms of advanced HIV disease and immunosuppression (Naif 2013). As the disease develops and progresses, individuals infected with HIV develop the symptoms of the disease as a result of progressive disruption of a cell mediated response and destruction of the CD4⁺ cell (Agosto, Uchil and Mothes 2015; Naif 2013; Levy 1993; Sheppard *et al.* 1991). At this stage, known as the symptomatic late phase, individuals lose weight, become ill and are very susceptible to opportunistic infections, like tuberculosis (Naif 2013).

The host reaction against HIV, through neutralising antibodies and particularly through strong cellular immune responses, can keep the virus suppressed for many years. Long-term survival appears to involve infection with a relatively low-virulence strain, maintaining a healthy immune system and ARV drug utilisation to control cell antiviral activity (Naif 2013; Levy 1993).

2.2.5 Treatment and Management of HIV

HIV is treated and managed with antiretroviral drug therapy (ARV) (Goldschmidt, Chu and Dong 2016; Warnke, Barreto and Temesgen 2007; Simon, Ho and Abdool Karim 2006; Levy 1993). The literature indicates that it is recommended to start ARV treatment as early as possible, especially in those infected people with low CD4+ counts (Goldschmidt, Chu and Dong 2016; Gibert 2016; Tseng, Seet and Phillips 2015; Arts and Hazuda 2012). The mechanism action of ARV drugs is to block the various stages of the HIV virus lifecycle as it enters cells (Goldschmidt, Chu and Dong 2016; Arts and Hazuda 2012). This mechanism inhibits viral growth and replication, and leads to viral suppression if the drugs are taken regularly (Goldschmidt, Chu and Dong 2016). ARVs do not kill the virus, but block various stages in the HIV life cycle (Goldschmidt, Chu and Dong 2016).

Due to viral mutation and drug resistance, there are 48 different ARV combination regimens (U.S Food Drug Administration 2021; Tseng, Seet and Phillips 2015). The choice of an individualised initial ARV regimen is based on various factors which include: CD4+ count, viral load drug resistance patterns, allergies, drug interaction potential, hepatic and renal function, presence of viral hepatitis coinfection or other comorbidities (Goldschmidt, Chu and Dong 2016). Due to patient adherence and compliance being a major factor, patient preferences about dosing frequency and pill burden are also considered (Goldschmidt, Chu and Dong 2016; Tseng, Seet and Phillips 2015).

The response of an infected individual to ARV treatment and management is monitored by measurement of viral load and CD4+ count (Tseng, Seet and Phillips 2015; Arts and Hazuda 2012). Viral suppression is a key indicator of successful response and optimal viral suppression is indicated by a viral load below the level of detection (Goldschmidt, Chu and Dong 2016; Tseng, Seet and Phillips 2015). This is typically achieved in eight to 24 weeks after treatment begins (Goldschmidt, Chu and Dong 2016).

Adverse side effects to ARV drugs exist and account for the major cause of non-adherence, switching of drugs or even discontinuation of therapy (Cambou and Landovitz 2020; Reust 2011; Warnke, Barreto and Temesgen 2007). Common side effects include drug hepatotoxicity and nephrotoxicity, especially in those individuals with co-morbidities. Additionally, weight gain, rash, decrease in bone density, insulin resistance and

cardiovascular complications can develop (Cambou and Landovitz 2020). Neuropsychiatric effects like mood changes and neuropathies have also been noted (Reust 2011).

2.2.6 The Clinical Sequelae of HIV infection

HIV infection results in physical and mental changes (Marcellin *et al.* 2020; Balderson *et al.* 2013; Lee *et al.* 2009; Davis 2004), accompanied by a host of clinical symptoms, and at a later stage the introduction of chronic illness (Lerner, Eisinger and Fauci 2020). Some of the earliest reported symptoms in HIV infected individuals are fatigue, pain, anxiety, depression, and sleep disturbances (Sabin *et al.* 2018; Balderson *et al.* 2013; Lee *et al.* 2009; Davis 2004). Musculoskeletal and neuropathic pain are ranked as the most common clinical symptoms reported and associated with HIV infected individuals (Walker-Bone *et al.* 2016; Baron, Binder and Wasner 2010). This is due to the ongoing presence of chronic inflammation (Goldschmidt, Chu and Dong 2016).

The manifestation of clinical sequelae in HIV are linked to the length of infection and viral load and as a result are more distinct in older people or those with low viral loads (Sabin *et al.* 2018; Farrant *et al.* 2014). Additionally, the burden of pain is directly linked to ARV drug use (Sabin *et al.* 2018; Goldschmidt, Chu and Dong 2016; Farrant *et al.* 2014). Neuropathies are often seen in 60% of infected people on ARV treatment (Egan, Caldwell and Eckmann 2021; Scott *et al.* 2020; Lawson *et al.* 2015; Baron, Binder and Wasner 2010). Neuropathy is characterised by disabling pain, that is sharp and of a burning sensation, characteristically seen in the feet (Egan, Caldwell and Eckmann 2021).

Due to immune activation and ARV usage, co-morbidities are also common in HIV positive individuals (Lerner, Eisinger and Fauci 2020). Common illnesses include cardiovascular disorders particularly ischaemic heart disease. Cancer, osteoporosis and hepatitis are also common (Lerner, Eisinger and Fauci 2020; Balderson *et al.* 2013). These sequelae are strongly linked to ARV treatment as discussed above. Due to the burden of the disease and influence over quality of life, psychosocial sequelae are concomitant presentations. These include stress, anxiety, and depression (Rogers *et al.* 2020; Scott 2019).

2.3 CHRONIC PAIN

2.3.1 Aetiology of Chronic Pain

Chronic pain is a common, complex, and challenging condition, where understanding the biological, social, physical, and psychological contexts is vital to successful outcomes in primary care (Mills, Torrance and Smith 2016). According to the International Association for the Study of Pain (IASP), CP is defined as an “unpleasant sensory and emotional experience” that lasts longer than 3-6 months, and persists beyond the typical period of direct tissue injury and repair of 2-4 weeks.

The pathophysiological underpinning of CP is due to two causes (Mills, Torrance and Smith 2016; Merlin 2015; Woolf and Doubell 1994). These two causes are peripheral and central sensitisation. In peripheral sensitisation, the peripheral nervous system receptors are hyper-sensitised by local tissue inflammation, for example, from an inflammatory disease like HIV or tissue damage from physical trauma. These phenomena cause pain to remain even after the inflammation or injury is no longer present. In central sensitisation, there is no inflammation in the periphery, but the brain produces a strong signal of pain (Mills, Torrance and Smith 2016; Merlin 2015; Lynch 2011; Shekelle *et al.* 1999; Woolf and Doubell 1994). Clinicians have conceptualised CP as a symptom of disease or injury (Mills, Torrance and Smith 2016; Lynch 2011).

2.3.2 Prevalence of Chronic Pain

The prevalence of CP varies in high income versus low to medium income countries (Jackson *et al.* 2015). Estimates of the global prevalence of CP vary between 8% and 45% across the world, with 10% newly diagnosed cases each year (Mills, Torrance and Smith 2016; Goldberg and McGee 2011). Fayaz *et al.* (2016) reported the prevalence of CP in the UK to range from 35% to 51.3%, with Lynch (2011) reporting Canada to have a prevalence of 29%. India has a CP prevalence between 37% to 63% (Dureja *et al.* 2014). Recent study on the prevalence of CP in adults in the USA revealed that more than 1 in 5 adults in USA experience CP daily (Yong, Mullins and Bhattacharyya 2021). In the African context, CP is more prevalent due to the presence of underlying conditions and lack of healthcare (Jackson *et al.* 2015; Johnson, Elzahaf and Tashani 2013). Studies

conducted in South Africa, on different populations, revealed that CP was more prevalent in rural areas (Jackson *et al.* 2015; Rauf *et al.* 2013; Igumbor *et al.* 2011). Prevalence of CP in SA is 41% (Rauf *et al.* 2013; Igumbor *et al.* 2011). Literature has further revealed that globally, the prevalence of CP that increases with age is more common in females and more prevalent in workers than in the general adult population (Jackson *et al.* 2015; Goldberg and McGee 2011).

2.4 CHRONIC PAIN IN HIV

2.4.1 Aetiology of Chronic Pain in HIV

Chronic pain is an important comorbidity and the most prevalent physical symptom in HIV-infected individuals (Baker *et al.* 2021; Marcellin *et al.* 2020; Merlin *et al.* 2015b). In HIV, both peripheral and central sensitisation exist, (Bruce *et al.* 2017; Uebelacker *et al.* 2015; Merlin 2015) and thereby link the aetiology of CP in HIV to underlying disease.

Scholars have informed on the underlying aetiologies of CP in HIV. Miaskowski *et al.* (2011) reported that pain in HIV patients could result from multiple causes, including direct effects of HIV on the nervous system, antiretroviral therapy, opportunistic infections, or other conditions unrelated to HIV. Similarly, Krashin, Merrill and Trescot (2012) reported that pain conditions in HIV patients could be divided into three major causative categories. These include pain unrelated to HIV, such as discogenic back pain; pain related directly to HIV, such as HIV neuropathy, opportunistic infections; and pain secondary to HIV treatments, such as neuropathy due to antiretroviral therapy.

Alternatively, Merlin *et al.* (2016) highlighted that CP in HIV is no longer only linked to the biomedical persistence of pain, but that individuals with HIV, who have CP, experience a distinct psychological, and social context that contributes significantly to the pain cycle. This aetiology was further supported in recent studies by Rogers *et al.* (2020) and Baker *et al.* (2021), who both highlighted that emotional dysregulation has an influence and effect on CP severity in people living with HIV. Furthermore, CP also impacts activities of daily living and is linked with poor quality of life (Baker *et al.* 2021).

Due to these multifactorial aetiologies, CP can be regarded as a chronic disease within the HIV spectrum (Merlin 2015; Parker, Stein and Jelsma 2014).

2.4.2 Prevalence of Chronic Pain in HIV

Pain is one of the most frequent and distressing symptoms in HIV infected individuals (Pullen *et al.* 2020; Sabin *et al.* 2018; Parker, Stein and Jelsma 2014; Del Borgo *et al.* 2001) and has always been an important part of HIV disease (Lawson *et al.* 2015; Marcus *et al.* 2008). A study by Merlin *et al.* (2015b), on quantifying CP in HIV patients, revealed that clinicians treating HIV-infected patients use various instruments to estimate the prevalence of CP, from asking about pain “today”, to asking about pain repeatedly over time.

The exact global estimates of CP prevalence in HIV are not established in the literature. Studies suggest that the prevalence of CP in HIV-infected patients may be anywhere from 30%, to as high as 85% (Sabin *et al.* 2018; Pullen 2017; Merlin *et al.* 2015b). The prevalence also increases in later stages of the illness (Baker *et al.* 2021; Pullen 2017; Krashin, Merrill and Trescot 2012; Marcus *et al.* 2008; Larue, Fontaine and Colleau 1997). Lawson *et al.* (2015) revealed the prevalence of CP in HIV infected patients to be 63% in the UK. American studies by Merlin (2015), Bruce *et al.* (2017) and Pullen *et al.* (2020) revealed the average prevalence of CP in people living with HIV is 85%. The prevalence of pain in HIV in sub-Saharan Africa is 82.7% (Harding, Higginson and Gwyther 2016) but it does vary in different countries. In Nigeria, a study by Wahab and Salami (2011) revealed pain to be present in only 27.8% of patients living with HIV, whilst in South Africa, CP prevalence in HIV is high, with a prevalence of 83% (Wadley *et al.* 2021; Parker, Stein and Jelsma 2014).

Across the globe, the majority of the studies have revealed one similarity and that is that the prevalence of CP in HIV is higher in females in older age groups (Baker *et al.* 2021; Wadley *et al.* 2021; Sabin *et al.* 2018) and pain has been reported to be the most burdensome symptom associated with the disease (Harding, Higginson and Gwyther 2016).

2.4.3 Clinical Symptomology of Chronic Pain in HIV

In HIV infected people, pain is highly significant due to the broad clinical spectrum (Wadley *et al.* 2021). It is associated with functional impairment and morbidity (Marcellin *et al.* 2020; Merlin *et al.* 2015b). The experience of the pain is also highly subjective in every individual infected with HIV (Merlin 2015; Lawson *et al.* 2015). The two major categories of CP syndromes found in HIV are neuropathic and musculoskeletal pain, with neuropathic pain being the most dominant, as it is observed in 20 to 30% of infected individuals (Scott *et al.* 2020; Bruce *et al.* 2017; Merlin *et al.* 2015b).

Neuropathic pain is characterised by a spontaneous ongoing or shooting type of pain and evokes amplified pain responses after noxious or non-noxious stimuli (Baron, Binder and Wasner 2010). It develops as a result of lesions or disease of the somatosensory system, including both peripheral and central fibres (Colloca *et al.* 2017; Baron, Binder and Wasner 2010). Musculoskeletal pain is multifaceted and more commonly seen in HIV patients as part of the pain spectrum (Jiao *et al.* 2016; Robinson-Papp 2016; Lawson *et al.* 2015). With encompassing both these syndromes, common complaints in CP in HIV patients include leg and back pain with burning, claudication of the peripheries; headaches, abdominal pain; widespread joint pain; myofascial pain, and pain due to Kaposi sarcoma, which is cancer that causes lesions in the soft tissues of HIV infected people (Wadley *et al.* 2021; Marcellin *et al.* 2020; Bruce *et al.* 2017; Merlin *et al.* 2016; Lawson *et al.* 2015; Krashin, Merrill and Trescot 2012; Larue, Fontaine and Colleau 1997).

Psychological factors strongly influence the clinical presentation of CP in HIV (Uebelacker *et al.* 2015). Stress, depression, mood disorders, and addiction to opioid drugs and substances are the common overarching psychological complaints reported in patients with CP in HIV (Rogers *et al.* 2020; Uebelacker *et al.* 2015; Balderson *et al.* 2013; Farrant *et al.* 2012).

2.4.4 Impact of Chronic Pain in HIV

Due to CP being a common occurrence in HIV (da Silva *et al.* 2017), it has a negative impact on quality of life and antiretroviral (ARV) adherence (Madden, Parker and Goodin

2020; Uebelacker *et al.* 2015; Peltzer *et al.* 2009). The literature has shown that the presence of CP dramatically decreases the quality of life and interferes with the ability to perform daily activities, including work activities (Addis, DeBerry and Aggarwal 2020; Sabin *et al.* 2018; da Silva *et al.* 2017; Pullen 2017; Phaladze *et al.* 2005). It further affects mood and social relations (da Silva *et al.* 2017) and is associated with psychological and functional morbidity, even in the absence of advanced disease complications (Madden, Parker and Goodin 2020; Bruce *et al.* 2017).

People with CP and HIV report more mood disturbances than those who do not have CP, and many explicitly identify psychosocial factors as strong influences over their pain (Madden, Parker and Goodin 2020). The disease burden causes considerable disability and mental dysfunction (Pullen *et al.* 2020; Madden, Parker and Goodin 2020; Bruce *et al.* 2017; Krashin, Merrill and Trescot 2012; Phaladze *et al.* 2005).

De Ruddere and Craig (2016) revealed that non-malignant CP sufferers, like those of HIV patients, also suffer the impact of a stigma associated with the pain. This was supported by Scott (2019), whose study on the psychosocial context of CP in HIV revealed that CP sufferers experienced stigma and injustice in relation to HIV and pain, mental health, and socio-economic status. Recently, Madden, Parker and Goodin (2020) revealed that stigma due to HIV and CP may interact to compromise health-promoting behaviours like medication adherence, retention in care and good patient–provider relationships. Stigma therefore has a negative impact and influence on CP in HIV.

Support plays an integral role in the impact of CP in HIV. Evidence from Wadley, Pincus and Evangeli (2019) indicated that CP sufferers feel like their partners, relatives and friends do not believe the extent of their pain. They believe practitioners think their pain is exaggerated or imagined and they feel blamed, misled and even report being dismissed by healthcare providers. Stigma is also experienced in the work environment, where patients perceive hostility from their colleagues. The burden of this negative stigma and lack of support affects CP sufferers negatively (Wadley, Pincus and Evangeli 2019; De Ruddere and Craig 2016; Farrant *et al.* 2014; Phaladze *et al.* 2005).

The treatment and management of CP is an additional factor that has an impact on the CP process in HIV sufferers. The CP associated with the disease is undertreated

(Balderson *et al.* 2013; Veehof *et al.* 2011; Larue, Fontaine and Colleau 1997) and more complex to manage for a number of reasons. These include complex anti-retroviral drug regimens, higher risks of side effects, and higher rates of comorbid psychiatric illness, such as depression, mood disorders and substance abuse (Uebelacker *et al.* 2015; Krashin, Merrill and Trescot 2012). Further to this, CP causes substantial functional impairment and is highly subjective, thereby making it challenging for practitioners to understand, treat and manage (Baker *et al.* 2021; Sabin *et al.* 2018; Bruce *et al.* 2017; da Silva *et al.* 2017; Merlin *et al.* 2015a; Veehof *et al.* 2011). As a result, the under-treatment of CP in HIV sufferers further affects pain progression and quality of life.

Marcus *et al.* (2008) investigated HIV as a chronic pain model and the biopsychosocial effects surrounding the management of the pain. The study revealed that HIV patients face many stressors during the course of illness. Pain can have a profound impact on functional adaptation, levels of emotional distress, and overall quality of life.

Balderson *et al.* (2013) discussed that the effects of chronic illness on the of quality of life showed depression and other mental health problems to be a prominent outcome with CP in HIV individuals. Uebelacker *et al.* (2015) supported this by reporting a significant relationship between CP and its interference with life activities. Additionally, Rogers *et al.* (2020) revealed, in a study on emotional dysregulation in the experience of pain in people living with HIV, that psychological and psychosocial factors can intensify pain, together with its associated disability and distress. The presence of CP in HIV imposes a high burden of stress and decreased quality of life in HIV sufferers (Baker *et al.* 2021; Rogers *et al.* 2020; Madden, Parker and Goodin 2020; Farrant *et al.* 2014).

2.4.5 Treatment and Management of Chronic Pain in HIV

The experience of unaddressed CP is demoralising, decreases quality of life and function, and disrupts treatment adherence, especially for health conditions such as HIV (Merlin *et al.* 2021; Bruce *et al.* 2017). Despite the clinical burden of CP in this population (Merlin *et al.* 2016), every medical provider has a duty to listen to and reasonably respond to a patient's report of pain, and every person deserves to have his or her pain reasonably managed by adequately trained healthcare professionals (Bruce *et al.* 2017; Merlin 2015).

Due to the primary complaints of pain in HIV being predominantly neuropathic and musculoskeletal in nature, literature has revealed both pharmacological and non-pharmacological methods as the key approaches to treating and managing the pain (Parker *et al.* 2019). The most common and preferred element of pain treatment and management is the pharmacological usage of opioids and analgesics (Isenberg *et al.* 2017; Krashin, Merrill and Trescot 2012). These drugs, however, bring with them a complex set of issues and risks (Merlin *et al.* 2016; Uebelacker *et al.* 2015) and have limited efficacy (Parker *et al.* 2019).

Numerous studies have explored the pharmacological interventions for CP in HIV. Miaskowski *et al.*'s (2011) study on adults living with HIV in San Francisco revealed that 91.2% of individuals made use of pain medications. Merlin *et al.* (2016) systematically reviewed the pharmacological and non-pharmacological treatments for CP in HIV. The study revealed opioid analgesics and non-steroidal anti-inflammatory drugs to be the pharmacological treatment of choice. Both studies, however, revealed drug interaction with ARVs, addiction and behavioural changes as shortfalls in drug treatments (Merlin *et al.* 2016; Miaskowski *et al.* 2011). Pullen *et al.*'s (2020) study on the associations between CP, analgesic use and physical therapy among adults living with HIV in Atlanta, Georgia, USA, also concluded increased opioid and analgesic use in patients.

The non-pharmacological approach to treating CP in HIV is the use of traditional complementary alternative therapy (TCAM). TCAM has been widely reported in the literature both locally and internationally (James *et al.* 2018; Puoane *et al.* 2012; Peltzer *et al.* 2011; Littlewood and Vanable 2008; Fritts *et al.* 2008b; Malangu 2007). Due to the range of symptoms reported, the literature has shown the use of traditional herbs, micronutrients, and physical therapies to be the most widely used TCAM modalities (Marais, Steenkamp and Du Plooy 2015; Swendeman, Ingram and Rotheram-Borus 2009; Tsao *et al.* 2005; Furler *et al.* 2003).

Furler *et al.* (2003) investigated TCAM usage in HIV outpatients in Canada. The study revealed a 76.9% usage of CAM, with 89.4% being micronutrient usage and herbal therapies. These micronutrients included vitamins and minerals, namely vitamins C, and B12, whilst the herbal therapies included ginseng and echinacea. Homeopathic therapies

were also utilised. Physical therapies from chiropractors, massage therapists or physical therapists amounted to 37.5% of utilisation by the HIV outpatients. Merlin (2015), indicated similar outcomes in the USA, indicating that clinicians need to know and understand that complementary therapies, like physical therapy and nutrients, are highly utilised and beneficial in CP in HIV.

In the South African context, Peltzer *et al.* (2008) showed a high usage of TCAM in HIV infected people in KZN, SA, for pain. Amongst the treatments utilised, traditional African medicine, physical therapy, and micronutrients were popular. Disciplines for physical therapy included chiropractic and yoga (James *et al.* 2018; Mbutho, Gqaleni and Korporaal 2012; Peltzer *et al.* 2011). A more recent study by Marais, Steenkamp and Du Plooy (2015) reported 29.6% of HIV infected individuals in Gauteng used herbal remedies for the ailments and pain associated with the condition. Traditional healers and homeopaths often provide herbal remedies and micronutrients (Marais, Steenkamp and Du Plooy 2015; Mbutho, Gqaleni and Korporaal 2012; Peltzer *et al.* 2011). It is apparent in the literature that TCAM practices are actively utilised for CP in HIV. The focus of treatment is pain management, symptomatic relief, and palliative care.

2.5 TRADITIONAL COMPLEMENTARY AND ALTERNATIVE MEDICINE

Traditional, complementary and alternative medicine (TCAM) refers to a set of healthcare practices (indigenous or imported) that are delivered outside of the mainstream healthcare system (James *et al.* 2018; Bodeker and Kronenberg 2002). In the African setting, it may encompass local herbal medicines or products, indigenous healthcare practices, as well as imported complementary and alternative medicine practices like acupuncture and chiropractic (James *et al.* 2018; Gqaleni *et al.* 2007). The terms ‘complementary’ or ‘alternative’ medicine (CAM) are often used interchangeably with ‘traditional’ medicine. However, CAM is viewed as less specific to particular ethnicities or regions (Street *et al.* 2019). In contrast, traditional medicine is often viewed as indigenous to a particular region and the term is used more widespread in low and middle-income countries (Street *et al.* 2019).

The appeal of TCAM can be attributed to a number of factors, including diversity, flexibility and better accessibility in many parts of the world (Braun *et al.* 2016). The usage of the biopsychosocial model of treatment and management is an additional major contributing factor as all aspects of pain are addressed (Merlin *et al.* 2014). These factors and patterns of TCAM health-seeking behaviour vary among countries and across regions in the world. In high-income countries where the health system structure is usually well developed, TCAM is used as complementary therapy (Street *et al.* 2019). In contrast, in many low and middle-income countries, particularly in rural areas, traditional health practitioners are the main or sole providers of healthcare in their communities (Abrams *et al.* 2020; Mbatha *et al.* 2012).

2.5.1 Global View of Traditional Complementary Alternative Medicine Treatment and Management of Chronic Pain in HIV

People living with HIV experience a wide range of physical and psychological symptoms throughout their disease process (Uebelacker *et al.* 2015; Lawson *et al.* 2015), with pain being reported as the most frequent and distressing symptom (Pullen *et al.* 2020; Nkhoma *et al.* 2019; Parker, Stein and Jelsma 2014; Del Borgo *et al.* 2001). The prevalence of pain among patients infected with the disease varies between 30% to over 90%, depending on the stage of disease (Lawson *et al.* 2015; Krashin, Merrill and Trescot 2012). Pain is more common in females than in males and in older age groups (Parker, Stein and Jelsma 2014). Throughout the disease trajectory, pain frequently evolves into a chronic symptom (Uebelacker *et al.* 2015). The presence of CP in people living with HIV is severe and disabling and has been associated with substantial morbidity (Mgbemena *et al.* 2015; Lawson *et al.* 2015).

Due to the burden of pain, TCAM is the most popular non-pharmacological choice of treatment for CP in HIV across the globe (Merlin *et al.* 2015a; Littlewood and Venable 2011). People living with HIV have become more knowledgeable about TCAM treatment options (Bodeker and Graz 2020; Kirksey *et al.* 2002). Cultural preference, high costs and unavailability of pharmacological drugs are factors people with HIV consider when they opt for TCAM treatment to manage HIV-related pain (Bodeker and Graz 2020; Littlewood and Venable 2011). Popular forms of TCAM include herbal or nutritional supplements,

mind-body practices, such as yoga or meditation, acupuncture, and spiritual/religious healing (Peltzer and Pengpid 2018; Littlewood and Venable 2011; Wiese, Oster and Pincombe 2010; Tsao *et al.* 2005). In regions where there is a strong traditional system of medicine, for example China, Africa and India, it is not uncommon for HIV-positive individuals to seek some form of traditional healing or herbal remedies prior to seeking out treatment from a medical clinic or hospital (Peltzer and Pengpid 2018).

People living with HIV across the globe have reported multiple benefits to the usage of TCAM, which include pain relief, pain management and improved quality of life (Merlin *et al.* 2016; Lawson *et al.* 2015). The potential risks and side effects are more limited with TCAM usage (Merlin *et al.* 2015a; Uebelacker *et al.* 2015), thereby allowing infected patients a sense of empowerment or control in their healthcare (Peltzer and Pengpid 2018; Littlewood and Venable 2011).

Despite the growing popularity and usage of TCAM for CP in HIV patients across the globe, limited evidence of TCAM's safety, effectiveness and efficacy (Fischer *et al.* 2014) exists and the usage of the system is often challenged in mainstream healthcare.

2.5.2 African View of Traditional Complementary Alternative Medicine Treatment and Management of Chronic Pain in HIV

Sub-Saharan Africa is one region of the world in which TCAM has long been utilised, with a considerable number of its population relying on it to maintain their health or prevent and treat communicable and non-communicable diseases (James *et al.* 2018; Abdullahi 2011). TCAM in Africa predominantly encompasses local herbal medicines or products, indigenous healthcare practices and, of recent, imported complementary and alternative medicine products and practices, like acupuncture or chiropractic (James *et al.* 2018; Abdullahi 2011). The use of TCAM in HIV patients for pain in Africa is high, with an average prevalence of 62% (James *et al.* 2018).

Despite the increasing uptake of TCAM services across the continent in recent decades (Street *et al.* 2019), an in-depth insight into the nature of TCAM use, the profile of TCAM users as well as the drivers and barriers that facilitate and limit the use of TCAM requires further investigation (James *et al.* 2018).

This is especially vital for communicable diseases like HIV, which possess a wide spectrum of symptoms, especially pain (Street *et al.* 2019).

2.5.3 South African View of Traditional Complementary Alternative Medicine Treatment and Management of Chronic Pain in HIV

South Africa has a high prevalence of HIV infected individuals (Harding, Higginson and Gwyther 2016), with many of the infected individuals affected by CP (Parker, Stein and Jelsma 2014). South Africa is a diverse multi-cultural country (Carstens 2020). This diversity is based on race, culture, language and religious belief (Carstens 2020). Due to its diversity, various forms of TCAM practices are utilised in the country, making TCAM not a new concept of practice (James *et al.* 2018; Gqaleni *et al.* 2007; Bodeker *et al.* 2006). In addition, South Africa is one of the few nations that have made significant progress to integrate traditional and complementary medicine into the legislative framework for health practitioners (James *et al.* 2018; Gqaleni *et al.* 2007).

TCAM has been reported to be commonly used among individuals with HIV and AIDS (James *et al.* 2018; Mbutho, Gqaleni and Korporaal 2012; Peltzer *et al.* 2011). In 2003, the WHO reported 75% of HIV-infected patients take some remedies or treatment from TCAM practitioners in South Africa, especially for pain. Peltzer *et al.* (2008) supported this, by highlighting that 87% of TCAM usage in HIV individuals, in KZN alone, was mainly for pain relief. Similarly, Nlooto and Naidoo (2016) reported that TCAM usage in HIV showed clinical relevance for pain, quality of life and CD4 count. HIV positive patients suffering with CP often utilise TCAM first due to comfort, cost, privacy and family expectation, whereby traditionally family referral for traditional treatments is preferred (Puoane *et al.* 2012).

There is evidence of cooperation on TCAM usage for CP in HIV to grow in South Africa (Ngcobo *et al.* 2012; Mbutho, Gqaleni and Korporaal 2012; Gqaleni *et al.* 2007) but several important gaps in the HIV CP literature exist that require investigation. One such gap is the TCAM practices. Despite the usage, an understanding of what TCAM practitioners do, how they treat and what is utilised in treatment and management is required.

2.6 THE USE OF TRADITIONAL COMPLEMENTARY MEDICINE FOR CHRONIC PAIN IN HIV IN SOUTH AFRICA

Traditional complementary alternative medicine (TCAM) is used by a large majority of the South African population (James *et al.* 2018; Chitindingu, George and Gow 2014). TCAM in South Africa broadly comprises of herbal remedies, spiritual practices and prayer, acupuncture, acupressure, chiropractic care, massage therapy and the use of micronutrients, which include vitamins, minerals, and multivitamins (Mbutho, Gqaleni and Korporaal 2012; Peltzer 2009). TCAM has been demonstrated to be widely used by people living with HIV, both on and off ARV therapy, as a primary treatment for HIV/AIDS and for HIV related problems (Chitindingu, George and Gow 2014; Gqaleni, Shongwe and Seleti 2012; Peltzer *et al.* 2011; Gqaleni *et al.* 2007).

A study conducted by Peltzer *et al.* (2008), in KZN, on the use of TCAM in HIV patients, revealed that TCAM was commonly used for HIV and this was further reiterated in a study by Mbutho, Gqaleni and Korporaal (2012). The reasoning surrounding the rise of TCAM use for CP in HIV is evident in the literature. A study by (Malangu 2007) reported that the primary use of TCAM was for pain and minor ailments. Malangu (2007) also reported that the use of TCAM was easier, with fewer side effects, when compared to allopathic medicine. Similarly, Walwyn and Maitshotlo (2010a), Mbutho, Gqaleni and Korporaal (2012), and Puoane *et al.* (2012) reported that trust, safety, comfort, lack of stigma and quicker results are amongst some of the reasons provided for use of TCAM in HIV infected individuals. The majority of patients further believe that TCAM practices provide a more holistic approach to managing their pain care needs with fewer side effects (Carstens 2020; Puoane *et al.* 2012).

2.7 TREATMENT AND MANAGEMENT OF CHRONIC PAIN IN HIV BY CHIROPRACTORS

Chiropractic is defined as a science of healing without drugs (Ernst 2008). It is a health profession concerned with the diagnosis, treatment and prevention of mechanical disorders of the musculoskeletal system, and the effects of these disorders on the

function of the nervous system and general health (Ernst 2008; Dagenais and Haldeman 2002; Shekelle 1998). There is an emphasis on manual treatments including spinal adjustment and other joint and soft-tissue manipulation (Dagenais and Haldeman 2002). Due to the two major categories of CP syndromes in HIV being neuropathic and musculoskeletal in origin (Bruce *et al.* 2017; Krashin, Merrill and Trescot 2012), chiropractic is a common manual TCAM treatment utilised in patients with CP in HIV (Injeyan *et al.* 2018; Littlewood and Vanable 2008; Furler *et al.* 2003).

In earlier studies by Sparber *et al.* (2000) and Furler *et al.* (2003), in Australia and Canada respectively, chiropractic treatment was utilised by 36% to 40% of HIV infected patients for pain relief. Treatments included massage, spinal manipulation, physical therapy exercises and use of electro-modalities for neuropathies. Subsequently, a systematic review by Littlewood and Vanable (2008) supported these findings and reported chiropractic treatment to be utilised by at least 25% of HIV infected patients across the world. The reasons were primarily for pain relief and to prevent peripheral neuropathy progression.

A case report conducted by Kanga *et al.* (2015), in Botswana, of a patient suffering with chronic low back pain with HIV and opportunistic tuberculosis (TB), revealed chiropractic treatment to be of utmost benefit. The patient was treated with myofascial release of the cervical and lumbar paraspinal muscles, mobilisation of the lumbar spine, and active rehabilitation including neck and lower limb isometric strengthening and education. The patient responded well to chiropractic care and noticed significant improvement in his strength. Kanga *et al.* (2015) reported on an additional case in Canada of a patient with CP due to HIV and TB. The patient presented with neck pain, low back pain and headaches. The patient was also treated with mobilisation, soft tissue therapy and exercises. The patient reported a significant improvement in pain and mobility.

A more recent study by Injeyan *et al.* (2018) on the prevalence and characteristics of HIV/AIDS patients presenting at a chiropractic outpatient clinic in Toronto, Ontario, revealed similar results. The majority of the patients presented with low back and neck pain. Additional complaints included neuropathies and widespread joint pain and osteopenia. Chiropractic treatment proved beneficial.

Like international countries, chiropractic is actively utilised in South Africa. Peltzer *et al.* (2008) reported that although herbal medicines were the most popular choice of TCAM therapy, chiropractic care was utilised by HIV positive patients for pain relief in KZN. Treatments from the chiropractor that included exercise were highly beneficial. A subsequent follow up longitudinal study by Peltzer *et al.* (2011) revealed chiropractic treatments also to be effective for stress relief. The study did, however, show that there was no substantial significant increase in usage over the years. Similarly, Friend-du Preez and Peltzer's (2010) study on HIV symptoms and health related quality of life was performed in KZN. This study showed chiropractic treatment to be utilised for pain and headaches prior to anti-retroviral treatment in HIV positive patients. Seeking alternative care did improve quality of life in these patients. Chiropractic treatment was not only beneficial for pain relief, but patients reported good relationships with their practitioners. This allowed dealing with their illness to be less stressful and burdensome (Merlin 2015; Friend-du Preez and Peltzer 2010; Roberts 2002).

It is to be noted that chiropractic treatment is utilised more in urban than rural areas in South Africa. The identity of the profession still remains questionable in a South African context (Keyter 2010). There is still a large knowledge deficit on what chiropractic entails by both the public and healthcare sector. Understanding what chiropractic treatments are provided by chiropractors for CP in HIV and documentation into a guideline will be of benefit to the broader and wider population sectors within South Africa.

2.8 TREATMENT AND MANAGEMENT OF CHRONIC PAIN IN HIV BY HOMEOPATHS

Homeopathy is a 200-year-old therapeutic system that uses small doses of various substances to stimulate auto-regulatory and self-healing processes (Gupta and Mittal 2018; Jonas, Kaptchuk and Linde 2003). Homeopathy selects substances by matching a patient's symptoms with symptoms produced by these substances in healthy individuals (Jonas, Kaptchuk and Linde 2003). Medicines are prepared by serial dilution, which proponents claim imprints information into water (Jonas, Kaptchuk and Linde 2003). Homeopathy aims to stimulate the body's natural defence mechanisms in order to prevent

or treat illness (Fritts *et al.* 2008a). Treatment involves administration of very dilute doses of substances called "remedies" that would produce similar symptoms of illness in healthy people if they were given in larger doses. Treatment is individualised, and practitioners select remedies according to symptoms, lifestyle, and emotional and mental states (Fritts *et al.* 2008a).

Homeopathy is utilised in HIV infected patients, although little is known of its risks and benefits (Fritts *et al.* 2008a). Homeopathic medicines accommodate individuals who are HIV positive, for those with early signs of AIDS, and for those with non-extreme instances of mild symptomatology of AIDS (Gupta and Mittal 2018).

In a study by Sparber *et al.* (2000) on CAM interventions in HIV patients, homeopathy was utilised by patients prior to diagnosis and increased post diagnosis. The study mentioned the use of minerals and vitamins prescribed, but not specific remedies. The study concluded that homeopathy was utilised for alleviating HIV related symptoms. These symptoms included pain, rash and the opportunistic infections associated with HIV.

Littlewood and Venable (2008) systematic review on CAM use in HIV positive individuals revealed homeopathy to be utilised more in high income countries like Australia and Canada. The study revealed that homeopathy improved quality of life and decreased symptoms of pain.

Homeopathy is popularly known for its unique methods to tackle infection in viral diseases (Gupta and Mittal 2018; Muraleedharan *et al.* 2010). A study in India, on the effectiveness of homeopathic medicines in HIV positive patients by Muraleedharan *et al.* (2010), revealed various remedies to be beneficial in HIV patients. The frequently used remedies were *Lycopodium clavatum*, *Natrum muriaticum*, phosphorus and *Pulsatilla*. *Lycopodium clavatum* was revealed to be the most statistically significant in individualised effect when treating pain; however, no significant effect was noted in CD4+ count, but overall improvement in pain and quality of life was reported.

In South Africa, homeopathy is still gaining popularity, but patients usually consult homeopaths after their health problems are not solved by mainstream medical treatment (McIntosh and Ogunbanjo 2008). Most patients raised concerns about the side effects of long-term mainstream medication and therefore sought homeopathic care (McIntosh and

Ogunbanjo 2008). There is a paucity of literature in the South African context that have investigated homeopathy in the care of people with HIV. Most studies allude to its usage for vitamins and minerals in HIV patients suffering with CP, but none directly discuss homeopathic remedy medicinal usage for CP in HIV (Peltzer *et al.* 2011; Peltzer *et al.* 2008). An emphasis needs to be placed on the actual treatment methods that homeopaths utilise to add to the existing body of knowledge.

2.9 TREATMENT AND MANAGEMENT OF CHRONIC PAIN IN HIV BY TRADITIONAL HEALTH PRACTITIONERS

The WHO (2014) refers to traditional medicine (TM) as “the knowledge, skills and practises based on the theories, beliefs and experiences indigenous to different cultures, used in the maintenance of health and in the prevention, diagnosis, improvement or treatment of physical and mental illness”. TM is utilised in countries with strong cultural heritage, which predominantly include Africa, China and India (Bodeker and Graz 2020). Due to traditional medicine practice being broad, a traditional health practitioner (THP) is one who engages in any traditional health practices (Carstens 2020). These practices encompass the performance of a function, activity, process or service based on a traditional philosophy that includes the utilisation of traditional medicine or traditional act (Carstens 2020).

The primary role of a THP is the maintenance or restoration of physical or mental health or function; the diagnosis, treatment or prevention of a physical or mental illness; or the rehabilitation of a person to enable that person to resume normal functioning within the family or community (Carstens 2020). TM excludes the professional activities of a person practising any of the other health professions and any other activity not based on traditional philosophy (Carstens 2020; Abdullahi 2011). THPs practice TM throughout the world, in varying degrees, to millions of people (Bodeker and Graz 2020).

In Africa, prior to the introduction of western medicine, TM used to be the dominant medical system available to millions of people in both rural and urban communities (Abdullahi 2011). The reasons for TM use and popularity, particularly in rural areas, include the reality that THPs may either be the easiest to access or the sole providers of

healthcare in their community, or may be able to provide care more quickly (Abrams *et al.* 2020).

TM is utilised in patients living with HIV globally (Bauer *et al.* 2016; Bodeker *et al.* 2006). According to the WHO, South Africa and India are the countries with the highest numbers of people with HIV, an estimate of at least two thirds or more of the population of these countries rely on TM for their everyday healthcare needs (WHO 2015). By extrapolation, there is high use of TM for HIV-related illness.

Gyasi, Tagoe-Darko and Mensah's (2013) study on the use of TM in people living with HIV in Ghana revealed that TM usage occurred alongside the use of ART. This was because of the availability and easy access to a wide variety of TM care, the intrinsic cultural beliefs, and the freedom of patients to select and utilise treatment modalities of their choice on one hand, and unsatisfactory effects, high cost, non-availability, and adverse effects using conventional medicines. The use of TM was predominantly for complaints of body weakness, headaches, and joint pains. Herbal therapies were mostly utilised.

Similarly in Zimbabwe, TM use in HIV patients is high, as discussed by Mudzviti *et al.* (2012). This study interviewed 388 HIV-patients in a study of impact of herbal drug use on adverse drug reaction profiles of patients on ART in Zimbabwe and found that 98.2% of participants were using at least one herbal drug together with ART. The reasons that patients used these herbal medicines was to alleviate the pain, and neurological discomfort caused by antiretroviral drugs.

Studies in South Africa report that about 70% to 80% of South Africans consult THPs (James *et al.* 2018; Hughes *et al.* 2012; Puoane *et al.* 2012; Peltzer *et al.* 2011; Peltzer and Mngqundaniso 2008; Peltzer *et al.* 2008). In SA, there are many different THPs, but pertinent to the treatment and management of conditions are the diviner and herbalist (Carstens 2020). The diviner, or '*sangoma*', refers to a person who engages in traditional health practice and is involved in diagnostic and therapeutic interventions. This may involve rehabilitative, palliative and preventative health services (Carstens 2020). Sangomas are also clairvoyants and diagnose illnesses, and their discipline commonly involves the casting of bones when assisting a patient (Carstens 2020). The 'herbalist' or

'nyanga' means a person who engages in traditional health practice and has an extensive knowledge in dispensing and prescription of traditional herbs (Carstens 2020).

Peltzer *et al.* (2008) assessed the use of TCAM by 618 HIV patients in three public hospitals in KZN, South Africa, and found that 51.3% relied on traditional therapies, which predominantly utilised herbs. These herbal therapies were used predominantly for pain relief. Babb *et al.* (2007) studied 44 individuals with moderate or advanced HIV disease attending a workplace clinic providing ART in South Africa. They observed that 32% of the patients were using TM, most frequently traditional herbs. These herbs, predominantly the African potato and aloe vera, were utilised for a feeling of wellness, rejuvenation and pain relief (Babb *et al.* 2007). TM users reported utilising herbal or medicinal mixtures that claimed to heal all conditions (Babb *et al.* 2007).

It is apparent in the literature that TM is widely utilised by HIV positive patients, predominantly for pain. However, due to the challenges surrounding TM and allopathic medicine relationship, many gaps in the literature exist (Puoane *et al.* 2012; Walwyn and Maitshotlo 2010b; Wiese, Oster and Pincombe 2010). There are queries into TM drug-interaction with ART treatment (Peltzer *et al.* 2011), patient-physician relationships, stigma, and the disclosure of all treatments being utilised (Street *et al.* 2019; Wadley, Pincus and Evangelini 2019; Roberts 2002). Lastly the disjuncture and lack of integration between mainstream healthcare and traditional practices fosters the greatest challenge in treating and managing patients who employ both methods of care (Moshabela, Zuma and Gaede 2016; Nlooto 2015; Chitindingu, George and Gow 2014; Mbutho, Gqaleni and Korporaal 2012). This leaves THPs' methods and clinical relevance questionable (Nlooto and Panjasaram Naidoo 2014).

2.10 SUMMARY OF THE REVIEWED LITERATURE

The safety and efficacy of TCAM is often questioned in the healthcare sector (Fischer *et al.* 2014). In South Africa, several gaps exist, despite TCAM not being new to the country. Nlooto's (2015) study in South Africa, on the views and experiences of healthcare professionals on the use of TCAM in HIV patients, highlighted the awareness on the usage to be high; however, levels of acceptance of TCAM in the healthcare system in

South Africa remains low. Similar outcomes were noted by Gqaleni *et al.* (2007) and Mbutho, Gqaleni and Korporaal (2012) that, although healthcare providers are aware of the usage by HIV patients, there is a lack of knowledge on the exact treatment regimens, as well as their safety and efficacy (James *et al.* 2018). This could be due to the lack of undergraduate education and poor knowledge, as there is a paucity of curricula in the biomedical domain, which incorporate TCAM (Chitindingu, George and Gow 2014).

Although traditional and homeopathic medicines are considered “safe”, the safety, efficacy and quality remain questionable (Abdullahi 2011; Adewunmi and Ojewole 2004). Further to this, although there is a widespread use of medicinal plant species to manage HIV infection and its associated symptoms, much of the information surrounding them remains undocumented and unverified (Anywar *et al.* 2020). Despite treatment processes being questioned, TCAM practitioners are often negatively reflected in the medical fraternity (James *et al.* 2018; Moshabela, Zuma and Gaede 2016) . Because of this, infected patients do not disclose the use of TCAM to their mainstream healthcare providers (James *et al.* 2018; Richter 2003).

This study will fill the knowledge gap on how TCAM practitioners treat and manage CP in HIV and potentially provide TCAM treatment and management guidelines for CP in HIV. Medical providers need to understand the basic concepts of pain management across all domains of medicine. This includes the point at which specific treatments should be recommended, their potential risks, benefits, and the adverse drug reactions and drug–drug interactions that can occur when pharmacotherapies are prescribed (Street *et al.* 2019). This study is beneficial in this regard.

The study can facilitate and foster collaboration between TCAM and conventional medicine in the management of a global burden. A study of this nature is in keeping with both global and local clinical guidelines, and national health policy in South Africa, on incorporation and integration of TCAM in the management of chronic disease (Bruce *et al.* 2017; Vawda 2017; Ngcobo *et al.* 2012; Gqaleni *et al.* 2007; Bodeker and Kronenberg 2002).

2.11 SUMMARY OF THE CHAPTER

The literature reviewed in this chapter revealed that, although traditional complementary alternative therapies are utilised for CP in HIV, there is a lack of understanding on the actual practices of treatment and management. The review further revealed that CP in HIV is rife. This warrants further investigation, especially in an African context, where the burden of the disease is high. The developed guidelines will assist in facilitating a comprehensive approach for the selected TCAM practitioner to utilise when managing an HIV patient. It will further give perspective and foster guidelines for collaboration with allopathic practitioners when managing a patient presenting with CP in HIV.

In Chapter 3, the conceptual framework that was adopted to guide the study is presented.

CHAPTER 3 CONCEPTUAL FRAMEWORK

3.1 INTRODUCTION

In this chapter, the researcher develops and discusses the conceptual framework that was used to formulate the understanding of TCAM treatment and management practices of CP in HIV.

In the previous chapter, the researcher highlighted the utilisation of TCAM therapies for CP, but there is no research the type of treatment therapies. In order to understand and gain richness of this topic, a qualitative, exploratory, descriptive approach was utilised in this study. This chapter first explains what a conceptual framework is, its selection, and how to integrate it into the thesis.

3.2 CONCEPTUAL FRAMEWORK TO GUIDE THE STUDY

The previous chapter embarked on unpacking the literature surrounding TCAM treatment and management of CP in HIV to understand the theory behind it. All research must be connected to the literature or the concepts that support the need for the study, be related to the study's purpose statement, and situate the study in terms of previous work (Rocco and Plakhotnik 2009). A conceptual framework is synthesised from a number of concepts, research findings and theoretical perspectives, some of which may be in opposition or competition with one another (Adom, Hussein and Agyem 2018; Green 2014). Hence, the literature review of this study was done to synthesise the conceptual framework.

A conceptual framework draws on concepts from various theories and findings to guide research (Green 2014; Imenda 2014). The goal of a conceptual framework is to categorise and describe concepts relevant to the study and map relationships among them. To achieve this goal, qualitative researchers incorporate both relevant theory and empirical research that help to organise the conceptual framework and “to see where the overlaps, contradictions, refinements, or qualifications are” (Imenda 2014; Rocco

and Plakhotnik 2009). Therefore, the conceptual framework for this study provides coherence on the research of TCAM treatment and management of CP in HIV.

3.3 SELECTION OF CONCEPTUAL FRAMEWORK FOR THE STUDY

The selection of a framework is based on the research problem/problem statement, aim, significance, and objectives of the study (Green 2014; Rocco and Plakhotnik 2009). The scope of a conceptual framework is usually applicable only to the specific research problem for which it was created (Imenda 2014).

The problem statement of the study states: “The use of TCAM is widespread in many countries of the world, specifically amongst patients with chronic or long-term illnesses” (Chitindingu, George and Gow 2014). Research has revealed that as many as two-thirds of people with HIV have used TCAM (Mbutho, Gqaleni and Korporaal 2012; Peltzer *et al.* 2011; Coulter and Willis 2004) and most commonly for the CP associated with the disease (James *et al.* 2018; Parker, Stein and Jelsma 2014; Littlewood and Venable 2008). James *et al.* (2018) revealed that despite this evidence of increased usage, challenges exist amongst both practitioners and patients. The evidence surrounding TCAM benefits and efficacy is limited and questioned. This could be due to lack of knowledge on the treatment practices in this field of medicine, therefore warranting such an investigation.

Based on the problem statement, several constructs exist, as depicted in Table 3.1.

Table 3.1: Conceptual framework for the study

Construct	Concepts	Category	Ideas
High utilisation of TCAM for CP in HIV.	Patient choice.	Reason of treatment choice.	Familiarity, culture, comfort, cost, stigma.
Principles and practices of TCAM practitioners in the treatment and management of CP in HIV.	What is the treatment and management methods utilised for CP in HIV?	Identification and diagnosis of CP in the patient.	Description, understanding and characteristics of CP in the patient.
		Treatment of CP in the patient.	Treatment modalities, herbs, remedies utilised.
		Management of the patient.	Investigations, referral to other practitioners, home care, regular follow-up consultations.
		Evaluation of the patient.	Feedback from patients.
Knowledge of TCAM in the medical domain.	Does the biomedical domain understand TCAM practices?	Lack of knowledge on traditional and complementary knowledge systems.	History of indigenous knowledge systems.
		Understanding the processes of TCAM treatment.	Lack of evidence of what treatment protocols entail in the literature Safety and efficacy of the treatments prescribed when combined with allopathic medicine. Benefit of prescribed TCAM medicine or treatment modality.
Integrative Practice.	Processes.	Inter-referral relationships. Multi-disciplinary approach when dealing with a broad condition like HIV.	Communication with patient in consults on different treatments utilised. Referrals received from other practitioners.

3.4 APPLICATION OF THE CONCEPTUAL FRAMEWORK FOR THE STUDY

The conceptual framework should be aligned to the literature review by concept mapping defined as the process of representing and organising ideas. It provides a frame to guide the research methodology, interpretation of the results, and discussion and reporting of the results (Green 2014; Imenda 2014).

Regardless of the various labels under which they are known, such as ‘traditional’, ‘complementary’, ‘alternative’, integrative’, or ‘natural’, non-conventional medicines represent the foundation of any health system (Mpinga *et al.* 2013). Societies have used them through the millennia for the maintenance of health (Mpinga *et al.* 2013) and TCAM practitioners have maintained their system’s existence in private practice outside of the mainstream healthcare system (Wiese, Oster and Pincombe 2010).

The WHO adopted a world strategy to facilitate the integration of traditional medicines into health systems. These developments are occurring in a global health context, marked by new health challenges that call for more effective organisation in the health sector. The most prominent among these challenges is the HIV pandemic (Mpinga *et al.* 2013).

Guidelines, such as the *Clinical Practice Guideline for the Management of Chronic Pain in Patients Living with HIV* by Bruce *et al.* (2017) do exist, but these guidelines are not within the context of South Africa, and fail to answer the objectives of this study. There are recommendations for HIV medical providers to develop and participate in interdisciplinary teams to care for patients with complex CP. Integration, however, is only viable when all knowledge systems are understood and, hence, the concept of this study.

According to the South African HIV AIDS Society HIV Palliative Care Guidelines, CP is a major complaint. The guidelines report, pain in HIV-infected South Africans is likely to accompany an identifiable clinical cause and the most valuable contribution the HIV and palliative care physician can make to pain management is to identify the cause and treat it (Spencer *et al.* 2019). There is no mention of TCAM in the guidelines, despite it being utilised by a high percentage of infected individuals in SA. This is evident in the constructs of the literature reviewed and concepts synthesised in the study. This will be addressed in objective four of the study, which entails the development of practitioner guidelines.

3.5 SUMMARY OF THE CHAPTER

The chapter explained and discussed the conceptual framework. Based on the literature review and research objectives and problem statement, it showed how the conceptual framework was constructed. Additionally, it explained that the constructed framework would guide the entire study.

In the next chapter, the researcher discusses the methodological underpinning of the study.

CHAPTER 4 RESEARCH METHODOLOGY

4.1 INTRODUCTION

This chapter focuses on the research methodology, and the steps and processes that were used to collect the data. Methodology refers to ‘the theoretical, political and philosophical backgrounds to social research and their implications for research practice and for the use of particular research methods (Creswell 2007). Methods, in contrast, refer to the techniques used to acquire and analyse data to create knowledge (Polit and Beck 2010; Creswell 2007). Methodology is thus a strategy of enquiry that guides a set of procedures (Petty, Thomson and Stew 2012; Polit and Beck 2010).

4.2 RESEARCH DESIGN

Research design is the overall plan for obtaining answers to the research questions (Polit and Beck 2010). A qualitative, explorative, descriptive contextual design within an interpretivist paradigm was employed to guide this study (Polit and Beck 2010; Creswell 2007).

4.2.1 Qualitative Research

Qualitative research focuses on the meaning, experience, and understanding of the phenomenon, and it allows the researcher to interact with individuals or groups to understand their experiences (Brink 2012; Creswell 2007; Creswell 1998; Guba and Lincoln 1989).

A qualitative research design consists of the following key features that are applied across different disciplines (Rutberg and Bouikidis 2018; Creswell 2014; Creswell 2007):

- Research is conducted in a real-life situation.
- The focus is more on the process, and less on the product.

- The main purpose of qualitative research is in-depth description and understanding of people's beliefs, actions and events in all their complexity.
- The rationale of the research is not to generalise the findings, but to understand them in context.
- The research is often inductive in nature and, as such, generates more questions and hypotheses.
- The researcher is the main instrument in qualitative research and is subjectively involved in the research process.
- Research often involves merging various data collection strategies, such as triangulation.
- Research benefits from ongoing data analysis to guide subsequent strategies and decisions about when data collection is done.

These key features of qualitative design were maintained in this study. The researcher explored how the selected TCAM practitioners treated and managed CP in HIV patients. The main purpose of the study was to understand this process and develop practitioner guidelines for selected TCAM practitioners to utilise in the treatment of CP in HIV.

To maintain the inductive nature of qualitative research, the researcher, with the assistance of a research assistant, obtained information by listening to and observing the research participants during the interview process. Face to face interviews were utilised for data collection and data were continually analysed throughout the collection process until data saturation was attained.

4.2.2 Explorative Research

Explorative research is an investigation of a phenomenon, the way it is manifested and the other factors to which it is related (Rutberg and Bouikidis 2018; Polit and Beck 2010). According to Stevens and Wrenn (2013) , it is utilised when a researcher has the following objectives:

- Define a problem.
- Generate ideas.

- Provide insight.
- Establish priorities for future research.
- Identify variables and levels of variables for descriptive and causal research.

In this study, little was known and understood on the treatment and management practices utilised by TCAM practitioners for CP in HIV. This gap was identified by the researcher, and explored to fully understand the protocols utilised by TCAM practitioners for CP in HIV. This exploration was critical in the development of practitioner guidelines and further substantiated that CP should be an important consideration in HIV primary care across all medical disciplines.

4.2.3 Descriptive Research

The purpose of descriptive research is to observe, describe, and document aspects of a situation (Polit and Beck 2010). This is further substantiated by Creswell (2014), who explained that a descriptive strategy provides a picture of a situation as it is naturally happening, without manipulation of any variables. In this study, the researcher explored and described specific protocols utilised by selected TCAM practitioners for CP in HIV. This aspect of the design was chosen because the researcher was able to gather the data, analyse the data thematically and interpret the findings. Through this descriptive method, the researcher was able to develop practitioner treatment and management guidelines.

4.2.4 Interpretivist Paradigm

A research paradigm inherently reflects the researcher's beliefs about the world (Creswell 2014). It constitutes the abstract beliefs and principles that shape how a researcher sees, interprets and acts within the world. It is the conceptual lens through which the researcher examines the methodological aspects of their research project to determine the research methods that will be used and how the data will be analysed (Kivunja and Kuyini 2017; Creswell 2007). Paradigms are thus important because they provide beliefs and dictate to scholars in a particular discipline; influence what should be studied; how it should be studied; and how the results of the study should be interpreted. The paradigm defines a researcher's philosophical orientation and has

significant implications for every decision made in the research process (Kivunja and Kuyini 2017; Schwandt, Lincoln and Guba 2007; Guba and Lincoln 1989).

The interpretivist paradigm works to understand the subjective world of human experience (Guba and Lincoln 1989). This approach tries to 'get into the head' of the subjects being studied so to speak, and to understand and interpret what the subject is thinking or meaning and making of the context being explored. Every effort is made to try to understand the viewpoint of the subject being observed, rather than the viewpoint of the observer (Kivunja and Kuyini 2017). Emphasis is placed on understanding the individual and their interpretation of the world around them. Hence, the key tenet of the interpretivist paradigm is that reality is socially constructed (Kivunja and Kuyini 2017; Creswell 2007; Creswell 1998).

The aim of this research was to explore the treatment, and management practice methods of various TCAM practitioners. The interpretivist paradigm was a suitable paradigm for the study, as it allowed the researcher to gather data and to understand the subjective world and experience of the selected TCAM practitioners. In this constructive manner, the researcher was able to generate data.

4.3 STUDY SETTING

The study setting is the physical location in which the study will take place (Yilmaz 2013), which was in the eThekweni municipality region, KwaZulu-Natal, South Africa. The research site of this study was at the selected TCAM practitioners' practices situated within the eThekweni Municipality. These practices were located in Kwa Mashu, Overport, Musgrave, Durban Central business district, Westville, Queensburgh and Umlazi.

Figure 4.1 below displays the eThekweni municipality.



Figure 4.1: Map of eThekweni Municipality (Google Map 2020)

4.4 STUDY POPULATION

Population refers to the target population, who will meet the specific criteria to be included in the study (Tashakkori and Teddlie 2003). The study population is selected to satisfy a phenomenon in a research study (Tashakkori and Teddlie 2003). The population of this study consisted of selected TCAM practitioners, namely chiropractors and homeopaths, who are registered with the Allied Health Professions Council of South Africa (AHPCSA), and traditional healers in the categories of *nyanga* and *sangoma* of the Interim Traditional Healers Practitioners Council-KZN sector (ITHPC). These practitioners include registered chiropractors, homeopaths, and traditional health practitioners (THPs).

The study population was selected based on the literature to support the TCAM practitioners that are predominantly utilised for CP in HIV in South Africa. Based on the

literature, traditional African medicine, micronutrients, herbs and physical therapy were the most popular modalities utilised.

4.5 SAMPLING PROCESS

Sampling refers to the selection of cases to represent an entire population so that inferences about the population can be drawn (Polit and Beck 2010). Purposive and snowball sampling were the strategies employed in this study to select the study participants. Purposive sampling is a form of non-probability sampling. It involves the conscious selection, by the researcher, of certain participants for inclusion in the study; it allows for representativeness and comparability to be achieved by selecting this cohort (Robinson 2014).

The snowball sampling method is when research participants are used to recruit more participants for a study and it is employed when the characteristics of the sample population are similar (Handcock and Gile 2011). The researcher selected registered chiropractors, homeopaths and THPs who fulfilled the inclusion criteria of the study.

Participants who were initially recruited by the researcher referred other participants to the researcher. In the homeopath group, two participants were purposively recruited and two were referred via the snowball method. In the THP group, two participants were purposively recruited and three were referred via snowball. All the chiropractors were purposively sampled.

4.5.1 Sample Size

In qualitative research, the sample size cannot be determined through statistical extrapolation (Creswell 2014; Creswell 2007), and neither does a larger sample size mean that more data will be collected, nor does it mean that there will be more information acquired (Gale *et al.* 2013; Creswell 2007). Furthermore, the time-consuming nature of qualitative data analysis makes large sample sizes impractical (Pope, Ziebland and Mays 2000).

Data saturation refers to the point in the research process when no new information is discovered in data analysis, and this redundancy signals to researchers that data collection may cease (Faulkner and Trotter 2017). Saturation means that a researcher can be reasonably assured that further data collection would yield similar results and serve to confirm emerging themes and conclusions. When researchers can claim that they have collected enough data to achieve their research purpose, they should report how, when and to what degree they achieved data saturation (Faulkner and Trotter 2017).

Therefore, a minimum sample size of 12 was employed to guide this study. Data saturation was attained at 13 participants, which included five traditional health practitioners, four homeopaths and four chiropractors. Saturation was assessed when an additional three participants were interviewed and no new information, when compared to existing information, was obtained.

4.5.2 Inclusion Criteria

- Selected chiropractors registered with Allied Health Professions Council of South Africa (AHPCSA).

- Selected THPs registered with Interim Traditional Health Practitioners Council (ITHPC) – KZN sector.
- Selected homeopaths registered with AHPCSA.
- Practitioners who treated HIV positive patients who presented with CP as a complaint.
- Practitioners with a minimum duration of two years in private practice.

4.5.3 Exclusion Criteria

- Practitioners not registered with AHPCSA or ITHPC.
- Practitioners who did not provide informed consent.

4.6 RECRUITMENT PROCESS

The researcher contacted AHPCSA and ITHPC for a list of registered practitioners in the eThekweni region. The researcher contacted participants telephonically and via email. Participants, who were interested in participation and met the inclusion criteria of the study, were accepted. The date, time and venue of the interview were determined in conjunction with the participant. The participants were provided with a letter of information (Appendix 2a) and informed consent (Appendix 3a). Any of the participants who did not understand English were provided with an isiZulu translated letter of information (Appendix 2b) and informed consent (Appendix 3b).

4.7 DATA COLLECTION PROCESS

Data collection is a process of gathering information to address the research problem (Polit and Beck 2010). In order to obtain the details of the participants, a guide for demographic data was used (Appendix 4a in English and Appendix 4b in isiZulu). Interview guides (Appendix 5 for Chiropractors; Appendix 6 for Homeopaths and Appendices 7a and 7b for THPs) were utilised to facilitate the interview discussions.

In-depth, one-on-one semi-structured interviews were conducted with each participant. The researcher facilitated the interview sessions. Permission was sought from the

participants to use a voice recorder to capture the discussions. An isiZulu speaking research assistant was utilised in the study for assisting with translation of questions for the THPs.

Data were collected until the point of data saturation. A total of five traditional health practitioners, four homeopaths and four chiropractors were interviewed. The semi-structured interviews were recorded, using a voice recorder to ensure that the data were participants' verbatim responses. The researcher used field notes to ascertain points, moods, and facial expressions of the participants during the interview.

4.8 DATA ANALYSIS

In qualitative studies, data analysis decreases, organises, and gives meaning to data (Creswell 2014; Chamberlain 2009; Creswell 2007). Data analysis has numerous constituents as the researcher tries to make sense of the data. The qualitative data were transcribed from the voice recorder into a Word document. Thereafter, the data were organised and stored, using the Nvivo programme. This programme helped the researcher to systemically organise data into themes and sub-themes with codes to evaluate and interpret qualitative texts. Tesch's eight steps of thematic analysis was used to analyse the data. (Creswell 2014; Vaismoradi, Turunen and Bondas 2013; Pope, Ziebland and Mays 2000).

Tesch's proposed eight steps in thematic data analysis include:

Phase 1: Familiarising oneself with the data

The researcher read the entire transcript multiple times to gain insight into the content of the research.

Phase 2: Generating initial codes

The researcher selected an interview and understood the underlying information. The researcher manually coded the data and made notes on the transcripts.

Phase 3: Searching for themes

A list of all the themes and topics was made. Similar themes and topics were identified and clustered together.

Phase 4: Reviewing themes

The researcher applied the themes and topics to the data collected. The themes or topics were coded and the researcher looked for new categories.

Phase 5: Defining and naming themes

The researcher utilised descriptive wording for the themes or topics and categorised them according to the relationships found.

Phase 6: Final coding

A final decision was made by the researcher on the codes used.

Phase 7: Producing a report

The researcher analysed the data and produced a coherent and concise report.

Phase 8: Recoding

The researcher recoded the data where necessary.

4.9 DEVELOPMENT OF TCAM TREATMENT AND MANAGEMENT PRACTITIONER GUIDELINES FOR CHRONIC PAIN MANAGEMENT IN HIV

Clinical practice guidelines (hereafter referred to as guidelines) are one of the foundations of efforts to improve healthcare (Woolf *et al.* 2012). Guidelines are defined as “systematically developed statements to assist practitioner and patient decisions about appropriate healthcare for specific clinical circumstances” (Hunter *et al.* 2017; Woolf *et al.* 2012; Shekelle *et al.* 1999). The methods of guideline development should ensure that treating patients according to the guidelines would achieve the outcomes that are desired (Hunter *et al.* 2017; Shekelle *et al.* 1999). The aim of guidelines is to reduce unnecessary variations in service delivery, by informing a rational approach to the management of patients, as well as guiding healthcare policies (Hunter *et al.* 2017).

The researcher developed guidelines from the data collected from the selected TCAM practitioners.

As outlined by Shekelle *et al.* (1999) and Woolf *et al.* (2012) on guideline development, the researcher adopted the following process to develop treatment and management guidelines for TCAM treatment and management of CP in HIV.

4.9.1 Identifying and Refining the Subject Area

If a topic is not refined, the development of a guideline remains too broad (Shekelle *et al.* 1999). An interpretive approach was used to appraise and synthesise the information provided by the selected TCAM practitioners. This was an inductive process. As similar statements were identified in the data, the researcher reviewed the data for relevant themes applicable to the use, practice, and management protocols utilised by the TCAM practitioner for CP in HIV. These themes were refined and categorised in order of priority. The data were also compared to the literature reviewed.

4.9.2 Translating Evidence into a Clinical Practice Guideline

A translation of the evidence is key in the development of a guideline (Woolf *et al.* 2012). This avoids developing a guideline that is of limited scope or applicability. The researcher developed the guideline based on the distinct themes that strongly supported treatment of CP in HIV by the selected TCAM practitioners. Each practitioner guideline was grouped accordingly. Therefore, within the guideline development process, a decision was taken about how opinion was both used and gathered.

4.9.3 External review of the guideline

Guidelines should receive external review to ensure content validity, clarity, and applicability (Woolf *et al.* 2012).

External reviewers should cover three areas:

- People with expertise in clinical content, who can review the guideline to verify the completeness of the literature review and to ensure clinical sensibility.
- Experts in systematic reviews or guideline development, or both, who can review the method by which the guideline was developed.

- Potential users of the guideline, who can judge its usefulness.

The researcher selected five relevant stakeholders to review the guidelines. These included research experts in guideline development and selected TCAM practitioners in clinical practice and academia.

4.10 RESEARCH TRUSTWORTHINESS

Trustworthiness refers to the accuracy and adequacy in qualitative research (Schwandt, Lincoln and Guba 2007; Holloway 1995). The criteria used to establish trustworthiness by Schwandt, Lincoln and Guba (2007) is credibility, dependability, confirmability and transferability. Guba's model of trustworthiness ensured validity and reliability of the research project.

4.10.1 Credibility

Credibility relates to the truth in the data of the research study and the analysis of data (Polit and Beck 2010). It attempts to portray a true reflection of the phenomenon under investigation (Pope, Ziebland and Mays 2000). Credibility is established by peer reviews, member checks, and validation or co-analysis of the data. Credibility helps to reduce discrepancies in the data collected by the researcher during the interview (Rolfe 2006). To ensure credibility in this study, field notes were written during the interview. Voice recordings were also done. Information was probed during interviews until data were saturated and detailed notes were written immediately after the interview. The researcher cross checked with the respective professional council to ensure that each participant is an actively registered practitioner.

4.10.2 Dependability

Dependability involves the sturdiness of the data over a period of time, such as throughout the interview process (Polit and Beck 2010). The interviews were consistent with all participants. Consistency was ensured by utilising and following the same interview guide for each participant. The researcher and the same research assistant were utilised for all interviews that required isiZulu translation. Although dependability is a complicated criterion in qualitative research (Rolfe 2006), a research assistant was

employed to assist with the translation of questions in the interview process, as well as for translation during the transcribing process. This ensured that accuracy was maintained in understanding the data received from the participants.

An audit trail was maintained through the safe keeping of raw data of each interview for future reference. An audit involves a close scrutiny of the data collected and any supporting documentation by an external reviewer, in this case the supervisor. Although the researcher coded the interviews herself, the data and analysis were checked for discrepancies by the research supervisors, who acted as independent coders. The results, recommendations, and processes were discussed with peers who were not involved in the data collection.

4.10.3 Confirmability

Confirmability refers to a correlation in the data when reviewed by two or more independent researchers (Polit and Beck 2010). Confirmability is achieved when no discrepancies are found, demonstrating that the findings of the research emerged from the data and not the researcher's predisposition (Pope, Ziebland and Mays 2000). To ensure confirmability in this study; the researcher's data analysis was reviewed by the research assistant and supervisors. The themes and sub-themes identified by the researcher and supervisors were compared to those of the research assistant to identify any discrepancies in the data.

4.10.4 Transferability

Transferability refers to the differences that may be encountered when comparing the data of a study group with those in another environment. The reader was provided with sufficient data on the field of research to determine if the findings of the research context corresponded when applied to a different setting (Polit and Beck 2010). This can be avoided by carefully selecting participants through a panel of judges.

The researcher ensured transferability of the results by providing a detailed description of the research setting and research processes. This confirmed transferability of the study, making it possible to build on these findings when conducting further research.

4.11 ETHICAL CONSIDERATIONS

Ethical approval to conduct this study was obtained from the Institutional Research and Ethics Committee (IREC) of the Durban University of Technology (DUT): ethical clearance number IREC 050/20 (Appendix 1). The participants were provided with a letter of information (Appendices 2a and 2b) and consent (Appendices 3a and 3b) to ensure all participants understood the research and its processes. Both English and isiZulu letters were provided, as isiZulu is the main language spoken in eThekweni district. Only the participants who provided signed consent were included in the study and were informed that participation in the study was voluntary and they could withdraw from the study without any penalties.

The principles of research ethics, namely autonomy, non-maleficence, beneficence and justice, were maintained in the study.

4.11.1 Autonomy

Autonomy refers to the ability of the participants to engage in independent decision making (Polit and Beck 2010). All participants were able to make their own decisions and there was no influence from the researcher in any manner. The researcher, in exchange for participation, offered no form of enticement or incentive. The participants were able to withdraw from the study before or during the interview process.

The principles of autonomy were stated in the letter of information (Appendices 2a and 2b) provided to each of the participants before the interview.

4.11.2 Non-Maleficence

Non-maleficence refers to the precautions taken by the researcher to ensure the participants do not face any harm, risks or side effects (Polit and Beck 2010). Non-maleficence was maintained by ensuring that the participants were not at risk to harm or any side effects in the study and this was stipulated in the letter of information (Appendices 2a and 2b), which was made available to the participants before the interview.

4.11.3 Beneficence

Beneficence refers to the duty of the researcher to ensure maximal benefit and minimal harm to the participants. It honours and upholds the physical, financial, social, emotional, and legal well-being of the participants (Polit and Beck 2010). The principle means doing good, acts of kindness or goodness, and avoiding harm. To adhere to this principle, a researcher needs to secure the well-being of the participants, be it physical, psychological, emotional, spiritual, economic, social or legal.

The right to freedom from harm and discomfort was maintained as participants were not subjected to any risk of harm or injury.

Before the study was conducted, it was first approved by the Institutional Research Ethics Committee. The letter of information advised the participant of the reason for the research study by clearly outlining the aim and objectives of the study, enabling the participant to identify the benefit the research holds (Appendices 2a and 2b). By signing an informed consent (Appendices 3a and 3b) prior to the interview, participants were reassured of their confidentiality.

4.11.4 Justice

Justice refers to fair treatment and the right to privacy (Polit and Beck 2010). Justice was maintained by ensuring all information from the participants was stored on a password protected computer, which was accessible only by the researcher. No identification details were available on the transcript documents. Every participant was given equal opportunities to voice their opinions, therefore ensuring the interview process was fair. The right to self-determination was also maintained as participant had a right to ask questions, to refuse to give information and to withdraw from the study as indicated in the Information letter and consent.

4.12 SUMMARY OF THE CHAPTER

This chapter presented the methodology and processes that guided this research. The method that was used to develop the intended guidelines for TCAM treatment and

management for CP in HIV were discussed. The maintenance of research trustworthiness of the study was highlighted in this chapter.

In Chapter 5, the findings of the study are presented.

CHAPTER 5 PRESENTATION OF THE RESULTS

5.1 INTRODUCTION

This chapter presents the results of the interview data obtained from the TCAM practitioners interviewed for this study. These practitioners treated patients with chronic pain in HIV in the eThekweni Municipality. The interview data were analysed for relevance to the research questions of the study. This chapter describes the participants and presents the results of the study as themes. The chapter concludes with a summary.

The study was intended to understand the treatment and management practices of selected TCAM practitioners for CP in HIV. The results were utilised to develop treatment and management guidelines for CP in HIV to provide insight into the TCAM practices that are utilised in the South African healthcare system.

5.2 DESCRIPTION OF THE PARTICIPANTS OF THE STUDY

The participants of the study comprised of 13 TCAM practitioners. Of these, four participants were chiropractors, four were homeopaths and five were traditional health practitioners, which included both *izinyanga* (herbalists) and *izangoma* (diviners).

5.2.1 Demographic Data of the Participants

The demographics of all participants were varied. All race groups were depicted in the sample, with the black race being the most dominant. IsiZulu was the dominant first language amongst THPs and English for the chiropractors and homeopaths. The demographic profile of the sample participants included ten females and three males. The age range was between 30-71 years of age and the work experience across the professions varied from five years to 53 years. All participants had training in their respective disciplines. All participants had prior experience in treatment of chronic pain in HIV. The majority of the participants were THPs in the field of *izangoma* (diviners). Table 5.1 displays the demographic data of the study participants.

Table 5.1: Demographic data of the participants

P	Gender	Age	Education Level	Type of TCAM practitioner	Work Experience
1	Female	57	High School	THP (<i>Isangoma</i>)	22 years
2	Female	53	High School	THP (<i>Isangoma</i>)	36 years
3	Female	71	High School	THP (<i>Isangoma</i>)	53 years
4	Male	63	Tertiary	THP (<i>Inyanga</i>)	30 years
5	Male	54	Tertiary	THP (<i>Inyanga</i>)	38 years
6	Female	35	Tertiary	Chiropractor	6 years
7	Female	31	Tertiary	Chiropractor	6 years
8	Female	35	Tertiary	Chiropractor	5 years
9	Male	42	Tertiary	Chiropractor	15 years
10	Female	38	Tertiary	Homeopath	10 years
11	Female	34	Tertiary	Homeopath	5 years
12	Female	34	Tertiary	Homeopath	5 years
13	Female	52	Tertiary	Homeopath	23 years

Key: P = Participant Number

5.3 CONCEPTUALISATION OF THEMES OF THE STUDY

Four major themes emerged from the interviews of the TCAM practitioners irrespective of discipline. These themes included:

Theme 1: The knowledge and understanding of HIV disease.

Theme 2: The principles and practice of treatment of chronic pain in HIV.

Theme 3: The management of chronic pain in HIV.

Theme 4: Challenges and barriers in the treatment and management of chronic pain in HIV.

These main themes formed an integral component in the development and understanding of the practices, beliefs, and attitudes of TCAM practitioners in the treatment and management of chronic pain in HIV. These main themes guided the development of the treatment and management guideline of this study.

Figure 5.1 depicts the main themes that emerged from the study.

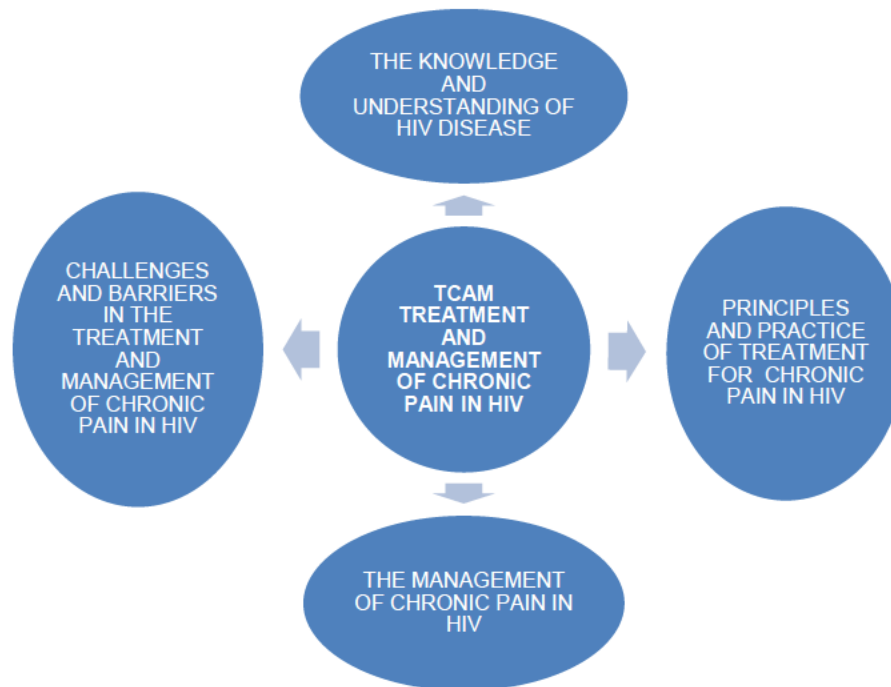


Figure 5.1: Main themes that emerged from the study

Numerous sub-themes emerged from the study. Each sub-theme will be discussed in relation to its related main theme. Table 5.2 depicts the main themes and sub-themes derived from the study.

Table 5.2: Main themes and sub-themes from interviews with TCAM practitioners

MAIN THEME	SUB-THEME
1. Knowledge and understanding of HIV disease.	1.1 Understanding HIV as an individualised experience.
	1.2 Understanding the process of CP in HIV.
	1.3 Involvement of ARV drugs in CP development.
2. The principles and practice of treatment of chronic pain in HIV.	2.1 Diagnosis of CP in HIV.
	2.2 Treatment methods and practices for CP in HIV.
3. The management of chronic pain in HIV.	3.1 Evaluation of treatment.
	3.2 Referral patterns.
4. Challenges and barriers in the treatment and management of chronic pain in HIV.	4.1 The patient.
	4.2 Lack of collaborative practice with mainstream healthcare.
	4.3 Lack of knowledge on TCAM.

5.4 DESCRIPTION OF THE THEMES

5.4.1 Theme 1: Knowledge and Understanding of HIV Disease

Although there was no direct question on the knowledge of HIV, the majority of the practitioners stated, in response to CP treatment, that HIV is a complex disease that comes with various complications and, therefore, before attempting treatment of CP present in HIV, one needed to be guided on what the disease is. Given this, treating CP associated and present in HIV requires an understanding of the disease itself, as well as the underlying physiology of the disease process. The practitioners reported that patients with CP in HIV can present normally and can also be in the advanced stages of the disease, and therefore the knowledge on HIV is essential.

These opinions were based off the clinical experience of each practitioner treating the disease and the varied clinical presentations of each patient presenting to them with CP. All the practitioners who were interviewed had to have had experience in the treatment of CP in HIV and therefore their opinions were based thereon.

The practitioners also made mention of the role of ARV drugs and their side effects in CP development, which seemed to be common amongst patients.

5.4.1.1 Sub-Theme 1: Understanding HIV as an Individualised Experience

In explaining how they treated CP in HIV, each practitioner firstly explained that HIV is a widespread chronic systemic disease and treating CP associated or present with the disease required the understanding of HIV itself first. They also reinforced that like any condition, it is an individualised experience and two patients with the same disease can present very differently.

The following extracts explain this:

“In homeopathy we look at things holistically, so when treating we need to understand the disease process first as we need to get to the cause or root of the problem before dealing with the complaint. HIV is a widespread chronic

illness that has many complaints associated to it. Every patient is different.”
(Participant #13; Homeopath)

“HIV is a serious sickness, we have to understand it, because HIV patients all come to me with many problems.” (Participant 3; THP)

“HIV patients are so varied when they present to you. Some are so weak, some appear so normal, before I treat the CP complaint, I try to refresh my understanding and knowledge on the condition itself, as many treatments can be contraindicated.” (Participant #8; Chiropractor)

“I treat a range of HIV patients from the very healthy to those in advanced disease stage, therefore I need to understand it.” (Participant #7; Chiropractor)

5.4.1.2 Sub-Theme 2: Understanding the Process of CP in HIV

With reference to CP in HIV, the practitioners mentioned that although HIV is a viral inflammatory disease, CP in HIV is a disease in itself. It is constant and debilitating in most HIV infected patients. CP in HIV is multifactorial and is complex to treat. They further stated that CP is a very subjective experience and, when present in HIV, encompasses not only physical manifestations but can almost always include psychological involvement. This is linked to the stigma and fear of having the disease and knowing that it is incurable. CP was also the most common complaint that HIV patients presented to them for. Therefore, when treating and managing CP in HIV, one as a practitioner must have a background on what CP is.

This is illustrated by the following excerpts:

“CP in HIV needs to be understood. I as a practitioner need to know if it is a primary thing, secondary thing, mechanical thing. This is because CP in HIV is

complicated. I mean it can even be linked to ARV drugs. Most patients with HIV that I see, even if healthy are always in pain.” (Participant #6; Chiropractor)

“CP in HIV in my patients is ongoing, this is because patients are always inflamed, and are on so many meds and sometimes depressed. I need to understand the CP process in each patient before I start treating it.” (Participant #10; Homeopath)

“People with HIV are always in pain, they often have pain on their entire body all the time – ‘ubuhlungu bomzimba wonke’, and so you need to know what you are dealing with when they come to you. It is not always easy.” (Participant #2; THP)

“CP is a condition that itself is very complex, I mean even non-infected patients suffer CP, so with an underlying disease process it can be worse.” (Participant #9; Chiropractor)

5.4.1.3 Sub-Theme 3: Involvement of ARV Drugs in CP Development

The practitioners emphasised that it is vital to understand and identify the involvement and role of ARV drugs in the development of CP in HIV. The majority of the practitioners, mainly the chiropractors and homeopaths, associated some physical CP symptoms and complaints in HIV patients to be as a result of the side effects of ARV drugs. They further mentioned that patients did usually present to them for constant pain and burning sensations after having started taking ARVs or when the ARV medication was changed. The homeopaths also reported that in addition to burning sensations in the feet, signs of liver toxicity were also prevalent in patients taking ARV drugs. These two groups of practitioners further highlighted that, although the consumption of ARV medication is always encouraged by them, the drug side effects cannot be ignored when treating pain. The following extracts illustrate this:

“AZT often cause pain in my patients. Often, they experience extreme headaches or extreme nausea. They also have signs of liver toxicity and poor circulation. So, when treating them it is vital to know if they on ARVs or have recently changed their ARV meds.” (Participant #13; Homeopath)

“Majority of my patients take ARVs although they complain of burning feet, headache and nausea when they start. The burning feet and headache bring them to me” (Participant #7; Chiropractor).

“A lot of my patients on ARVs require detox treatment first especially because they have an inflamed liver which causes widespread pain, I still encourage them to take ARVs and I manage the pain and liver together.” (Participant #12; Homeopath)

“My patients on ARV meds, although healthy always have burning feet that is sometimes unresponsive to treatment. Definitely a side effect.” (Participant #9; Chiropractor)

5.4.2 Theme 2: The Principles and Practice of Treatment of Chronic Pain in HIV

The overall principles guiding patient treatment for CP in HIV were similar within the practitioner groups. Despite the three practitioner groups having different treatment practice methods, all practitioners, irrespective of discipline, emphasised the importance of a correct diagnosis in order to provide accurate and holistic care to the patient. All practitioners reiterated that utilising the correct principles and practice of treatment within their respective discipline and scope, ensure maximum treatment outcomes and benefits for the patient. Two key sub-themes emerged from this theme were: a) Diagnosis of CP in HIV and b) Treatment of CP in HIV. These sub-themes will

be discussed according to practitioner groups as the principles of practice differ among them.

5.4.2.1 Sub-Theme 1: Diagnosis of CP in HIV

The practitioners revealed that an integral part of treating and managing CP in HIV involved them making an accurate diagnosis. All aspects surrounding the pain complaints needed to be eliminated. This included both physical complaints and psychological contributions to the pain. The diagnosis of CP in HIV in their patients was achieved by a thorough case history, physical assessment, and sending off for investigations where necessary.

With reference to diagnosis, all chiropractors relied on the patients' medical history and physical examination for direction. In depth neurological and orthopaedic assessments helped rule out the pain origin, and level of chronicity of the pain. Most chiropractors utilised radiological X-rays and bloodwork to confirm their diagnosis. These investigations were further utilised to establish the accurate and global clinical picture of the patient, which assisted in ruling out any red flags in the patients. This was reported by the practitioners to be important when dealing with patients with underlying chronic disease like HIV, as it guided their treatment protocol.

Chiropractic treatment, although safe, is contraindicated in certain instances. The following extracts support these statements:

“The case history and physical exam especially neurological exam are my key tools for finding out what is wrong with the patient, especially with my very sick HIV patients. I also do a full blood and X-ray work up” (Participant #8; Chiropractor)

“I have treated a range of HIV positive patients for CP, more so the ones who are seemingly healthier. But because of the range from healthy to very thin and wasted, my case history and physical exam needs to be thorough.” (Participant #7; Chiropractor)

“X-rays are a huge part of my practice, I send for X-rays to rule out anything else like for example osteoporosis that could contraindicate my treatment. With HIV anything is possible.” (Participant #9; Chiropractor)

“I send for bloods and X-rays especially in the weaker patients. I even triple check by sending them back to their GP. I need to be sure” (Participant #8; Chiropractor)

The homeopaths reported that they rely on the process of a case history, physical examination and the establishment of the individualised constitution of the patient before making a diagnosis. The constitution in homeopathy refers to the underlying overall health of the patient rather than the surface symptoms with which they present. When dealing with a chronic illness like HIV, this is imperative for treatment and management. These tools then assist them in establishing the “simillimum”. A simillimum refers to the remedy best adapted for the treatment of any special condition in accordance with the fundamental therapeutic principle of homeopathy. The following statements affirm this:

“We do a full homeopathic case history, and understand the patient in their context mentally, emotionally and physically. We ask about the site of pain, severity, associated signs and symptoms and radiation. We also assess the patient physically. We then try to individualise the pain characteristics and establish the constitution of the patient which allows to establish the simillimum.”
(Participant #13; Homeopath)

“In homeopathy we search for the cause of the pain, although HIV is present there is a definite underlying cause to pain. Start with a history which involves even the family history and psychosocial history of the patient, then I find a constitutional remedy depending on the cause.” (Participant #11; Homeopath)

“I am very clinical in my practice approach, a part of my diagnosing process I require a full work up of the patient. Bloods is essential in all my patients and even more in my HIV positive patients. I need to know what I am working with.” (Participant #10; Homeopath).

The THP group of practitioners also utilised the process of case history and physical assessment to get to the route of the pain. *Izangoma*, however, utilised an additional mechanism of a spiritual connection with ancestors to guide the diagnosis. They indicated that the spiritual connection allows the practitioner to attain guidance on what could be wrong with the patient in entirety, as well as the correct treatment processes that need to be utilised. It also assists them in ruling out any aspects of spiritual ancestral involvement. They indicated that ancestors play an important role in the manifestation of disease and sometimes connect to show patients that something is wrong.

The *Izinyanga* made no mention of ancestral intervention. They purely took a case history and examined the patients to establish a diagnosis. The following extracts highlight the process of diagnosis:

“They come to me and tell me what their problem is, we discuss, ask about their lives, their family and medication they are taking especially if they treating their HIV. I then check them spiritually with the ancestors ‘ngiyabahlola’ before touching them. This helps to see for anything hidden.” (Participant #1, THP)

“We talk first, we talk about the status, what it does to the body, what medication they take as some even have TB. I then touch them and check the areas of pain, thereafter with their permission I consult the ancestors spiritually for a deeper insight.” (Participant #2; THP)

“Before I treat or do anything I talk to the patient. I do not interrupt, as the patient talks I receive a spiritual connection, I then speak to my ancestors for guidance before moving forward.” (Participant #3; THP)

“I listen, after listening I look at the place or feel the place where something is wrong. I then know exactly what herbs to mix.” (Participant #5; THP)

5.4.2.2 Sub-Theme 2: Treatment Practices and Methods for CP in HIV

Each practitioner group has a select treatment protocol that they utilise. All practitioners mentioned that their goal of treatment was to alleviate pain. Common trends existed within these practitioner groups. These included the area of pain and the symptoms that patients with CP were presenting. The most common areas of complaint across all practitioner groups were feet, head, large joints and back. The symptoms reported included burning painful feet, headaches, and widespread persistent joint and back pain. The symptoms were also reported to be longstanding and sometimes disabling. All the CP pain patients also reported associated stress, anxiety and or feelings of depression due to their pain.

Within the groups, the treatment protocols were all very similar. In the chiropractic group, treatment methods were all similarly aligned; the homeopathic group all utilised almost identical remedies, minerals and vitamins and herbs; and in the THP group, although not all herb names were disclosed, all utilised a very synonymous treatment approach.

The specific treatment and management methods will be discussed and outlined individually as per practitioner group.

Treatment Methods and Practices of CP in HIV by Chiropractors

a) Primary areas of complaint and symptoms

All the chiropractors who participated in the study reported the same areas of complaint and similar symptom presentation in patients with CP in HIV. These included

predominantly foot pain with burning, headaches, and painful joints. Spinal pain, especially in the thoracic region, were also reported; however, this was predominantly in those patients with a history of associated TB. The following examples reflect this:

“I treat a lot of headaches and upper thoracic region pain, however in patients who have advanced HIV I treat a lot of joint pain.” (Participant #7; Chiropractor)

“Widespread joint pain and peripheral neuropathies are the primary complaints.”
(Participant #9; Chiropractor)

“I treat upper back pain, headaches and burning feet the most in this patient group.” (Participant #8; Chiropractor)

b) Treatment Methods Utilised by Chiropractors for CP in HIV

The chiropractic treatment options that were widely utilised included joint manipulation, soft tissue therapy and the use of electro modalities. In some instances, adjunctive treatments, like stretching and the use of muscle taping techniques, were also mentioned. The chiropractors reported that their treatment approach depended on the stage of the disease the patient presented. Patients in the advanced stage, who appeared weak, frail or emaciated and had low CD4+ counts, were often treated more conservatively and modalities like needling and joint manipulation were often avoided. This was due to skin and bone fragility. These patients received mild joint mobilisation, and soft tissue therapy via massage.

The healthier patients received spinal and or joint manipulation, the use of electro-modalities, specifically interferential current therapy, and soft tissue therapy, like ischaemic compression and needling of myofascial trigger points. Although dry needling is high risk in HIV patients, the chiropractors felt confident in their skill of

execution and supported the use of the treatment due to the effective treatment outcomes.

Stretching and home exercises were also widely utilised by the chiropractors in this sample. Only one chiropractor in this group reported the use of nutritional support by advising on minerals and vitamins, food choices and by dispensing vitamins and minerals when necessary.

Their treatment choice was also guided by the mechanism of action behind the treatment modality. With CP, pain symptoms are long standing and often patients want to feel better much quicker. According to some chiropractors, some treatments that they provided offered a quick and effective outcome but they were not longstanding outcomes for CP. These treatments included manipulation and dry needling. They therefore needed to see CP in HIV patients for more regular follow ups for long term results.

The treatment methods employed by the chiropractors are depicted in these excerpts:

“Dependant on the complaint, whether it is headaches for example I utilise a lot of soft tissue therapy especially ischaemic compression. I adjust the joints and I use IFC on the upper back region” (Participant #6; Chiropractor)

“For upper back pain for instance in a patient who is advanced, I will mobilise, very light soft tissue massage and stretches. I do not needle due to the skin turgor and muscle wasting. For most of my patients though, manipulation is a must” (Participant #8; Chiropractor)

“In my healthier HIV patients; I only needle active trigger points, otherwise I stay away from needling, just to be safe. I use IFC, PNF stretching and manipulation a lot.” (Participant #7; Chiropractor)

The chiropractic group further reported that for the common complaint of burning foot pain, they utilised transcutaneous electrical nerve stimulation, also known as 'TENS' machine and kinesiotaping of the feet. They also encouraged home exercises of cold therapy application and stretches. These statements reflect this:

"TENS works incredibly for nerve pain especially in the feet. I also K-Tape it supports the foot structure and decreases sensitivity." (Participant #8; Chiropractor)

"I use K Tape and TENS, they work well for neuropathies, but I also give advice on footwear and refer for orthotics." (Participant #6; Chiropractor)

"After treating in the rooms, I give the patient the cold coke bottle stretching and rolling exercise to do at home as well, the cold helps with burning feet." (Participant #7; Chiropractor)

Treatment Methods and Practices for CP in HIV by Homeopaths

a) Primary Areas of Complaint and Symptoms

The homeopaths who participated in the study reported that the majority of patients that presented to their rooms with CP in HIV reported headaches, foot pain and generalised muscle or body ache. They often felt anxious, sad, and reported to be in prolonged bouts of pain that led to them feeling depressed. The pain symptoms often left them stressed because as one symptom resolved, something else would present. They reported chronic fatigue and lethargy also to be a common complaint in patients that they treated and linked this to liver toxicity due to the variety and number of medication their patients were on.

The following statements confirm this:

“Headaches and body pain especially in areas of the large muscles is what they mostly come in for and complain about. Widespread joint pain is also very common.” (Participant #10; Homeopath)

“Mostly the feet and headaches are common in 90% of my HIV positive patients.”
(Participant #11; Homeopath)

“Headaches and myopathies are the common complaints. There is like a pseudo paresis that takes place in these patients, especially those on AZT. Patients are also chronically fatigued and tired.” (Participant #13, Homeopath)

b) Treatment Methods Utilised by Homeopaths for CP in HIV

The homeopathic treatment approaches for CP in HIV revealed in this study involved the utilisation of remedies; tissue salts which are minute doses of minerals and vitamins; herbs; and psychological support via counselling of the patient. The homeopaths mentioned that their treatment approach and choices were based on the area of complaint, the level of chronicity of pain, and the patients' constitution.

All the homeopaths emphasised that with CP in HIV, a patient's body has undergone tissue changes and is inflamed, therefore their treatment needed to occur in stages for the best outcomes. This further guided their remedy choice, remedy dosage and number of times they saw the patient. Remedies were also administered orally in powders or tinctures, or via subcutaneous or intramuscular injection. The process of choosing and the choice of remedy were documented as the simillima. A simillimum is individualised and unique to every patient and similar simillima/remedies were utilised by the practitioners in this study for pain. These remedies included *arnica*, *belladonna*, and *traumeel*. The homeopaths made mention that these remedies were administered because their mechanism of action involves reducing inflammation and providing localised and global pain relief. Another common remedy utilised was *nux vomica*. This

remedy was reported by the homeopaths to be utilised for detoxifying the system and aided with symptoms of nausea and headache.

The homeopaths further mentioned that they utilised tissue salts, predominantly *magnesium*, as this nourished soft tissue structures, especially muscles and assisted with headaches. *Magnesium* also further assists with immune support. When it came to the use of herbs, most of the homeopaths advocated for the use of *curcumin* which is a natural herb. They mentioned that curcumin is a natural anti-inflammatory and provided immune support. This was essential in the patients with CP in HIV.

Highlights of their treatment choices are displayed in the following extracts:

“I like to target inflammation, so curcumin is the best. With homeopathic remedies I use arnica and belladonna, these are the best for pain whether local or generalised pain. I also give traumeel injections for the localised pain areas. Furthermore, for support I give magnesium tissue salts, this helps with muscle pain and even assists to sleep at night.” (Participant #10; Homeopath)

“There is no specific homeopathic remedy for HIV patients in CP, I look at the cause, so for general pain I use arnica. For local pain I use traumeel injections. I also use a lot of magphos (magnesium) when treating an HIV patient in pain. It helps a lot.” (Participant #11; Homeopath)

“I prescribe based on the cause and if the pain is localised or generalised. For a localised complaint I inject traumeel, for general I use arnica together with other remedies specific to the patient’s constitution. I follow a system like this as no two patients are the same” (Participant #13; Homeopath)

The homeopaths further highlighted that an important part of them treating CP in HIV patients involves detoxifying the patient for full treatment effect of the remedies for pain and to get the patients feeling healthy. They reported that many CP in HIV patients have a degree of tolerance to medication, because they have been on analgesics,

opioids, psychiatric medication and ARVs for periods of time. This overworks the liver and leads to liver and kidney toxicity.

The following statements depict these thoughts:

“When looking at causality of the pain, we sometimes identify that it could be sometimes due to the AZT or analgesics that the patient is taking over a long period of time. The liver is obviously overworked in these cases. It is these patients we use nux vomica. This remedy detoxifies liver and reduces the side effects of other drugs the patient is taking.” (Participant #13; Homeopath)

“Some of these patients are taking heavy drugs, so they suffering from gastric disturbances, liver problems and acidic bodies. I detox with nux vomica first to assist the patient.” (Participant #12; Homeopath)

“A lot of these patients are taking hard drugs; their drug tolerance is depleted so detox is required.” (Participant #10; Homeopath)

Treatment Methods and Practices for CP in HIV by THPs

a) Primary Areas of Complaint and Symptoms

The THPs mentioned similar traditional treatment approaches for CP in HIV. They all understood the HIV disease process and that CP is an important and prominent complaint in HIV patients. The primary areas of complaint were very similar amongst all the THPs. They all reported chest pain, *‘isifuba’*; headaches, *‘ikhanda elinamandla’*; body and joint pain; *‘ubuhlungu bonzima wonke’*; and pain due to repeated shingles, *‘ibhande’*, to be prominent amongst the patients. They did also report that many of the patients in pain felt low and sad and often did not want family to know about their problems. One THP mentioned that most of his patients were always tired and fatigued, *‘ukhukhathala komzimba wonke’*.

The following excerpts reveal the areas of complaint presenting to THPs:

“They often come with headaches and body pain to me. They also have shingles many times in the year, and the pain of shingles lasts a long time. This worries them.” (Participant #1; THP)

“They have headaches and shingles. They also have chest pain.” (Participant #4; THP)

“They come for headaches, chest pain and body pain and generalised tiredness of the body.” (Participant #5; THP)

b) Treatment Methods Utilised by THPs for CP in HIV

The treatment methods between *izangoma* and the *izinyanga* were quite similar. They both targeted pain complaints directly and utilised a combination of dried powdered herbs that were taken orally, inhaled, or mixed with a lubricant and applied topically or by drinking the herbal solutions. *Izangoma* further all utilised a mechanism of herbal compress (*ukuthoba*) and in extreme cases herbal enemas. The mechanism of treating was done based on the complaint the patient presented.

For the complaints of pain that were associated with headaches, joint pain and tiredness, a common treatment method included a prescription of a drinking liquid. This drinking liquid is referred to as *imbiza*. *Imbiza* is a combination of herbs, both dried and wet mixed with water, or any other herbal liquid. The potency of the dosage is provided based on the severity of the pain. The exact herbal names utilised in this drinking solution were not revealed by the THPs.

The THPs revealed that each of them has a unique way of mixing their own herbal constituents “*ukuhlanganisa amakhubalo namakhambi*”. These are specific to their heritage and therefore cannot be shared. They further mentioned that it is not a

standardised combination of herbs. The *imbiza* is unique and individualised to each patient, based on what was revealed in the history, physical and spiritual intervention in the case of *isangoma*. *Imbiza* is meant to work internally and is very effective in directly relieving pain.

In addition to *imbiza*, both *izangoma* and *izinyanga* prescribed *imithi*. *Umuthi* is the prescription of herbs that are mostly dried, grounded and powdered. These herbs are administered orally by sucking, inhaling via the nostril, or topically in an ointment. These herbs are extremely strong but effective. The dried herbs are most effective when taken orally or inhaled. The practitioners stated that the mechanism of action of the herbs when taken via the oral route allows for it to get readily absorbed directly into the body and helps to remove and absorb pain directly from the source. Once taken, patients usually utilise the toilet and purge themselves. The THPs report this to be a cleanse and removal of the toxins from the inside of the body that are causing the pain. Dependant on the severity, location of the pain and the patient's health status, *umuthi* is reported to be taken twice daily at maximum, usually in the morning and at night, before bed.

Umuthi when added into ointments and applied topically, is commonly utilised for shingles (*ibhande*), back pain, body ache and foot pain. The ointment is applied over the affected area of pain. The THPs mention that it helps to dry out the shingle and helps reduce swelling and pain in joints and muscles. The application of the ointment is usually 3-4 times daily. The THPs reported that this route of treatment is never given independently. It is always given in combination with the oral *umuthi* or *imbiza*. This is because the THPs cannot rely solely on the patient to actually apply the medicine and because you need to also clean a patient both internally and externally to be effective.

In very rare cases of extreme pain, or when a patient is unresponsive to treatment via oral or topical routes, the THPs reported patients are given an enema and *umuthi* are given via the rectum. This process is referred to as *ukuchatha*. It works instantly to relieve pain and cleanse the patient internally. The THPs highlighted that this process is very difficult due to the potency and strength of the herbs and is therefore administered in rare cases.

The *sangoma* THP mentioned one additional form of utilising *imithi*. They utilise a cotton cloth soaked in warm water with the dried herbs and form a compress. This compress is reported to be applied over big joints, back muscles and the feet. The process is called *ukuthoba*. It is highly beneficial in pain relief and for burning sensations in the feet which was often reported by their HIV positive patients with CP. The following extracts illustrate the treatment methods revealed by the THPs:

“I mix my herbs myself, I use these herbs for pain, but the herbs I mix depend how bad the patient’s pain is. For headache I give it to them to suck umuthi wokukhotha. If they have a burning feet ngiyabathoba, with warm water mixed with herbs.” (Participant #3; THP)

“I am a herbalist. I got this gift from my ancestors. I know every plant and what they do. For pain that is worrying them all the time like headache or body pains I start by giving them herbs to sniff,’ ngiyabubhemisa’. I then use a drinking solution which is strong and cleans you from the inside out. This drinking medicine is imbiza or isiphanga” (Participant #4; THP)

“I start off by applying herbal mixture to the back, feet and legs using a cloth and warm water. I then apply an ointment to the area of pain, they are given something to drink and then take that drink and ointment home.” (Participant #2; THP)

“When dealing with chronic pain that is not getting better I start by giving a drinking solution, I then follow up with a herb that they need to suck. Both works fast and are strong. They heal you from inside, but have no side effect. Herbs work like this. I mix all my own stuff, this was taught to me by my grandfather and other ancestors.” (Participant #5; THP)

“I like to start by using imbiza and then after ngiyathoba especially for burning feet and muscle pain. This helps.” (Participant #1; THP)

“Imbiza is very important, it helps you inside and then you can work on the outside stuff. Imbiza is strong, I use it all the time. After that I give herbs and after that I monitor the patient. In my rooms I use a cloth and apply herbs as well, this helps immediately for pain.” (Participant #1; THP)

5.4.3 Theme 3: The Management of Chronic Pain in HIV

The discussion of management of CP in HIV yielded concepts that encompassed the evaluation of the treatment, referral patterns and the processes of improving the quality of life of the patients suffering with CP in HIV. All the practitioners who participated in the study discussed the process of management surrounding the patient and wanted to decrease the effects of the complaints of the patients by incorporating integrated care. The patient was the centre point of discussion and all the practitioners reported that the patient is a pivotal component in the management process. Two key sub-themes evolved from this theme: the evaluation of treatment and referral patterns. All practitioners mentioned these as the most important elements in managing CP in HIV adequately.

5.4.3.1 Sub-Theme 1: Evaluation of Treatment

The practitioners all reported that once the treatment began, it was important to ensure the treatment was helping the patient. This was achieved by follow up treatments and subjective discussions with the patient. With CP in HIV, all patients required repeated consultations with the practitioners to have maximum treatment effects. All practitioners, except for the THPs, mentioned that, after at least two visits, they queried with the patients on their response to treatment. If the response was negative, they re-evaluated their respective treatment regime, and some even referred to other practitioners.

The chiropractors all explained that if a proposed treatment did not work, they changed the treatment protocol after at least three visits and often queried with patients on their compliance when it came to home therapy. They emphasised that the role of the patient in home care was as important aspect of their treatment programme. They reported their treatment process to be systematic, as follow up consultations were often booked immediately and within two-three days. Being a manual form of therapy, the chiropractors further mentioned that they did not solely rely on patient feedback to evaluate their treatment. They could easily assess if improvement was made and if the treatment was beneficial. They reported utilising many objective measures like palpation techniques, orthopaedic and neurological tests. These objective measures supported patient feedback and helped them decide on changes that needed to be made. In addition to these, they made mention of sending for investigations like bloodwork or X-rays if they did not do so initially. These investigations assisted them in management and where necessary referral. Subjective measures, like querying with the patient on how they felt, were also reported.

The homeopaths highlighted that remedies take time to work and therefore they persisted with treatment for longer durations before changing remedies or tissue salts. They mentioned follow up sessions were usually scheduled at least two weeks after the initial session, unless a patient required to see them prior. This allowed for the treatment regimens to work on the patient. Subjective measures were important to homeopaths. They reported that they asked patients to document any new symptoms, change in symptoms or thoughts in a notebook or cellular telephone. The homeopaths further reported that at follow up sessions, thorough discussions were held. This helped them understand how the remedies worked on the patient. The homeopaths also understood and mentioned that CP patients take many drugs, and homeopathy does not work as fast as others. They therefore work to encourage the patient to be compliant and reinforce the benefits of the treatment.

The THPs all mentioned that their treatments were adequate and effective. They reported checking up on patients at times telephonically, but did not have active records of every visit and every treatment. Follow up sessions were not mandatory; often patients would call them to inform them that the treatment helped. The THPs reported

that the majority of the time feedback from patients were almost always positive. They constantly reaffirmed that their treatments were good. They did, however, mention if they did find instances where they were unsure or received feedback that treatment did not assist, they would send the patient to another THP, *isangoma* or *inyanga*. The THPs also mentioned they counselled their patients and encouraged them to live healthy lives.

The following statements reflect the evaluation of management of patients by the TCAM practitioners:

“My management protocols include regular follow ups with the patient, I also encourage maintenance care if they are feeling better after some time. Initially I usually see the patient 3 times in the week and then twice the following week and thereafter once a month.” (Participant #7; Chiropractor)

“With remedies, there is no quick fix, we need to understand and encourage the patient as well. Some patients are taking an entire lucky packet of meds, and then I add mine. That’s why I do not change remedies, I give it time to work. I explain to the patient at every visit, why they need the homeopathic meds, the benefits, the process of how it works. I also listen a lot, because with CP pain there are mental consequences. This is a part of management in a holistic way.” (Participant #13; Homeopath)

“I spend time, I counsel them. But most of the time my treatments help the patients. I encourage my patients to have a good life.” (Participant #2; THP)

“There are no follow up visits, most of the time they come back to me to thank me for helping them or for something new.” (Participant #5; THP)

5.4.3.2 Sub-Theme 2: Referral Patterns

All the TCAM practitioners believed and mentioned the importance of referral in the management of CP in HIV. The TCAM practitioners spoke of referring in various methods and to a variety of practitioners. The homeopaths and chiropractors often referred to allopathic practitioners like physicians, specialists like rheumatologists or orthopaedic surgeons. Inter-referral between chiropractors and homeopaths was also

very strong and both mentioned that they worked in teams or networks. Chiropractors also actively made mention of active referral to neurologists.

The THPs mentioned referrals to institutions like the local clinic or hospital. They also mentioned they sent patients and encouraged their patients to go to their GPs. *Izangoma* all mentioned referring to *izinyanga* for herbal medicine if stronger doses were needed, as *izinyanga* were more learned on the herbal mixtures and potencies. However, *izinyanga* in this study did not mention referring to *isangoma*.

Although the psychological component was a major aspect mentioned with regards to CP in HIV, no mention was made of direct referral to psychologists or psychiatrists by any of the practitioner groups. The practitioners all mentioned that referral was important in ensuring the patients were getting the most beneficial care.

The following excerpts display this:

“I often refer to the physician and neurologist, especially for neuropathy cases.”
(Participant #8; Chiropractor)

“I work in a multi-disciplinary setting, so I always refer to a chiropractor for the manual care. It is really beneficial for the patient.” (Participant #10, Homeopath)

“I send patients to the clinic or to the GP, I don’t mind them taking painkillers or getting the care they need. Sometimes they need to check their blood levels or urine or pressure. This is important.” (Participant #5; THP)

When discussing referral, it is important to mention that the majority of TCAM practitioners mentioned that although they referred out, most allopathic practitioners did not refer to them or encourage the patients to return for complementary care.

The following quotes from the practitioners indicate this:

“The clinic doesn’t like the patients to see me, they tell the patients to stop my medication and not to come back. Some tell them they will die from my medication.” (Participant #4; THP)

“I do not actively get referrals from GP’s or physicians. I believe they don’t believe in homeopathy and its practices.” (Participant #10; Homeopath)

“Although I refer to specialists, specialists don’t refer to me. They are afraid of chiropractors and I think they think we do more harm than good. We break bones they believe.” (Participant #6; Chiropractor)

5.4.4 Theme 4: Challenges and Barriers in the Treatment and Management of Chronic Pain in HIV

The challenges and barriers highlighted by the practitioners affected their overall treatment and management of CP in HIV. All the TCAM practitioners mentioned similar barriers and challenges. These barriers and challenges were both internal and external. They mentioned the patient, lack of collaborative practice by allopathic practitioners, lack of knowledge on TCAM and cost of care to be the most pertinent challenges that they face when treating and managing CP in HIV.

5.4.4.1 Sub-Theme 1: The Patient

The TCAM practitioners interviewed in this study all made mention of how difficult dealing with a CP patient is, especially one with a viral inflammatory disease like HIV, that can have multifactorial underlying aetiologies linked to the pain. They also mentioned that CP in HIV is so vast and varied, the spectrum of the patient is not consistent. They reported some patients to be very ill and others to be very healthy. The CP presentation is also reported to be very different and subjective to each individual. The majority of the TCAM practitioners reported that patient’s attitude, compliance and mental health were important aspects always to consider when treating them.

The practitioners further reiterated that treating CP in HIV is not easy. HIV positive patients are considered high risk and that they need to be certain of what they were doing all the time.

The following extracts display their thoughts on the patient:

“Patients with CP in HIV are a challenge, sometimes they come with a whole ice cream bowl of meds and tell you about how each med is affecting them, and expect you to now cure them of pain. They are also full of emotion, I can understand this, living with HIV is not always easy, living with pain and HIV is worse. I have to now think, how to I assist this patient without increasing their burden. So, with homeopathy I try to find the right dose.” (Practitioner #13; Homeopath)

“I feel with CP in HIV patients I need to take more care, not that I don’t care for all my patients, but I feel extra cautious with these patients. They come with so much wrong at times, or with such desperation for help, I need to just take more care. This can be a challenge as it takes more time.” (Participant #8; Chiropractor)

“I find those patients who have suffered pain for a long time to be difficult, they want me to heal the fast or on the first day.” (Participant #3; THP)

5.4.4.2 Sub-Theme 2: Lack of Collaborative Practice with Mainstream Healthcare

The TCAM practitioners in the study mentioned that although they refer to mainstream allopathic practitioners or institutions, there is no collaborative practice that exists between the two domains of healthcare. The TCAM practitioners mentioned that they hardly or never receive referrals for care from allopathic practitioners.

The TCAM practitioners mentioned that patients report to them that they are discouraged to utilise TCAM healthcare, and the attitudes towards the system of health is negative.

The following statements depict these thoughts:

“I send the patients to the hospital and they come back and tell me the nurses and doctors shout at them for taking my meds. They tell them it is bad for them.”
(Participant #3; THP)

“Chiropractic care is not popular with most mainstream disciplines. They believe we break bones, I am yet to treat a patient in a team with a mainstream practitioner like an orthopaedic.” (Participant #6; Chiropractor)

“Patients come to me as a last resort, after going to all different specialists. I do not rely on mainstream allopathic practitioners for referrals but we have our place. It can only benefit the patient to work as a team, rather than receive a negative outlook about your profession.” (Participant #10; Homeopath)

5.4.4.3 Sub-Theme 3: Lack of Knowledge of TCAM Healthcare Practices

The TCAM practitioners strongly feel that knowledge on their practices is lacking and often felt undermined. Although the systems of healthcare have been around for quite some time, there is still a knowledge gap on the disciplines of practice. The homeopaths stated that, at times, they feel that their practices are questioned and labelled as unscientific, especially because they take time to work, as opposed to allopathic medicine. The THPs mentioned that even though traditional medicine is indigenous to this country, many align it with witchcraft due to a lack of knowledge. They are also labelled as uneducated as they do not attend any tertiary institution to be trained. Chiropractors said that although their practice is based on evidence-based science,

many people in SA believe it to be quackery or that all chiropractors do is break bones or injure patients more.

The following statements depict this:

“Many people think to be a THP, I practice witchcraft or I harm people. This is not the case.” (Participant #4; THP)

“Because I did not go to university, people think I can’t be a healer. They believe we do witchcraft, which is wrong. This is passed down from our forefathers.” (Participant #5; THP)

“Homeopathy is slowly finding its place, but people believe it is not scientific.” (Participant #12; Homeopath)

“Chiropractic has grown from when I started practicing to date, however you get those people that believe we only break bones, or injure people. I often hear statements where they say don’t go to a chiro.” (Participant #9; Chiropractor)

5.5 REFLEXIVITY

All qualitative research is contextual; it occurs within a specific time and place between two or more people (Dodgson 2019). Therefore, in qualitative research, it is assumed that who the researcher is makes a difference in the findings of their study. Objectivity is not always present with every researcher. In qualitative research it is said that “the researcher is the research instrument” (Dodgson 2019). It is due to this that qualitative studies have to ensure reflexivity.

Reflexivity refers to a method in which qualitative researchers ensure rigor and quality in their work and it is the gold standard for determining trustworthiness (Dodgson 2019;

Palaganas *et al.* 2017). Reflexive practice can be some of the most challenging and important work in qualitative research (Palaganas *et al.* 2017). The researcher needs to be aware of the social context of the project and how their process of collecting data can affect the research processes and outcomes (Haynes 2012).

With regards to reflexivity in this study, the researcher has been a chiropractor for a period of eight years. In private practice, the researcher engages with patients who are HIV positive and suffer with chronic pain. Many of the said patients reported having received treatment from other TCAM practitioners, which included a large number of THPs. Due to this experience and engagement, the researcher had a strong interest in exploring the opinions, practices and approaches of CP treatment and management by TCAM practitioners. The motivation was to add to the body of existing knowledge because, even as a practitioner, one is not always familiar with the treatment options utilised by patients. An understanding of this would better benefit both the patient and practitioner.

The researcher had access to the select chiropractors and homeopaths, being in similar profession and belonging to the same professional council. However, with the THPs, the researcher had to seek assistance by approaching the Interim Traditional Healers Practitioners Council (ITHPC) of KZN. The process was facilitated by the assistance of the main supervisor. The researcher then invited the THPs council executives for a meeting, where the research topic was presented and details of the research was shared. The research executive of ITHPC then disseminated this information to all council members. All interested participants thereafter contacted the researcher directly to participate. The research co-supervisor was present for the meeting between the researcher and ITHPC executives.

The researcher interviewed all participants in English or isiZulu. The THP group were interviewed with two research assistants who spoke isiZulu. They were utilised for translating purposes and to ensure the research questions were fully understood and answered accurately in the data collection phase. During data analysis, they further assisted with translation and ensured all themes and sub-themes were accurate.

The researcher then relied on literature and the supervisors to ensure that the results were produced with accuracy. Both the supervisors have extensive experience of supervision of master's and doctoral students in qualitative research and therefore could help by advising the researcher appropriately. Research trustworthiness as outlined in Chapter 4 were maintained, and ethical clearance for the study was obtained by the institutional research ethics committee.

5.6 SUMMARY OF THE CHAPTER

This chapter presented the key findings and presented them as main themes and sub-themes that emerged in the study.

In the next chapter, these results will be interpreted and discussed by the researcher.

CHAPTER 6: DISCUSSION OF FINDINGS

6.1 INTRODUCTION

In this chapter, the researcher will unpack and interpret the results presented in Chapter 5. The themes and sub-themes that emerged during data analysis in Chapter 5 were presented and supported by the participants' verbatim responses.

6.2 OVERVIEW OF THE RESEARCH STUDY DISCUSSION

The discussion and triangulation of the study findings are contextualised based on the conceptual framework that guided this study and by the process of critical theory.

Critical theory is a method orientated towards critiquing and providing an explanation of how things work (Collins and Stockton 2018; Reeves *et al.* 2008). Critical theory analyses the construction of knowledge and can propose explanations of underlying phenomena (Collins and Stockton 2018). It can further provide a differential lens through which a research problem is viewed and analysed and is highly beneficial in health research, health policy and patient care (Hansen 2020; Collins and Stockton 2018; Reeves *et al.* 2008). The use of critical theory in healthcare provides practitioners with a broader understanding of the situations they face in their daily lives (FitzPatrick 2019; Reeves *et al.* 2008). It further guides for the development of knowledge and can help move practitioners beyond individual insights gained from their professional lives to a situation where they can understand the wider significance and applicability of phenomena (Hansen 2020; FitzPatrick 2019; Reeves *et al.* 2008).

The discussion in this chapter will be unpacked in three sections.

Firstly, the presentation of the demographic profiles of the participants of the study will be made.

Secondly, the results as themes, sub-themes and findings will be discussed, based on Table 5.2, as follows: (a) Knowledge and understanding of HIV disease and its complexities, (b) The Principles and Practice of treatment of chronic pain in HIV, (c)

The management of chronic pain in HIV and (d) Challenges and Barriers in the treatment and management of chronic pain in HIV.

Thirdly, a discussion of the results in relation to the objectives of the study, the discussion of the reference literature that was used to build the conceptual framework, and the new literature found as a result of the themes that emerged through thematic analysis will be presented.

6.3 DEMOGRAPHIC PROFILE OF THE TCAM PRACTITIONERS WHO TREATED CHRONIC PAIN IN HIV

The TCAM practitioners who participated in this study included chiropractors, homeopaths and traditional health practitioners (THPs), in the discipline of *izangoma* and *izinyanga*. The total compliment of practitioners was 13 of which four were chiropractors, four homeopaths and five THPs. All the TCAM practitioners were registered with their respective statutory bodies which were Allied Health Professions Council for the chiropractors and homeopaths, and the Interim Traditional Healers Council of KZN for the THPs.

The demographic of each group are discussed below.

6.3.1 Chiropractors

The chiropractors consisted of three females and one male, with work experience that varied between five and 15 years respectively. Their age groups were in a similar range of 31-42 years of age, and was in relation to their work experience. The race groups included two coloured females, one black female and one white male. The study demographics of this group of practitioners are not synonymous with that of studies conducted in South Africa by Keyter (2010) and (Zietsman 2019), who both revealed the male chiropractors of white race to be of a higher percentage in private practice and to treat a wider characteristic of patients.

English was the primary language and all practitioners were self-employed in their own private practices across the eThekweni municipality.

All the chiropractors had tertiary level of education and had attained a Master's degree.

6.3.2 Homeopaths

The homeopaths who participated in the study were all female. Their age groups spanned between the ages of 34-52 years of age with a work experience that was a minimum of five years and a maximum of 23 years in the discipline. This practitioner group had a broader range of clinical experience. The race group included one coloured female, two black females and one Indian female. The demographics of this group were consistent with the literature by Steinberg *et al.* (2008) and Modika (2020), who revealed female homeopathic practitioners to be of a higher percentage utilised and practicing than males. All the homeopaths were fluent and proficient in the English language, even though two of the practitioner's primary language was isiZulu. All homeopaths were self-employed in their own respective practices and all attended tertiary institutions and attained Master's degrees.

6.3.3 THPs

The THP group consisted of five participants. Of the five participants, three were female and two were male. The THPs were of an older age group with the ages varying from 53-71 years of age. Their work experience matched their age, with 53 years of experience being the highest in this group. Of the five THPs, the three females were *sangomas* (diviners) and the two males were *nyangas* (herbalists). The sangomas all had a high school level of formal education and the herbalists did attend and attain tertiary level of education. The results of this study differs to the studies of Mathibela *et al.* (2015) and Nkosi and Sibiya (2018), which revealed more male THPs than female practioners, and that most THPs did not have any form of higher education. The similarities, however, are that the THP group do not undergo any formal or tertiary training for their field.

6.4 THEME 1: KNOWLEDGE AND UNDERSTANDING OF HIV DISEASE

The discussions around the knowledge and understanding of HIV formed an integral part in guiding the treatment and management practices of the TCAM practitioners. The

practitioners all reported the need in understanding HIV as a disease in order to provide adequate and appropriate care. These opinions of the practitioners are congruent with that of the existing body of literature on knowledge management implementation and evidence based practice. Shahmoradi, Safadari and Jimma (2017) reported that the process of understanding any disease is highly beneficial, as healthcare and provision of healthcare is a knowledge driven process. It guides management protocols and informs decision making (Stecher 2021; Shahmoradi, Safadari and Jimma 2017). Knowledge on disease further provides quality and safety of care of patients and is essential in evidence based practice (Stecher 2021). With HIV having multi-systemic clinical manifestations, knowledge on the condition is necessary to provide beneficial care.

6.4.1 Sub-Theme 1: Understanding HIV as an Individualised Experience

The TCAM practitioners made mention of the varied spectrum of HIV positive patients they treated for CP. They further highlighted that although most patients presented with similar areas of complaint, they did find the experience of HIV and CP to be individualised. No two patients were alike. Some of the patients were reported to be healthy, whilst others were wasted and emaciated. The reports of the practitioners align with the literature as HIV manifests differently in each patient.

The pathophysiology of the disease and the immune response of the disease is dependent on the stage of the disease the patient presents with. This is consistent with the literature by Naif (2013) and Perreau, Levy and Pantaleo (2013), who stated that disease progression and clinical symptoms differs between all individuals. This is further supported by Agosto, Uchil and Mothes (2015), who reported that as the HIV disease develops and progresses the clinical symptomatology changes in patients. Some patients appear healthy, whilst others lose weight, become very ill, and are susceptible to opportunistic infections (Agosto, Uchil and Mothes 2015).

6.4.2 Sub-Theme 2: Understanding the Process of CP in HIV

Treating patients with CP in HIV were reported to be common by all the TCAM practitioners. Although they reported to treat a variety of patients, they mentioned that

most patients with HIV came in with pain as a primary complaint. Due to the multifactorial complaints, underlying disease processes and host of clinical sequelae, the practitioners reported the burden of the pain to be a condition on its own. They further reported that the pain aetiology of CP was not solely that of physical manifestation but also had a big psychological component. They mentioned a link to the stigma of having HIV, as well as to the burden of constantly being in pain. Further to this, the practitioners revealed that the clinical sequelae of HIV that led to the development of CP were multifactorial and sometimes complex to treat. They all mentioned there was a definite need to understand HIV and CP as two disease processes that occur simultaneously. These results were not new to the existing literature, but were confirmatory of older studies critiqued.

Marcellin *et al.* (2020) reported that due to chronic inflammation, HIV infection results in physical and mental changes that can result in chronic pain and eventually chronic illness. Rogers *et al.* (2020) and Scott (2019) reinforced that CP in HIV has a strong link to stress, anxiety, and depression associated with the disease, and the pathophysiological underpinning of CP has been demonstrated in the literature to be a symptom of disease or a disease in itself (Mills, Torrance and Smith 2016).

Similarly, studies by Merlin *et al.* (2021) highlighted that CP in HIV is no longer only linked to the biomedical persistence of pain, but that individuals with HIV who have CP experience a distinct psychological, and social context that contributes significantly to the pain cycle.

6.4.3 Sub-Theme 3: Involvement of ARV Drugs in CP Development

The chiropractors and homeopaths discussed the role of ARV drug treatment in the development of CP. They reported that most of their patients, who were compliant and taking their ARVs, almost always reported varying types of pain as a result thereof. Both practitioner groups mentioned patients complained of burning sensations, especially in their feet, as a result or side effect of ARV treatment. These statements and reports are confirmed in the literature over time.

Egan, Caldwell and Eckmann (2021), Scott *et al.* (2020) and Lawson *et al.* (2015) have all reported neuropathies to be prevalent in 60% of patients on ARV drug treatment.

Furthermore studies by Sabin *et al.* (2018) ,Goldschmidt, Chu and Dong (2016) and Farrant *et al.* (2014) have shown that the burden of CP in HIV is directly linked to ARV drug usage. These results demonstrate that these practitioners understand the role of drug interactions in patients and its contribution to CP development.

6.5 THEME 2: THE PRINCIPLES AND PRACTICE OF TREATMENT OF CHRONIC PAIN IN HIV

An exploration and evaluation of the treatment methods employed by the TCAM practitioners for CP in HIV were revealed. The study provided insight into the treatment practices and the benefits of each treatment choice. The key underlying factors across all practitioner groups that guided the treatment was the diagnosis of CP and treatment and practice choice for CP in HIV based on the diagnosis.

6.5.1 Sub-Theme 1: Diagnosis of CP in HIV

The TCAM practitioners emphasised the importance of an accurate diagnosis of CP in HIV. They mentioned the need for an accurate diagnosis was due to many underlying aetiologies linked to the CP complaint. All the practitioners made use of a case history, physical assessment and/or a special investigation to establish a route cause and diagnosis. Their approach and reasoning for ensuring a diagnosis are in keeping with existing literature, that revealed CP in HIV to have multiple aetiologies.

Numerous scholars have stated that CP in HIV could be categorised based on aetiology. Krashin, Merrill and Trescot (2012) mentioned CP in HIV could be linked to pain directly from HIV, pain from opportunistic infections, or pain from side effects of ARVs. Alternatively Merlin *et al.* (2016), Rogers *et al.* (2020) and Baker *et al.* (2021) have linked CP in HIV to be due to emotional dysregulation and major psychological influence.

This system adopted by the TCAM practitioners in this study is aligned with the biomedical model of healthcare. The biomedical model of patient care dictates that despite knowing what the underlying cause is, establishing an accurate diagnosis in healthcare is pivotal (Committee on Diagnostic Error in Health Care *et al.* 2015).

When a diagnosis is accurate and made in a timely manner, a patient has the best opportunity for a positive health outcome because clinical decision making will be tailored to a correct understanding of the patient's health problem (Centor, Geha and Manesh 2019; Committee on Diagnostic Error in Health Care *et al.* 2015). It is, therefore, good practice to note that although the practitioners of this study are considered traditional and alternative, they display evidence of best practice and utilise similar practice methods and principles like that of biomedical, mainstream healthcare practitioners.

6.5.1.1 Diagnosis of CP in HIV by Chiropractors

The chiropractors in the study stated that they utilised a case history, physical examination, and specialised orthopaedic and neurological examinations to confirm the diagnosis of CP. They further reported that they utilised investigations like x-rays and blood work to confirm or refute any underlying contributing factors or aetiologies of the pain. The chiropractors emphasised the need to be thorough as, although chiropractic treatment is safe, with a chronic illness like HIV, it can adversely affect the musculoskeletal system, and certain treatments may be contraindicated. The diagnostic methods of the chiropractors are similar to what is depicted in the literature globally.

A study by Puhl, Reinhart and Injeyan (2015), conducted in Canada, that assessed the diagnostic and treatment methods of chiropractors, highlighted that it is important to understand how chiropractors practice beyond their formal education. The study showed that 95.1% of chiropractors most commonly utilise orthopaedic testing, palpation, history taking, range of motion testing, and neurological examination to establish a diagnosis. Similarly, in Australia, in a study by Adams *et al.* (2017), chiropractic diagnosis was established and confirmed by utilising case history, neurological assessments and imaging.

These similarities are important to note, that irrespective of the magnitude of the patient complaint or the underlying root cause, the practice methods by chiropractors globally display uniformity and therefore aid in achieving an accurate diagnosis. This is essential in CP in HIV which, as highlighted, can be multi-factorial.

6.5.1.2 Diagnosis of CP in HIV by Homeopaths

The homeopathic practitioners emphasised the need of establishing the root cause and assessing the patient holistically by means of a case history, physical examination, and investigations where necessary. The establishment of the simillimum of the patient was integral in the feedback from the homeopaths, as this is the fundamental process of homeopathy. When it comes to HIV, Chappell and van der Zee (2012) have shown that establishing a simillimum allows for treating of the disease or complaints of the disease to be easier. Similarly Muraleedharan *et al.* (2010) and Gupta and Mittal (2018) highlighted the benefits of the correct simillimum promotes healing in patients.

These, and past literature, have revealed that establishing a diagnosis is beneficial in homeopathic care and provides insights into not just into the primary complaint of CP, but guides the ability for the practitioner to further understand the micro-complexities that contribute to the diagnosis of CP in HIV.

6.5.1.3 Diagnosis of CP in HIV by THPs

The THPs did report the use of history taking and assessment of patients for establishing a diagnosis of CP, but for the *sangomas*' group, the crux of the diagnosis involved the spiritual intervention of connection with the ancestors. The results of this study are similar to the studies of Mchunu, Ross and Sobuwa (2019) and that of Nkosi and Sibiya (2018). Although these studies looked at different aspects of THP care, one for low back pain and the other for cancer, the mechanisms employed for diagnosis were identical.

Specific to HIV, Davids *et al.* (2014) mentioned that although THPs generally rely on biomedical diagnosis of HIV before treating a client, they also seek guidance from the ancestors for a particular diagnosis associated to the disease; the plants to use for a specific treatment; when to harvest, and how to administer herbal remedies.

It is beneficial to highlight the difference in the traditional approach to diagnosis, versus a pure biomedical approach especially in South Africa, where indigenous practice is rife and widely utilised (Mothibe and Sibanda 2019).

6.5.2 Sub-Theme 2: Treatment Methods and Practices for CP in HIV

The treatment methods and practices outlined by the TCAM practitioners in the study evolved from two key components. As revealed in the study, these components included the primary area of complaint and reported symptoms and the treatment choice utilised for a complaint. The choice of treatment was guided by the primary complaint.

6.5.2.1 Primary Areas of Complaint

The most common areas of complaint for all TCAM practitioner groups included the head, feet, back and large joints. The most common complaints included burning and painful feet, headaches, widespread joint and back pain. These complaints are also depicted in the study by Injeyan *et al.* (2018) and Egan, Caldwell and Eckmann (2021), who reported neuropathy to be the most common complaint in HIV patients leading to CP. Likewise Baron, Binder and Wasner (2010) and Walker-Bone *et al.* (2016) reported that neuropathic and musculoskeletal pain are highly ranked complaints in HIV infected patient, manifesting in CP and leading to chronic illness.

Chronic fatigue, stress, and depression were also a common diagnosis and were reported to contribute to the chronicity of the pain. Similarly these conditions were noted by Madden, Parker and Goodin (2020) and Parker, Jelsma and Stein (2017).

The presence of opportunistic infections, like TB, was mentioned by the TCAM practitioners in this study as a common recurring condition that contributed to back and chest pain in their patients. The intensity, degree and extent of the complaints were closely linked to the health status of the patient. Kanga *et al.* (2015) reported on similar clinical sequelae in case reports of patients in Botswana and Canada.

The practitioners all reported the more ill, weak and wasted the patient presented, the more complaints and greater degree of pain the patient was in. These study results are consistent and indicative of past and present literature explored in the review. Lawson *et al.* (2015) and Merlin (2015) reiterated that, as clinicians, it needs to be understood that HIV is painful and CP in HIV is worse. It is strongly linked to physical and mental manifestations and the areas of complaint need to be appropriately unpacked by clinicians.

Therefore, by exploring these areas in this study, it is evident that what was revealed is congruent with existing literature

6.5.2.2 Treatment Methods Utilised by Chiropractors for CP in HIV

The chiropractors in this study primarily utilised joint manipulation or mobilisation, electro-modalities, soft tissue therapy and exercise therapy to treat patients. Although dry needling was reported to be used, the chiropractors displayed apprehension and caution when needling patients with CP in HIV. The chiropractors modelled their treatment choice based on the physical health status of the patient and CD4+ count. They reported to steer away from the more invasive treatments in the less healthy patients due to either contraindication or apprehension.

The treatment approach of the chiropractors in this study, is synonymous with the case reports by Kanga *et al.* (2015), which demonstrated positive treatment outcomes for chronic pain in the low back, neck pain and headaches of HIV patients with opportunistic TB infection. The treatments highlighted by Kanga *et al.* (2015) were mobilisation, exercise, and soft tissue therapy via myofascial release. Although not as recent, the chiropractors treatments in this study also correspond to other studies conducted in South Africa by Friend-du Preez and Peltzer (2010) and Peltzer *et al.* (2011), that revealed chiropractic treatment to be effective for pain relief in HIV patients suffering with CP.

6.5.2.3 Treatment Methods Utilised by Homeopaths for CP in HIV

The homeopaths in the study treated primarily with remedies, minerals and vitamins, herbs, and counselling therapy. The remedies were administered orally or via injectable route. The common remedies reported from this study were *arnica* and *nux vomica*. These remedies, in whichever way administered, worked to primarily reduce pain and inflammation as mentioned by the homeopaths in the study. The remedies mentioned in this study differed from those in the literature by Muraleedharan *et al.* (2010), but this could be due to the specificity of individualised simillima utilised in homeopathy, as well as due to paucity of literature on CP management in HIV.

Peltzer *et al.* (2011) revealed that homeopaths were widely utilised in HIV patients for minerals and vitamins. This study results are indicative of this, as *magnesium* was the

most widely utilised mineral in this group for pain, cramps, and immune support. Despite this, the concepts behind the remedy choice are similar to that of Muraleedharan *et al.* (2010) and Braun, Braun and Mabuza (2016), who mentioned that homeopathic treatment was highly beneficial in the treatment of pain associated with HIV. The homeopaths in this study did mention that homeopathy was often a last resort for treatment due to the treatment effect sometimes taking long and due to a lack of understanding by patients. These similar sentiments were shared by McIntosh and Ogunbanjo (2008).

6.5.2.4 Treatment Methods Utilised by THPs for CP in HIV

The treatment methods by the THPs in this study resembled studies by Davids *et al.* (2014), Nkosi and Sibiya (2018), and Mchunu, Ross and Sobuwa (2019). It is evident from all these studies that the *sangomas* rely strongly on ancestral connection for diagnosis and treatment, and the *nyangas* work solely with the administration of herbs.

These practice methods surrounding traditional medicine as mentioned by Carstens (2020) are based on traditional philosophy and can therefore the intricacies surrounding herbal names cannot be revealed to the public. The THPs indicated prescribing *imbiza* and *imithi* in this study. Both are herbal in origin and are reported by them to be very effective in pain relief. These findings are coherent with the findings of Babb *et al.* (2007); Peltzer *et al.* (2008); Davids *et al.* (2014); Nkosi and Sibiya (2018) and Mchunu, Ross and Sobuwa (2019).

The inability to disclose the exact constituents of the *imbiza* and *imithi*, and purely providing only the benefits by the THPs does pose a barrier in highlighting the specificity and efficacy of the THP treatments. This poses difficulty for practitioner and patients alike, as at times traditional practices make it difficult for a patient to be understood in a mainstream healthcare setting (Street *et al.* 2019). This also leaves the allopathic world confused on the authenticity of the practice methods.

6.6 THEME 3: THE MANAGEMENT OF CHRONIC PAIN IN HIV

The management protocols of the TCAM practitioners reflected that of holistic practice. The practitioners assessed and evaluated their treatment options and highlighted the referral patterns that surrounded the management of a patient with HIV suffering with CP.

6.6.1 Sub-Theme 1: Evaluation of Treatment

The TCAM practitioners highlighted the importance of evaluating their treatment to ensure that the treatment they were providing was of benefit. If their respective treatments did not work, they would opt for another treatment regime or refer the patient out for investigations or to another practitioner. The evaluation of their treatment was important to them as they all strongly believed in patient care and maximal treatment outcomes.

The approach of the TCAM practitioners in the study are similar to that of Marcus *et al.* (2008) who reported that in order to develop an optimally effective treatment plan for CP in HIV, practitioners need approach treatments comprehensively and constantly re-evaluate treatments to ensure them to be sufficient and effective. Likewise, Merlin (2015) mentioned that for CP in HIV, practitioners need to communicate and actively reassess patients about their treatments primarily because pain is subjective. Furthermore, by evaluating the treatment, a clinician may better understand what is working versus what is not (Merlin 2015).

6.6.2 Sub-Theme 2: Referral Patterns

Referral to other practitioners was a prominent feature amongst the TCAM practitioners for the treatment and management of CP in HIV. All the TCAM practitioners actively referred patients to specialists for concomitant care. The chiropractors and homeopaths were more active in referral than the THPs. Despite this, the THPs did feel the need of inclusion of GPs or care from local clinics for their patients from time to time and therefore encouraged it.

The term referral in this study means intervention strategies that focus mainly on setting up a communication channel that ensure proper referral of patients, whether they

access both health professionals simultaneously or consecutively (Green and Colucci 2020). The process of referral is consistent with the study by (Fournier, Savageau and Baldor 2008), who mentioned that referral patterns amongst physicians caring for patients with HIV have shifted. Increasingly, practitioners inter-refer to each other when treating patients with HIV. This was due to the rapid development and complex prescribing patterns of drugs for HIV/AIDS care, which became challenging for physicians to keep current. Furthermore, patients presented more and more differently with multiple symptoms, pain patterns and opportunistic conditions.

Similarly, a more recent study by a physiotherapist (Pullen 2019), stated in order to practice holistically a practitioners management methods should characterised by the treatment of the whole person, accounting for mental and social factors, rather than solely physical injury or disease and referral. Therefore referral patterns between practitioners for CP in HIV needs to mimic this, especially in HIV/AIDS care models (Pullen 2019). This ensures patient health, retention of health and positive treatment outcomes.

It is to be noted that the TCAM practitioners made mention that they did not receive referrals from other disciplines in the allopathic biomedical domain. This trend is synonymous with existing literature over a period of time. Peltzer and Khoza (2002) investigated the attitudes and knowledge of nurses towards traditional healing, faith healing and complementary therapies in the Northern Province (now called Limpopo) in South Africa. The study revealed that although knowledge and attitudes were positive, rates of referrals were low for any condition.

Specific to HIV and conditions associated with HIV, Madiba's (2010) study concluded that biomedical health practitioners were not ready to collaborate with THPs in HIV and AIDS care. Biomedical health practitioners wanted collaboration to be on their terms; they prefer the collaboration to be limited to one way referrals from TPHs to them, and expressed that they will teach THPs but they were not willing to learn from them and they had negative opinions of the traditional health practice. This was further supported by (Mendu and Ross 2019), who investigated biomedical healthcare and African traditional management of HIV/AIDS. The key findings were that African traditional

healers referred their patients to hospitals but never received referrals from biomedical healthcare practitioners. With regards to CAM therapies like chiropractic and homeopathy, Shere-Wolfe *et al.* (2013) revealed that although these systems are utilised actively for conditions like HIV, physicians did not refer, but felt at times that these therapies could be recommended. James *et al.* (2018) further shared similar results that allopathic healthcare providers displayed a negative attitude and a lack of interest in TCAM therapies and therefore did not refer.

6.7 THEME 4: CHALLENGES AND BARRIERS IN THE TREATMENT AND MANAGEMENT OF CP IN HIV

The TCAM practitioners in the study highlighted numerous challenges and barriers, both internal and external that had an effect on their treatment choice and management process. These factors primarily factored around the patient, lack of collaborative practice with mainstream allopathic practitioners and lack of knowledge on TCAM treatments.

These three emerged as the sub-themes.

6.7.1 Sub-Theme 1: The Patient

The TCAM practitioners all shared the sentiments that a patient with CP in HIV was challenging to treat. The patients often presented with multifactorial complaints and ailments and the majority displayed signs of psychological dysfunction. The attitudes of the patients also played a role, as compliancy to treatment was often negative. Further to this, many of the patients had issues of stigma of HIV on their minds which often delayed or hindered on their management progress.

Inclusive in the challenge of treating was the fact that patients could either be very ill or healthy. This broad spectrum of disease picture sometimes left the TCAM practitioners perplexed on treatment guidelines. The findings of this study are similar to that of Gonzalez *et al.* (2019), who reported patients with CP in HIV to have many psychological components contributing to the pain. Patient sometimes even develop pain resistance which can make them difficult to treat.

Likewise, in the literature by Goodin *et al.* (2018), and more recently Baker *et al.* (2021), it was highlighted that HIV and chronic pain stigma was significantly associated with severity of depressive symptoms. These studies further reiterated that the experience of both HIV and chronic pain stigma may synergistically perpetuate a negative mood in a patient and make such a patient a challenge to treat.

In a South African context, studies by Wadley, Pincus and Evangeli (2019), and Wadley *et al.* (2021) both showed that individuals living with both HIV and chronic pain live with two stigmatised conditions and this may compound both their depressive symptoms and pain intensity. As a result, treatment and management, as well as compliancy to treatment, can pose challenging.

6.7.2 Sub-Theme 2: Lack of Collaborative Practice with Mainstream Healthcare

The TCAM practitioners all reported that there is a lack of integrative practice between them and allopathic practitioners when treating CP in HIV. The TCAM practitioners reported that they do not receive referrals from mainstream practitioners. They further reported that patients themselves were apprehensive to inform their allopathic practitioners that they were receiving alternate care. These findings are in correlation with existent literature, despite the increased awareness and utilisation of TCAM practices. James *et al.* (2018) reported mainstream healthcare providers to have a negative attitude towards TCAM practices and lacked willingness to work with them. Street *et al.* (2019) mentioned that, although the appeal and utilisation of TCAM is high, the growing demand for TCAM practitioner services requires an evidence-informed response, thereby making relationships with mainstream practice strained.

Despite evidence of widespread TCAM use, and support for participation of TCAM practitioners in the conventional healthcare system, there is limited information on collaborative efforts between TCAM and biomedical practitioners to improve healthcare, healthcare delivery and practice (Abrams *et al.* 2020; Street *et al.* 2019). The reasons for this could lie in differences in beliefs and practice systems (Abrams *et al.* 2020; Street *et al.* 2019).

Similarly, Pemunta and Tabenyang (2020) findings revealed that traditional medicine is a healthcare system of diverse ethnic practices and the fact that it has not developed into a unified system, but rather practiced according to specific ethnic groups and cultural context, further poses an obstacle to integration with biomedicine. The study goes on to mention that, within this diverse ethnic configuration, attempts at integration is in conflict with biomedicine. This leads to the erosion of time-tested knowledge systems and medical practices because biomedicine is taken as a standard for the evaluation of traditional healing practices. To associate and collaborate traditional healing knowledge and practices using a biomedical approach, values, philosophies, accountability standards and efficiency measures are a major challenge and barrier (Pemunta and Tabenyang 2020).

It is evident in the literature that there is a complete lack of cohesiveness and collaboration in the healthcare system between the two schools of practice.

6.7.3 Sub-Theme 3: Lack of Knowledge on TCAM Healthcare Practices

The TCAM practitioners in this study revealed that a major barrier in treatment, management and integration is the lack of knowledge of TCAM treatments and practice methods. These study findings correlate with studies locally and internationally. In the local context, Mbutho, Gqaleni and Korporeal (2012) reported that despite TCAM being commonly used among individuals with HIV and AIDS disease, there is a lack of communication between healthcare workers and patients, as well as between healthcare workers and TCAM practitioners. This has been identified as one of the challenges that adversely affect treatment of HIV and AIDS patients (Mbutho, Gqaleni and Korporeal 2012).

James *et al.* (2018) expounded that conventional health workers lack knowledge on TCAM, due to the TCAM practitioners not divulging their practices and thereby leaving no room for scientific evidence-based practice. Likewise, Chitindingu, George and Gow (2014) reported that a knowledge deficit on TCAM exists from a medical tertiary level, seeing as there is a paucity of curricula which incorporate TCAM, or even mention it, hence leaving mainstream health sceptical. Internationally, Fischer *et al.* (2014)

reported that there is a lack of knowledge on the safety, efficacy and effectiveness of TCAM therapies and therefore there is scepticism on the discipline of practice.

Anywar, Ohia and Nalumansi (2021) support the notion by mentioning that traditional complementary or alternative practices are as old as mankind, but there is a knowledge deficit surrounding it, especially for traditional medicine. There needs to be well-researched systems of traditional medicine, to strengthening capacity by training and accrediting traditional health practitioners, researching and adding value to traditional medicines in order for it to become more recognised (Anywar, Ohia and Nalumansi 2021).

This study's findings are consistent with existing literature by displaying how the lack of knowledge poses a barrier in delivering healthcare.

6.8 RESULTS IN RELATION TO THE OBJECTIVES OF THE STUDY

The aim of this study was to explore the treatment and management practices for CP in HIV by selected TCAM practitioners, and to develop practitioner guidelines for CP management in HIV. The aim was achieved by unpacking the objectives of the study, which involved exploring the various ambits surrounding treatment, management, challenges and barriers for CP in HIV. This study outlined the treatment and management practices by TCAM practitioners for CP in HIV and identified and then described the barriers and challenges experienced by the TCAM practitioners when they treated CP in HIV infected individuals.

Through exploration of these aims and objectives, the study outputs facilitated guidelines for management.

6.9 SUMMARY OF THE CHAPTER

This chapter contributed to the existing body of literature and introduced new concepts on the treatment and management of CP in HIV. The study allowed for the researcher to display and describe practice of three different TCAM disciplines for CP in HIV. The findings emphasised the integral role TCAM has in the management of CP conditions

and highlighted the benefits of incorporating TCAM into the South African system of healthcare.

The subsequent chapters will display the guidelines developed and conceptualised from this study, followed by the limitations and conclusion of the research findings.

CHAPTER 7

TREATMENT AND MANAGEMENT PRACTITIONER GUIDELINES ON CHRONIC PAIN MANAGEMENT IN HIV INFECTED INDIVIDUALS

7.1 INTRODUCTION

In Chapter 6, the results of the study were discussed in coherence with existing literature. Certain gaps were highlighted and certain existing trends were noted.

This chapter describes the development of the guidelines and presents the guidelines which forms the final objective of this study. These guidelines are based on the findings of the current study, intuitive insight of the researcher and recommendations from scholarly work, as evidenced during the literature review.

7.2 PROCESS OF DEVELOPING GUIDELINES

The focus of the study was displayed in the first six chapters and is aligned to the following objectives:

- Identify and describe the specific treatment regimens used for CP in an HIV positive patient by the selected TCAM practitioner.
- Explore and describe the management protocols used for CP in an HIV positive patient by the selected TCAM practitioner.
- Assess barriers and challenges experienced by the selected TCAM practitioner in the treatment and management of CP in an HIV positive patient.
- Determine the implications of the barriers on the treatment and management of CP in HIV positive patients.

The findings of this study, in relation to the objectives above, and as discussed in previous chapters 5 and 6, have guided the final objective of the study which is to

develop practitioner treatment and management guidelines for CP management in HIV positive individuals. These guidelines were formulated in relation to the four major themes that emerged from the data analysis of this study and have subsequently answered the final objective of the study.

7.3 APPLICATION OF THE CONCEPTUAL FRAMEWORK TO THE DEVELOPMENT OF THE GUIDELINES

Green (2014) and Imenda (2014) highlighted that a 'conceptual framework' draws on concepts from various theories and findings to guide research. A conceptual framework further provides a rationale and structure that guides the development of the study (Adom, Hussein and Agyem 2018; Rocco and Plakhotnik 2009). It also forms an understanding on which the study is based, enabling the researcher to link the findings of the study to the body of knowledge and conceptualise this in practice (Adom, Hussein and Agyem 2018). It is also made up of propositions, sets of concepts and statements integrated into a meaningful configuration (Adom, Hussein and Agyem 2018).

Hence, in the development of the guidelines from this study, the conceptual framework, as outlined in Chapter 3, provided a guide and structure to synthesise the guidelines. Together with the study findings, the conceptual framework of this study, revealed and highlighted that the development of the TCAM practitioner guidelines is warranted.

7.4 PURPOSE OF THE DEVELOPED GUIDELINES

The developed guidelines were aimed to inform relevant stakeholders and mainstream healthcare professionals on what the TCAM practices are and the benefits surrounding the treatments. The purpose of the developed guideline is to possibly facilitate the process of incorporation of TCAM healthcare as a part of the multi-disciplinary team in managing CP in HIV. Application of the guideline can assist in an effective way by displaying how TCAM practitioners manage HIV patients with CP and how TCAM can be integrated into pain care models.

This process of application of the guideline can work to reducing the cost of healthcare for the patient by minimising excessive use of treatments. The guideline can foster relationships and collaborative practice between two domains of healthcare, and can promote education amongst healthcare professionals. This will, thereby, change prescribing habits, referral patterns and improve healthcare delivery. The developed guidelines are in no way legally binding but are recommended as a guide to facilitate and foster insight into TCAM practices.

7.5 RATIONALE FOR THE DEVELOPED GUIDELINES

Traditional complementary alternative medicine (TCAM) refers to a conglomerate of health-related interventions and therapies not usually considered mainstream by the Western medical system (James *et al.* 2018; Hunter *et al.* 2017). Although actively utilised globally, insufficient evidence about any TCAM intervention or practice in terms of clinical guidelines exists, thereby making it difficult to be understood or included in healthcare (Hunter *et al.* 2017). Considering this, clinical guidelines are urgently required to guide the safe and rational use of TCAM in practice (Hunter *et al.* 2017).

Evidence in HIV literature indicates that over half of all people with HIV will experience non-malignant chronic pain throughout their lifetimes, with increasing prevalence as they age (Madden, Parker and Goodin 2020). Various interventions are utilised by HIV patients to help minimise the CP experience, one of which is TCAM interventions (Mpinga *et al.* 2013; Peltzer *et al.* 2011; Peltzer *et al.* 2009).

The future of improved care for HIV patients and chronic pain depends heavily on internationally collaborative, adequately funded and strategically implemented research efforts, as well as the careful incorporation of research findings into better treatments and training of clinicians (Madden, Parker and Goodin 2020), and hence the development of guidelines is required.

7.6 SCOPE OF THE DEVELOPED GUIDELINES

The guidelines are targeted at various stakeholders, being the TCAM practitioners, allopathic practitioners, South Africa's Department of Health and Department of Higher Education and HIV positive patients, to inform and educate them of the benefits and outcomes of TCAM treatment and management for CP in HIV. These stakeholders all have a role in either informing and developing programmes or implementing policies that are inclusive of TCAM practitioners in the healthcare system of South Africa. The guidelines will aid with facilitation of the process.

7.7 RECOMMENDATIONS FOR DEVELOPMENT OF GUIDELINES FOR STAKEHOLDERS

The study results discussed in Chapter 6 highlighted the reflective practices of TCAM practitioner's treatment and management of CP in HIV. The results provided insight into the practices and demonstrated the role and benefit of TCAM practice techniques and methods for CP in HIV. The discussions of Chapter 6 further revealed the barriers and challenges of this domain of healthcare practice. Based on all these aspects, the researcher recommends that the developed guidelines be implemented by all stakeholders who are involved in the healthcare management of HIV patients who are CP sufferers.

The recommendations for developing the guidelines include the following:

7.7.1 Recommendations for Development of Guidelines for TCAM Practitioners

The TCAM practitioners play an active and important in delivering healthcare to patients, especially in the management of HIV related and associated illness like CP. As practitioners, they need to keep abreast with current literature on HIV disease progression and trends. They also need to provide clinical research and results on their practices. The practitioners equally have a responsibility to themselves and the patient they are managing. The role and relationship between the practitioner and patient are equally critical in the management process and these bonds need to be congruent and coherent.

During data analysis, the study results revealed the integral role the patient plays in the treatment and management process of CP in HIV. Patients need to be kept informed, need to be constantly examined and assessed both physically and in a psychosocial domain. CP patients also need active communication and engagement with the practitioner and the patient's support system, especially with the stigma that comes with having HIV. They require constant monitoring especially with HIV, where pain has always been an integral part of the disease and its experience.

Therefore, the guidelines in this respect have been proposed in accordance with the deviances noted from the existing literature, the study's results via the themes that emerged and the recommendations on HIV care.

7.7.2 Recommendations for Development of Guidelines for Policy Makers at Department of Health

The study results revealed the critical importance of collaborative and interdisciplinary care in maintaining pain control in HIV. The study results further recommended that all medical providers should form an integrated multidisciplinary team to attain maximum care for HIV CP sufferers. TCAM is not integrated into national healthcare systems and there is a lack of official recognition of the profession and TCAM providers by most allopathic disciplines. This was displayed in themes that emerged from the study. Therefore, the guidelines are developed as a recommendation to the policy makers at the Department of Health to work towards including TCAM into the primary healthcare sector.

7.7.3 Recommendations for Development of Guidelines for policy makers at Department of Higher Education

Based on the existing literature and this study's evidence, there is a paucity of knowledge on what TCAM actually is. This deficit is predominantly amongst mainstream healthcare practitioners due to a lack of education on TCAM. This results in a lack of referrals, apprehension in recommending this field of healthcare, and the lack of divulsion of utilisation of this form of healthcare by patients. As a result, mainstream healthcare providers develop a negative attitude with a perceived lack of

support and understanding that lead to mistrust and stigma in response to TCAM. The developed guidelines propose a recommendation of including TCAM into medical school curricula to assist with knowledge enhancement.

7.8 DEVELOPED GUIDELINES

The developed guidelines in this study are proposed for the individual stakeholders that are involved in TCAM and its treatment and management of CP in HIV. The guidelines developed are depicted in Table 7.1 below. The guidelines are subsequently discussed.

Table 7.1: Developed guidelines

Guideline	Targeted Stakeholder	Focus Area
Guideline A	Guidelines for TCAM Practitioners.	1. Continual education, knowledge regeneration and professional development on HIV and CP by TCAM practitioners
		2. Informed incorporation of TCAM into public health through research and innovation.
		3. Development of patient education programmes on CP management in HIV.
Guideline B	Guidelines for policy makers at Department of Health.	1. Development of an integrative policy that is inclusive of TCAM in the multidisciplinary team managing CP in HIV.
Guideline C	Guidelines for policy makers at National Department of Education.	1. Development of TCAM education programmes into medical school curricula.

7.8.1 Guideline A: Guidelines for TCAM Practitioners

A 1: Continual Education, Knowledge Regeneration and Professional Development on HIV and CP by TCAM Practitioners

The provision of quality healthcare starts with the practitioner. The TCAM practitioners need to remain abreast of trends and clinical practice methods that are in existence and continually being developed for HIV care. By remaining informed and equipped, clinical standards are maintained and effective care is ensured. Therefore, it is

imperative, that although their practices are utilised and show benefit, the TCAM practitioners incorporate continual development in HIV pain education and management in conjunction with TCAM treatment and management methods.

Rationale for implementation of the developed guideline

By extrapolation from the literature, a considerable number of patients with HIV who suffer with CP rely on TCAM to meet their needs of pain relief. With HIV disease progression, the variation of patient presentation and subjectivity of CP in patients, it is vital for TCAM practitioners to constantly educate and inform themselves on HIV and CP. There needs to be an ongoing understanding of the disease, drug interactions and psychological influences to the development of CP. TCAM practitioners need to link where and how their practices fit in within the HIV disease spectrum, based on ongoing evidence-based literature. Therefore, the inclusion and implementation of this guideline will maintain the delivery of good healthcare by the TCAM practitioners.

Recommendations for implementation of the developed guideline

The following recommendations for implementation of the above developed guideline should be considered:

- Continually develop short courses and programmes on HIV and CP pathophysiology accessible to TCAM practitioners.
- Develop discipline specific screening tools for CP in HIV for TCAM practitioners to utilise in clinical settings.
- Engage and participate in HIV and CP skills and education workshops, seminars, and conferences.
- Create an environment conducive and accessible for TCAM disciplines to be included in teaching and learning ambits of CP in HIV.

A 2: Informed Incorporation of TCAM Into Public Health Through Research and Innovation

TCAM practices are not well understood and the safety and efficacy are often questioned. Whilst there are international guidelines for standards of clinical research, research in traditional and complementary therapies may differ from clinical evaluation

of conventional drugs and conventional systems of healthcare. In saying this, TCAM disciplines need to focus on experimental research, especially in the domain of traditional medicines, where a lot of scepticism and uncertainty lies, due to the presence of traditional practices that are often not revealed. It essential for inclusivity and recognition. TCAM practices need to engage in empirical and innovative research.

Rationale for implementation of the developed guideline

Literature reveals that TCAM is widely utilised in sub-Saharan Africa where HIV is highly prevalent. Despite this, the quality of the identified literature remains low and further research may be required to further elucidate challenges, opportunities, safety, and efficacy related to TCAM therapies. Further to this, until innovative vigorous clinical research is conducted by TCAM practitioners, the full therapeutic potential of TCAM treatments that are claimed to be effective may never be known.

TCAM disciplines need to align themselves with more standardised and open ways of research. Innovative research will necessitate health departments, governments, and other medical practitioners to consider and familiarise themselves with the current role of TCAM and its future possibilities within the wider healthcare system.

Recommendations for implementation of the developed guideline

The following recommendations for implementation of the above developed guideline should be considered:

- Development of a public health agenda and call for experimental research.
- Provision of funding programmes and grants for TCAM research.
- Publication of research in peer reviewed journals.
- Presentation of research at conferences, seminars, and congresses.
- Development of patents.

A3: Development of Patient Education Programmes on CP Management in HIV

The patient plays an integral role in the management process of CP in HIV. All medical providers should monitor the treatment of chronic pain in patients with HIV. Periodic assessment of progress on achieving functional goals and documentation of pain intensity, quality of life, adverse events and treatments provided are necessary.

Due to each pain experience being subjective, the patient needs to be actively involved in the treatment and management process. For patients whose chronic pain is controlled, any new report of pain should be carefully investigated and may require added treatments or adjustments in the dose of pain medications. Evaluations of new complaints need to be consistent.

Patients need to be educated about the pain cycle and coping and behavioural mechanisms to deal with the pain. This aids the healing process. Therefore, the implementation of this guideline is needed.

Rationale for implementation of the developed guideline

Patient communication and education is pivotal in the management process of any condition. Routine monitoring and informing patients of treatment protocols is essential in healthcare to avoid overuse of medication and dependency on medication or treatment protocols. Patient education, especially when dealing with chronic illness, should be the base of treatment and management, such that modifiable factors associated with the condition can be addressed to ensure successful management.

Recommendations for implementation of the developed guideline

- Development of patient education programmes and workshops.
- Development of a chronic pain screening tool for patients to utilise before, during and after treatments to monitor progression and regression.
- Development of programmes highlighting treatment outcomes, benefits and success stories.
- Development of patient provider agreements with goals, outcomes and structured treatment plans that provide both the practitioner and patient with responsibility in the management process.
- Development of patient integrated care model with feedback mechanisms of care received.

7.8.2 Guideline B: Guidelines for Policy Makers at National Department of Health

B1: Development of an Integrative Policy That is Inclusive of TCAM in the Multidisciplinary Team Managing Chronic Pain in HIV

Chronic Pain in HIV requires a multi-disciplinary integrated health team. HIV clinical and research communities have increasingly recognised chronic pain as an important comorbidity. Although TCAM is widely utilised for CP in HIV, there is a lack of regulatory and legal mechanisms for inclusion and integration of TCAM therapies into national healthcare systems. There is equally a deficit in collaborative care and inter-referral with mainstream healthcare professionals. Although certain disciplines like chiropractic and homeopathy are recognised and affiliated to Allied health professions of South Africa, there is minimal recognition and inequitable distribution of benefits in indigenous Traditional medicine practices in South Africa. In addition, there is a lack of knowledge on the TCAM system of healthcare and inadequate allocation of resources for TCAM development and capacity building.

The WHO have introduced policies on TCAM. The newest WHO policy on TCAM focuses attention on regulation as well as safety and efficacy issues. A concerted effort and the provision for inclusion, and interdisciplinary practice and to develop pain management guidelines inclusive of TCAM is needed by the National Department of Health in South Africa.

Rationale for implementation of the developed guidelines

The widespread utilisation of TCAM in sub-Saharan Africa, South Africa and KwaZulu-Natal necessitates governments and health departments across the country to consider and familiarise themselves with the current role of TCAM and its future possibilities within the wider healthcare system. HIV medical providers should develop and participate in interdisciplinary teams to care for patients with complex chronic pain. Although social, cultural, and political values, as well as socioeconomic factors, influence TCAM use, the public is paying out of pocket, for most TCAM services that are still, for the most part, not covered by health insurance nor included in the NHI. Therefore, a consideration for inclusion and consideration is warranted.

Recommendations for implementation of the developed guideline

- Development of a policy framework guiding TCAM inclusion and collaboration by national department of health.
- Development of a policy framework that is sensitive and inclusive of traditional and cultural practices in healthcare.
- Recognition and distinguishing the role of TCAM practices in HIV and CP.
- Regular advisory boards on TCAM practices and policies for HIV.
- Formation of regulatory bodies for traditional medicine practices.
- Collaboration of existing professional bodies locally and internationally on policies pertaining to HIV.

7.8.3 Guideline C:Guidelines for Policy Makers at National Department of Higher Education

The provision for mainstream healthcare professionals to be accepting, understanding and knowledgeable on TCAM practices is for the inclusion of TCAM into medical curricula. Currently, the policy of the South African National Department of Health requires biomedical doctors to serve in rural or urban area following the completion of their training. Given the black African bias of rural populations of over 90%, many biomedically trained doctors would be treating patients who are accessing TM simultaneously and likewise exposure to those in urban areas seeking CAM care. Therefore, the need for doctors to be exposed to TCAM in their medical training is essential.

The literature has revealed that in the majority of medical schools there is a lack of commitment to teaching TCAM. This is even though biomedically trained doctors practice in a context where patients consult TCAM practitioners, as well as biomedical doctors.

Medical schools are not doing enough to ensure TCAM is covered within their curricula. At most of the medical schools TCAM is covered but in a tokenistic manner.

Rationale for implementation of the developed guidelines

The fact that TCAM is being widely utilised requires inclusion in curricula, especially in conditions like HIV, where implications of the issue of potential drug interactions when patients use TCAM and biomedicine simultaneously.

In addition, there is a constant interaction between biomedical and TCAM treatment practices. Exposing doctors to TCAM will assist them to understand the paradigm from which TCAM practitioners treat patients. This exposure can simulate and lead to a harmonisation and collaboration of treatment methods with the aim of improving patient health outcomes.

Therefore, there is an immediate need for all medical schools in South Africa to examine their curricula, with respect to TCAM, and standardise the TCAM content across the country.

Recommendations for implementation of the developed guideline

- Designing and implementation of TCAM curricula for medical schools.
- Ensuring accurate and precise learning outcomes from the developed curricula.
- Regular quality assurance and possible accreditation of the curricula.
- Designing post graduate certificate/diploma in TCAM for medical professionals.
- Provision of adequate resources and funding for curriculum development and renewal.
- Providing resources that promote non-bias, and valuable information on indigenous knowledge systems.

7.9 ANALYSIS AND EVALUATION OF THE GUIDELINES

Clinical practice guidelines can improve healthcare processes and patient outcomes, but are often of low quality. Guideline appraisal tools aim to help potential guideline users in assessing guideline quality (Hunter *et al.* 2017; Siering *et al.* 2013; Shekelle *et al.* 1999). Most guideline appraisal tools assess whether the literature, and the evaluation, synthesis and presentation of the evidence in guidelines follow the principles of evidence-based medicine (Hunter *et al.* 2017; Siering *et al.* 2013).

The proposed guidelines in the current study were subject to an appraisal process as outlined by Chela (1999) on developing HIV/AIDS guidelines. It is hoped that the use of a guideline appraisal tool further enhanced the credibility and the reliability of the proposed guidelines. The tool allows for the guidelines to be systematically assessed and compared using the same criteria. The guidelines consist of several quality criteria or items that assessed the extent to which each guideline met the criteria. The proposed guidelines in this study were evaluated for validity, clarity, applicability, flexibility, and credibility.

7.9.1 Validity

Validity was maintained in the proposed guidelines as the researcher interpreted the available findings after data analysis to draw conclusions, develop themes and discuss findings that assisted in the formulation of the proposed guidelines.

7.9.2 Clarity

Clarity was attained by ensuring that the proposed guidelines are clear, logical and are justified with the appropriate recommendations. Clarity also confirms that the proposed guidelines are specific to the current study. As per data analysis, a thread between the recommendations, literature search and the supporting evidence were maintained.

7.9.3 Applicability

This criterion ensures that the proposed guidelines provide advice on how the recommendations can be put into practice. This was demonstrated by the rationale and recommendations for each guideline. It also ensures that all the possible resources and monitoring implications for research participants have been considered.

7.9.4 Flexibility

Flexibility was ensured by providing recommendations that collectively cover all clinically relevant circumstances these included the diagnostic process, clinical management and referral. The developed guidelines were consistent with each other.

7.9.5 Credibility

Adding to the credibility of the proposed guidelines is the fact that the researcher is adequately and appropriately qualified in the context of the current study to formulate guidelines. It should be noted that the formulated guidelines are evidenced-based and are applicable to the target population and setting of the study. The guidelines were also developed based on the strength of the scientific evidence supported in the literature.

7.10 DISSEMINATION OF DEVELOPED GUIDELINES

It is envisaged that the developed guidelines will be disseminated to the TCAM and allopathic healthcare providers for its evaluation, recommendations, and implementation. The developed guidelines will be disseminated in various modes, such as presentations at national and international conferences and congresses, and published in peer reviewed accredited journals. Hard and soft copies of the thesis will be made available at the DUT library and online repository. These guidelines will also be disseminated to all relevant stakeholders, such as the National Department of Health and Department of Higher Education, for reference and implementation.

7.11 SUMMARY OF THE CHAPTER

This chapter displayed the guidelines for implementation of various stakeholders for TCAM treatment and management of CP in HIV. The findings and recommendations from the emerged themes, sub-themes and literature were integrated into the development of these guidelines.

Chapter 8 focuses on the conclusion, recommendations, and limitations of the study.

CHAPTER 8

CONCLUSION, RECOMMENDATIONS AND LIMITATIONS OF THE STUDY

8.1 INTRODUCTION

In this chapter, the conclusion, recommendations, and limitations of the study are presented.

8.2 SUMMARY OF THE STUDY

The study was conducted at the various practices of TCAM practitioners in the eThekweni Municipality. The study revealed the various treatment and management protocols employed by the TCAM practitioners for CP in HIV. The study went on to describe the benefits, challenges and barriers experienced by TCAM practitioners when managing CP in HIV. The results of the study displayed themes and sub-themes guided the development of TCAM practitioner guidelines for CP in HIV.

The proposed guidelines are intended for implementation by relevant stakeholders which include practitioners and policy makers. The guidelines are targeted at informing and fostering relationships for collaborative practice with the TCAM discipline in the healthcare sector in South Africa.

8.3 REALISATION OF THE STUDY AIM

The aim of the study was to explore the treatment and management practices for CP in HIV by selected TCAM practitioners and to develop TCAM practitioner guidelines for CP management in HIV. The aim of this study was realised by undertaking an explorative, descriptive, qualitative research design.

The themes and sub-themes that emerged from data analysis were discussed in Chapter 6, guided by the conceptual framework displayed in Chapter 3. The findings of

the study were used to develop the guidelines to facilitate knowledge regeneration on TCAM care for CP in HIV and integrative practice that is inclusive of TCAM.

8.4 REALISATION OF STUDY OBJECTIVES

The objectives of the study were realised and met by interviewing three TCAM practitioner groups on their treatment and management of CP in HIV. The objectives included exploring, describing, and assessing various aspects of treatment, and understanding the management protocols ensued. The challenges and barriers experienced in practice were also explored and described. Triangulation and thematic analysis of the data resulted in themes, recommendations, and conclusion of the study. This data then guided the development of guidelines, which concluded the objectives of the study.

8.5 RECOMMENDATIONS

The recommendations for this research study have been based on the findings that emerged from data analysis, which led to the development of TCAM practitioner guidelines for CP treatment and management in HIV.

The developed guidelines are recommended for the **TCAM practitioners** for the following purposes:

- Consideration when formulating treatment and management plans for CP in HIV as a guide to improve care practices.
- Consideration for continual professional development and education on HIV and CP integrative care models, such that delivery of healthcare is current.
- Consideration when informing and educating the public on TCAM practices via innovative scientific research, collaborations, and development of patents.
- Development of discipline specific screening tools for CP in HIV for TCAM practitioners to utilise in clinical settings.
- Engage and participate in HIV and CP skills and education workshops, seminars, and conferences.

- Create an environment conducive and accessible for TCAM disciplines to be included in teaching and learning facilities for CP in HIV.

The developed guidelines are recommended for the National Department of Health for the following purposes:

- Development of a policy framework guiding TCAM inclusion and collaboration by the National Department of Health.
- Development of a policy framework that is sensitive and inclusive of traditional and cultural practices in healthcare.
- Recognition and distinguishing the role of TCAM practices in HIV and CP.
- Regular advisory boards on TCAM practices and policies for HIV.
- Formation of regulatory bodies for traditional medicine practices.
- Collaboration of existing professional bodies locally and internationally on policies pertaining to HIV.

The developed guidelines are recommended for the Department of Higher Education for the following purposes:

- Designing and implementing TCAM curricula for medical schools.
- Ensuring accurate and precise learning outcomes from the developed curricula.
- Regular quality assurance and possible accreditation of the curricula.
- Designing post graduate certificate/diploma in TCAM for medical professionals.
- Provision of adequate resources and funding for curriculum development and renewal.
- Providing resources that promote non-bias, and valuable information on indigenous knowledge systems.

8.6 RECOMMENDATIONS FOR FUTURE RESEARCH

The study findings revealed TCAM is actively utilised for CP in HIV. Recommendations for future research to possibly explore patients experience and perceptions on the treatment received by TCAM practitioners is required. This will provide insight on the

patient perspective on the benefits, challenges, and experiences in the utilisation of TCAM treatments.

The study revealed a strong lack of integration and referral patterns from allopathic healthcare providers, so an exploration into the incongruent relationship and attitudes of allopathic practitioners towards TCAM is warranted.

A wider study of the inclusivity of stakeholders, such as professional associations, is recommended to explore the potential development of a framework that incorporates all disciplines in HIV holistic and palliative care, as well as into health funding like the NHI.

In the spectrum of HIV, more empirical research to assess the effectiveness of TCAM therapies on pain is warranted. These could include testing the efficacy and effectiveness of herbs, treatment modalities via trials and laboratory investigations.

8.7 CONTRIBUTION OF THE RESEARCH STUDY TO THE BODY OF KNOWLEDGE

The study explored a domain of healthcare that is often misunderstood and understudied. The exploration resulted in filling a gap on how and what TCAM practitioners of three different disciplines do in relation to treatment and management of CP in HIV. The study findings also informed of barriers to treatment and management. The study resulted in the development of guidelines that are intended for implementation with various stakeholders.

The researcher contends that this is the first study of this nature that has researched and developed guidelines in this domain. This study adds to the existing body of knowledge and provides education on a domain of healthcare that has gained popularity globally.

8.8 LIMITATIONS OF THE STUDY

Limitations of any particular study are potential weaknesses or barriers that are usually out of the researcher's control, and are closely associated with the chosen research design, statistical model constraints, funding constraints, or other factors. A limitation is an 'imposed' restriction which is, therefore, essentially out of the researcher's control. Still, it may affect the study design, results and, ultimately, conclusions, and should therefore be acknowledged clearly (Theofanidis and Fountouki 2018).

The following limitations were identified in this research study:

- The study location and participants are limited to the eThekweni Municipality and are therefore not widely represented. These study findings cannot be generalised to all TCAM practitioners in South Africa.
- The THPs did not fully disclose the names of the plants/herbs that they utilise and dispense.
- Although an appropriate design, the study employed the qualitative, descriptive and explorative design; the findings could have been different if other research methodologies, such as mixed methods or quantitative, were used.
- Not all TCAM disciplines in South Africa were included in the study. This was due to the fact that existent literature showed the selected three disciplines to be the most widely utilised for CP in HIV.

8.9 CONCLUSION OF THE STUDY

Chapter 8 of this study focused on the study summary, recommendations, and limitations. The literature review confirmed that there were gaps in the treatment and management practices by TCAM practitioners for CP in HIV. The literature further revealed that there were no developed guidelines with respect to TCAM involvement in management of CP in HIV, as well as how TCAM can be integrated into mainstream healthcare systems.

The main aim and objectives of the study were realised in the revelation of the themes and sub-themes in the study, and further achieved by the practitioner's guidelines on

management that were developed. Recommendations for implementation of the developed guidelines were suggested.

Despite the identified limitations of this study that could have resulted in different findings, the aim of the study was achieved.

REFERENCES

Abdullahi, A. A. 2011. Trends and challenges of traditional medicine in Africa. *African Journal of Traditional, Complementary and Alternative medicines (AJTCAM)*, 8(5Suppl): 115-123.

Abrams, A. L., Falkenberg, T., Rautenbach, C., Moshabela, M., Shezi, B., van Ellewee, S. and Street, R. 2020. Legislative landscape for traditional health practitioners in Southern African development community countries: a scoping review. *BMJ Open*, 10(1): e029958.

Adams, J., Lauche, R., Peng, W., Steel, A., Moore, C., Amorin-Woods, L. G. and Sibbritt, D. 2017. A workforce survey of Australian chiropractic: the profile and practice features of a nationally representative sample of 2,005 chiropractors. *BMC Complementary and Alternative Medicine*, 17(1): 14.

Addis, D. R., DeBerry, J. J. and Aggarwal, S. 2020. Chronic Pain in HIV. *Molecular Pain*, 16: 1744806920927276.

Adewunmi, C. O. and Ojewole, J. A. O. 2004. Safety of traditional medicines, complementary and alternative medicines in Africa. *African Journal of Traditional, Complementary and Alternative Medicines*, 1(1): 1-3.

Adom, D., Hussein, E. K. and Agyem, J. A. 2018. Theoretical and conceptual framework: Mandatory ingredients of a quality research. *International Journal of Scientific Research*, 7 (1): 438-441.

Agosto, L. M., Uchil, P. D. and Mothes, W. 2015. HIV cell-to-cell transmission: effects on pathogenesis and antiretroviral therapy. *Trends in Microbiology*, 23(5): 289-295.

Akullian, A., Vandormael, A., Miller, J. C., Bershteyn, A., Wenger, E., Cuadros, D., Gareta, D., Bärnighausen, T., Herbst, K. and Tanser, F. 2021. Large age shifts in HIV-1 incidence patterns in KwaZulu-Natal, South Africa. *Proceedings of the National Academy of Sciences*, 118(28): e2013164118.

Anywar, G., Kakudidi, E., Byamukama, R., Mukonzo, J., Schubert, A. and Oryem-Origa, H. 2020. Indigenous traditional knowledge of medicinal plants used by herbalists in treating opportunistic infections among people living with HIV/AIDS in Uganda. *Journal of Ethnopharmacology*, 246: 112205.

Anywar, G., Ohia, C. and Nalumansi, P. A. 2021. Chapter 26 - Traditional system of medicines in Africa. In: Egbuna, C., Mishra, A. P. and Goyal, M. R. eds. *Preparation of Phytopharmaceuticals for the Management of Disorders*. Academic Press, 483-489.

Arts, E. J. and Hazuda, D. J. 2012. HIV-1 antiretroviral drug therapy. *Cold Spring Harbor perspectives in medicine*, 2(4): a007161-a007161.

Babb, D. A., Pemba, L., Seatlanyane, P., Charalambous, S., Churchyard, G. J. and Grant, A. D. 2007. Use of traditional medicine by HIV-infected individuals in South Africa in the era of antiretroviral therapy. *Psychology, Health & Medicine*, 12(3): 314-320.

Baker, V., Nkhoma, K., Trevelion, R., Roach, A., Winston, A., Sabin, C., Bristowe, K. and Harding, R. 2021. "I have failed to separate my HIV from this pain": the challenge of managing chronic pain among people with HIV. *AIDS Care*, 33(10): 1-9.

Balderson, B. H., Grothaus, L., Harrison, R. G., McCoy, K., Mahoney, C. and Catz, S. 2013. Chronic illness burden and quality of life in an aging HIV population. *AIDS Care*, 25(4): 451-458.

Baron, R., Binder, A. and Wasner, G. 2010. Neuropathic pain: diagnosis, pathophysiological mechanisms, and treatment. *The Lancet Neurology*, 9(8): 807-819.

Bauer, B. A., Tilburt, J. C., Sood, A., Li, G.-x. and Wang, S.-h. 2016. Complementary and alternative medicine therapies for chronic pain. *Chinese Journal of Integrative Medicine*, 22(6): 403-411.

Bodeker, G. and Kronenberg, F. 2002. A public health agenda for traditional, complementary, and alternative medicine. *American Journal of Public Health*, 92(10): 1582-1591.

Bodeker, G., Carter, G., Burford, G. and Dvorak-Little, M. 2006. HIV/AIDS: Traditional systems of health care in the management of a global epidemic. *The Journal of Alternative and Complementary Medicine*, 12(6): 563-576.

Bodeker, G. and Graz, B. 2020. Traditional Medicine.: Ryan, E. T., Hill, D. R., Solomon, T., Aronson, N. E. and Endy, T. P. eds. *Hunter's Tropical Medicine and Emerging Infectious Diseases*. 10th ed. London: Content Repository.

Braun, B. J., Braun, K. P. and Mabuza, T. 2016. Retrospective observational study of people with HIV and AIDS receiving homeopathic treatment in Swaziland. *Homeopathy*, 105 (01)

Braun, L. A., Forrester, C. A., Rawlins, M. D., Levy, R. W., Penm, J., Graham, M. M., Mackie, K. F., Aran, S., Bridle, S. and Bailey, M. J. 2016. Complementary medicine use by people living with HIV in Australia: A national survey. *International Journal of STD & AIDS*, 27(1): 33-38.

Brink, H., Van der Walt, C. and Van Rensburg, G. 2012. *Fundamentals of research methodology for healthcare professionals*. 3rd ed. Cape Town: Juta.

Bruce, R. D., Merlin, J., Lum, P. J., Ahmed, E., Alexander, C., Corbett, A. H., Foley, K., Leonard, K., Treisman, G. J. and Selwyn, P. 2017. 2017 HIVMA of IDSA Clinical Practice Guideline for the Management of Chronic Pain in Patients Living With HIV. *Clinical Infectious Diseases*, 65(10): e1-e37.

Cambou, M. C. and Landovitz, R. J. 2020. Novel antiretroviral agents. *Current HIV/AIDS Reports*, 17(2): 118-124.

Carstens, P. 2020. THE regulation and application of traditional african medicine in South Africa. *International Journal of Health Law and Government Policy*, 3(2): 233-238.

Centor, R. M., Geha, R. and Manesh, R. 2019. The Pursuit of Diagnostic Excellence. *JAMA Network Open*, 2(12): e1918040-e1918040.

Chamberlain, B. 2009. Phenomenology: a qualitative method. *Clinical Nurse Specialist*, 23(2): 52-53.

Chappell, P. and van der Zee, H. 2012. *Homeopathy for diseases*. Haren: Homeolinks Publishers.

Chela, C. 1999. Developing HIV/AIDS treatment guidelines. In: *Developing HIV/AIDS treatment guidelines*.

Chitindingu, E., George, G. and Gow, J. 2014. A review of the integration of traditional, complementary and alternative medicine into the curriculum of South African medical schools. *BMC Medical Education*, 14(1): 40.

Collins, C. S. and Stockton, C. M. 2018. The central role of theory in qualitative research. *International Journal of Qualitative Methods*, 17(1): 1609406918797475.

Colloca, L., Ludman, T., Bouhassira, D., Baron, R., Dickenson, A. H., Yarnitsky, D., Freeman, R., Truini, A., Attal, N. and Finnerup, N. B. 2017. Neuropathic pain. *Nature Reviews Disease Primers*, 3(1): 1-19.

Committee on Diagnostic Error in Health Care, Board on Health Care Services, Institute of Medicine, and the National Academies of Sciences, Engineering, and Medicine. 2015. In: Balogh, E. P., Miller, B. T. and Ball, J. R. eds. *Improving Diagnosis in Health Care*. Washington (DC): National Academies Press.

Coulter, I. D. and Willis, E. M. 2004. The rise and rise of complementary and alternative medicine: a sociological perspective. *The Medical Journal of Australia*, 180(11): 587-589.

Creswell, J. W. 1998. *Qualitative Inquiry and Research Design. Choosing Among Five Traditions*. Thousand Oaks, CA: Sage Publications.

Creswell, J. W. 2007. *Qualitative inquiry and research design: Choosing among five approaches*. 2nd ed. Thousand Oaks, CA: Sage Publications.

Creswell, J. W. 2014. *Research design: Qualitative, quantitative and mixed methods approach*. Thousand Oaks: Sage Publication.

da Silva, J. G., da Rocha Morgan, D. A., Melo, F. C. M., dos Santos, I. K., de Azevedo, K. P. M., de Medeiros, H. J. and Knackfuss, M. I. 2017. Level of pain and quality of life of people living with HIV/AIDS pain and quality of life in HIV/AIDS. *AIDS Care*, 29(8): 1041-1048.

Dagenais, S. and Haldeman, S. 2002. Chiropractic. *Primary Care: Clinics in Office Practice*, 29(2): 419-437.

Davids, D., Blouws, T., Aboyade, O., Gibson, D., De Jong, J. T., Van't Klooster, C. and Hughes, G. 2014. Traditional health practitioners' perceptions, herbal treatment and management of HIV and related opportunistic infections. *Journal of Ethnobiology and Ethnomedicine*, 10(1): 77.

Davis, S. 2004. Clinical sequelae affecting quality of life in the HIV-infected patient. *Journal of the Association of Nurses in AIDS Care*, 15(5): 28S-33S.

De Ruddere, L. and Craig, K. D. 2016. Understanding stigma and chronic pain: a-state-of-the-art review. *Pain*, 157(8): 1607-1610.

Del Borgo, C., Izzi, I., Chiarotti, F., Del Forno, A., Moscati, A. M., Cornacchione, E. and Fantoni, M. 2001. Multidimensional aspects of pain in HIV-infected individuals. *AIDS Patient Care and STDs*, 15(2): 95-102.

Dodgson, J. E. 2019. Reflexivity in qualitative research. *Journal of Human Lactation*, 35(2): 220-222.

Dureja, G. P., Jain, P. N., Shetty, N., Mandal, S. P., Prabhoo, R., Joshi, M., Goswami, S., Natarajan, K. B., Iyer, R., Tanna, D. D., Ghosh, P., Saxena, A., Kadhe, G. and Phansalkar, A. A. 2014. Prevalence of Chronic Pain, Impact on Daily Life, and Treatment Practices in India. *Pain Practice*, 14(2): E51-E62.

Egan, K. E., Caldwell, G. M. and Eckmann, M. S. 2021. HIV neuropathy: A Review of mechanisms, diagnosis, and treatment of pain. *Current Pain and Headache Reports*, 25(8): 55.

Ernst, E. 2008. Chiropractic: a critical evaluation. *Journal of Pain and Symptom Management*, 35(5): 544-562.

Farrant, L., Gwyther, L., Dinat, N., Mmoledi, K., Hatta, N. and Harding, R. 2012. The prevalence and burden of pain and other symptoms among South Africans attending HAART clinics. *SAMJ: South African Medical Journal*, 102(6): 499-500.

Farrant, L., Gwyther, L., Dinat, N., Mmoledi, K., Hatta, N. and Harding, R. 2014. Maintaining wellbeing for South Africans receiving ART: the burden of pain and symptoms is greater with longer ART exposure. *South African Medical Journal*, 104(2): 119-123.

Faulkner, S. L. and Trotter, S. P. 2017. Data Saturation. *The International Encyclopedia of Communication Research Methods*, 1(5): 1-2.

Fayaz, A., Croft, P., Langford, R. M., Donaldson, L. J. and Jones, G. T. 2016. Prevalence of chronic pain in the UK: a systematic review and meta-analysis of population studies. *BMJ Open*, 6(6): e010364.

Fischer, F. H., Lewith, G., Witt, C. M., Linde, K., von Ammon, K., Cardini, F., Falkenberg, T., Fønnebø, V., Johannessen, H., Reiter, B., Uehleke, B., Weidenhammer, W. and Brinkhaus, B. 2014. High prevalence but limited evidence in complementary and alternative medicine: guidelines for future research. *BMC Complementary and Alternative Medicine*, 14(1): 46.

FitzPatrick, B. 2019. Validity in qualitative health education research. *Currents in Pharmacy Teaching and Learning*, 11(2): 211-217.

Fournier, P. O., Savageau, J. A. and Baldor, R. A. 2008. A shift in referral patterns for HIV/AIDS patients. *The Journal of Family Practice*, 57(2): E1-9.

Friend-du Preez, N. and Peltzer, K. 2010. HIV symptoms and health-related quality of life prior to initiation of HAART in a sample of HIV-positive South Africans. *AIDS and Behavior*, 14(6): 1437-1447.

Fritts, M., Crawford, C. C., Quibell, D., Gupta, A., Jonas, W. B., Coulter, I. and Andrade, S. 2008a. Traditional Indian medicine and homeopathy for HIV/AIDS: a review of the literature. *AIDS Research and Therapy*, 5(1): 25.

Fritts, M., Crawford, C. C., Quibell, D., Gupta, A., Jonas, W. B., Coulter, I. and Andrade, S. A. 2008b. Traditional Indian medicine and homeopathy for HIV/AIDS: a review of the literature. *AIDS Research and Therapy*, 5(1): 25.

Furler, M. D., Einarson, T. R., Walmsley, S., Millson, M. and Bendayan, R. 2003. Use of Complementary and Alternative Medicine by HIV-Infected Outpatients in Ontario, Canada. *AIDS Patient Care and STDs*, 17(4): 155-168.

Gaikwad, M., Vanlint, S., Moseley, G. L., Mittinty, M. N. and Stocks, N. 2017. Understanding patient perspectives on management of their chronic pain: Online survey protocol. *Journal of Pain Research*, 10: 31.

Gale, N. K., Heath, G., Cameron, E., Rashid, S. and Redwood, S. 2013. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, 13(1): 117.

Gibert, C. L. 2016. Treatment Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents: An Update. *Federal practitioner: for the health care professionals of the VA, DOD, and PHS*, 33 (Suppl 3): 31S-36S.

Goldberg, D. S. and McGee, S. J. 2011. Pain as a global public health priority. *BMC Public Health*, 11(1): 770.

Goldschmidt, R. H., Chu, C. and Dong, B. J. 2016. Initial management of patients with HIV Infection. *American Family Physician*, 94(9): 708-716.

Gonzalez, C. E., Okunbor, J. I., Parker, R., Owens, M. A., White, D. M., Merlin, J. S. and Goodin, B. R. 2019. Pain-Specific Resilience in People Living With HIV and

Chronic Pain: Beneficial Associations With Coping Strategies and Catastrophizing. *Frontiers in Psychology*, 10(2046).

Goodin, B. R., Owens, M. A., White, D. M., Strath, L. J., Gonzalez, C., Rainey, R. L., Okunbor, J. I., Heath, S. L., Turan, J. M. and Merlin, J. S. 2018. Intersectional health-related stigma in persons living with HIV and chronic pain: implications for depressive symptoms. *AIDS Care*, 30(sup2): 66-73.

Google Maps (2020) Ethekewini Municipality. Available from: www.googlemaps.com. [Accessed 22 August 2020].

Green, B. and Colucci, E. 2020. Traditional healers' and biomedical practitioners' perceptions of collaborative mental healthcare in low-and middle-income countries: A systematic review. *Transcultural psychiatry*, 57(1): 94-107.

Gqaleni, N., Moodley, I., Kruger, H., Ntuli, A. and McLeod, H. 2007. Traditional and complementary medicine: Health care delivery. *South African Health Review*, 2007(1): 175-188.

Gqaleni, N., Shongwe, V. and Seleti, Y. 2012. Traditional Medicine in the Era of HIV/AIDS in South Africa. *African Journal of Traditional, Complementary, and Alternative Medicines*, 9(3 Suppl): 1-1.

Green, H. E. 2014. Use of theoretical and conceptual frameworks in qualitative research. *Nurse Researcher*, 21(6): 34-38.

Guba, E. G. and Lincoln, Y. S. 1989. *Fourth generation evaluation*. Newbury Park, CA: Sage.

Gupta, A. K. and Mittal, A. 2018. Impact of homeopathy on people affected by HIV. *International Journal of Homeopathic Sciences*, 2(1): 13-16.

Gurmu, E A., Teni, F. S. and Tadesse, W. T. 2017. Pattern of traditional medicine utilization among HIV/AIDS Patients on antiretroviral therapy at a university hospital in Northwestern Ethiopia: A cross-sectional study. *evidence-based complementary and alternative medicine*. *eCAM*, 2017: 1724581-1724581.

Gyasi, R. M., Tagoe-Darko, E. and Mensah, C. M. 2013. Use of traditional medicine by HIV/AIDS patients in Kumasi Metropolis, Ghana: A cross-sectional survey. *American International Journal of Contemporary Research*, 3(4): 117-129.

Handcock, M. S. and Gile, K. J. 2011. Comment: On the concept of snowball sampling. *Sociological Methodology*, 41(1): 367-371.

Hansen, E. C. 2020. *Successful qualitative health research: a practical introduction*. Abingdon-on-Thames: Routledge.

Harding, R., Higginson, I. J. and Gwyther, L. 2016. HIV-related pain in low-and middle-income countries with reference to sub-Saharan Africa. *Chronic Pain and HIV: A Practical Approach*. Edison, NJ: John Wiley & Sons,

Haynes, K. 2012. Reflexivity in qualitative research. *Qualitative organizational research: Core methods and current challenges*: 72-89.

Holloway, I. 1995. Ethical issues in qualitative nursing research. *Nurse Ethics*, 2(3): 223-232.

Hughes, G., Puoane, T., Clark, B., Wondwossen, T., Johnson, Q. and Folk, W. 2012. Prevalence and predictors of traditional medicine utilization among persons living with AIDS (PLWA) on antiretroviral (ARV) and prophylaxis treatment in both rural and urban areas in South Africa. *African Journal of Traditional, Complementary and Alternative Medicines*, 9(4): 470-484.

Hunter, J., Leach, M., Braun, L. and Bensoussan, A. 2017. An interpretive review of consensus statements on clinical guideline development and their application in the field of traditional and complementary medicine. *BMC Complementary and Alternative Medicine*, 17(1): 116.

Igumbor, E. U., Puoane, T., Gansky, S. A. and Plesh, O. 2011. Prevalence and risk indicators of chronic pain in a rural community in South Africa. *Journal of Rural and Tropical Public Health*, 10: 61-69.

Imenda, S. 2014. Is there a conceptual difference between theoretical and conceptual frameworks? *Journal of Social Sciences*, 38(2): 185-195.

Injeyan, H. S., Connell, G., Foster, K., Kopansky-Giles, D., Sovak, G. and Tibbles, T. 2018. The prevalence and characteristics of HIV/AIDS patients presenting at a chiropractic outpatient clinic in Toronto, Ontario. A retrospective, observational study. *The Journal of the Canadian Chiropractic Association*, 62(2): 77-84.

Ipp, H. and Zemlin, A. 2013. The paradox of the immune response in HIV infection: when inflammation becomes harmful. *Clinica Chimica Acta*, 416: 96-99.

Isenberg, S. R., Maragh-Bass, A. C., Ridgeway, K., Beach, M. C. and Knowlton, A. R. 2017. A qualitative exploration of chronic pain and opioid treatment among HIV patients with drug use disorders. *Journal of Opioid Management*, 13(1): 5-16.

Jackson, T., Thomas, S., Stabile, V., Han, X., Shotwell, M. and McQueen, K. 2015. Prevalence of chronic pain in low-income and middle-income countries: a systematic review and meta-analysis. *The Lancet*, 385: S10.

James, P. B., Wardle, J., Steel, A. and Adams, J. 2018. Traditional, complementary and alternative medicine use in Sub-Saharan Africa: a systematic review. *BMJ Global Health*, 3(5): e000895.

Jiao, J. M., So, E., Jebakumar, J., George, M. C., Simpson, D. M. and Robinson-Papp, J. 2016. Chronic pain disorders in HIV primary care: clinical characteristics and association with healthcare utilization. *Pain*, 157(4): 931-937.

Johnson, M. I., Elzahaf, R. A. and Tashani, O. A. 2013. The prevalence of chronic pain in developing countries. *Pain Management*, 3(2): 83-86.

Jonas, W. B., Kaptchuk, T. J. and Linde, K. 2003. A critical overview of homeopathy. *Annals of Internal Medicine*, 138(5): 393-399.

Kamerman, P. R. and Mitchell, D. 2011. Current perspectives on HIV-related pain and its management: insights from sub-Saharan Africa. *Pain management*, 1(6): 587-596.

Kanga, I., Taylor, J. A., Jacobs, C. and Outerbridge, G. 2015. Tuberculosis of the neuromusculoskeletal system: a review of two cases presenting as chiropractic patients. *The Journal of the Canadian Chiropractic Association*, 59(1): 13-23.

Keyter, K. 2010. *The perceptions of South African chiropractors, regarding their professional identity*. Master's Degree in Technology, Durban University of Technology.

Kirksey, K. M., Goodroad, B. K., Kemppainen, J. K., Holzemer, W. L., Bunch, E. H., Corless, I. B., Eller, L. S., Nicholas, P. K., Nokes, K. and Bain, C. 2002. Complementary therapy use in persons with HIV/AIDS. *Journal of Holistic Nursing*, 20(3): 264-278.

Kivunja, C. and Kuyini, A. B. 2017. Understanding and Applying Research Paradigms in Educational Contexts. *International Journal of Higher Education*, 6(5): 26-41.

Kole, A. K., Roy, R. and Kole, D. C. 2013. Musculoskeletal and rheumatological disorders in HIV infection: Experience in a tertiary referral center. *Indian Journal of Sexually Transmitted Diseases and AIDS*, 34(2): 107-112.

Krashin, D. L., Merrill, J. O. and Trescot, A. M. 2012. Opioids in the management of HIV-related pain. *Pain Physician*, 15(3 Suppl): eS157-168.

Larue, F., Fontaine, A. and Colleau, S. M. 1997. Underestimation and undertreatment of pain in HIV disease: Multicentre study. *BMJ*, 314(7073): 23.

Lawson, E., Sabin, C., Perry, N., Richardson, D., Gilleece, Y., Churchill, D., Dean, G., Williams, D., Fisher, M. and Walker-Bone, K. 2015. Is HIV Painful? An Epidemiologic study of the prevalence and risk factors for pain in HIV-infected patients. *The Clinical Journal of Pain*, 31(9): 813-819.

Lee, F. H. and Raja, S. N. 2011. Complementary and alternative medicine in chronic pain. *Pain*, 152(1): 28-30.

Lerner, A. M., Eisinger, R. W. and Fauci, A. S. 2020. Comorbidities in Persons With HIV: The Lingering Challenge. *JAMA*, 323(1): 19-20.

Levy, J. A. 1993. Pathogenesis of human immunodeficiency virus infection. *Microbiological Reviews*, 57(1): 183-289.

Littlewood, R. A. and Vanable, P. A. 2008. Complementary and alternative medicine use among HIV-positive people: Research synthesis and implications for HIV care. *AIDS Care*, 20(8): 1002-1018.

Littlewood, R. and Vanable, P. 2011. A Global Perspective on Complementary and Alternative Medicine Use Among People Living with HIV/AIDS in the Era of Antiretroviral Treatment. *Current HIV/AIDS Reports*, 8: 257-268.

Lynch, M. E. 2011. The need for a Canadian pain strategy. *Pain Research & Management*, 16(2): 77-80.

Madden, V. J., Parker, R. and Goodin, B. R. 2020. Chronic pain in people with HIV: a common comorbidity and threat to quality of life. *Pain Management*, 10(4): 253-260.

Madiba, S. 2010. Are biomedicine health practitioners ready to collaborate with traditional health practitioners in HIV & AIDS care in Tutume sub district of Botswana. *African Journal of Traditional, Complementary and Alternative Medicines*, 7(3): 219-224.

Malangu, N. 2007. Self-reported use of traditional, complementary and over-the-counter medicines by HIV-infected patients on antiretroviral therapy in Pretoria, South Africa. *African Journal of Traditional, Complementary, and alternative Medicines*, 4(3): 273-278.

Marais, A., Steenkamp, V. and Du Plooy, W. J. 2015. Conditions frequently self-treated with herbal remedies by patients visiting a tertiary hospital in Gauteng, South Africa. *South African Family Practice*, 57(1): 8-11.

Marcellin, F., Di Beo, V., Aumaitre, H., Mora, M., Wittkop, L., Duvivier, C. 2020 Patient-reported symptoms during direct-acting antiviral treatment: A real-life study in HIV-HCV coinfecting patients. *Journal of Hepatology*, 72(3): 588-591.

Marcus, K. S., Kerns, R. D., Rosenfeld, B. and Breitbart, W. 2008. HIV/AIDS-related Pain as a Chronic Pain Condition: Implications of a Biopsychosocial Model for Comprehensive Assessment and Effective Management. *Pain Medicine*, 1(3): 260-273.

Mathibela, M. K., Egan, B. A., Du Plessis, H. J. and Potgieter, M. J. 2015. Socio-cultural profile of Bapedi traditional healers as indigenous knowledge custodians and conservation partners in the Blouberg area, Limpopo Province, South Africa. *Journal of Ethnobiology and Ethnomedicine*, 11(1): 219-224.

Mbatha, N., Street, R. A., Ngcobo, M. and Gqaleni, N. 2012. Sick certificates issued by South African traditional health practitioners: Current legislation, challenges and the way forward. *SAMJ: South African Medical Journal*, 102(3): 129-131.

Mbutho, N. P., Gqaleni, N. and Korporaal, C. M. 2012. Traditional complementary and alternative medicine: knowledge, attitudes and practices of health care workers in HIV and AIDS clinics in Durban hospitals. *African Journal of Traditional, Complementary, and Alternative Medicines*, 9(3 Suppl): 64-72.

Mchunu, T. B., Ross, A. H. and Sobuwa, S. 2019. Understanding and management of low back pain: A qualitative study of perceptions of traditional healers at the Warwick Muthi Market in Durban, South Africa. *African Journal for Physical Activity and Health Sciences* (AJPHEs), 25(3): 404-417.

McIntosh, C. and Ogunbanjo, G. A. 2008. Why do patients choose to consult homeopaths? An exploratory study. *South African Family Practice*, 50(3): 69-69c.

Mendu, E. and Ross, E. 2019. Biomedical healthcare and African traditional healing in the management of HIV and AIDS: complimentary or competing cosmologies? *African Journal of AIDS Research*, 18(2): 104-114.

Merlin, J. S. 2015. Chronic Pain in patients with HIV infection: What clinicians need to know. *Topics in Antiviral Medicine*, 23(3): 120-124.

Merlin, J. S., Bulls, H. W., Vucovich, L. A., Edelman, E. J. and Starrels, J. L. 2016. Pharmacologic and non-pharmacologic treatments for chronic pain in individuals with HIV: A systematic review. *AIDS Care*, 28(12): 1506-1515.

Merlin, J. S., Walcott, M., Kerns, R., Bair, M. J., Burgio, K. L. and Turan, J. M. 2015a. Pain self-management in HIV-infected individuals with chronic pain: A qualitative study. *Pain Medicine*, 16(4): 706-714.

Merlin, J. S., Westfall, A. O., Chamot, E., Saag, M., Walcott, M., Ritchie, C. and Kertesz, S. 2015b. Quantitative evaluation of an instrument to identify chronic pain in HIV-infected individuals. *AIDS Research and Human Retroviruses*, 31(6): 623-627.

Merlin, J. S., Hamm, M., de Abril Cameron, F., Baker, V., Brown, D., Cherry, C., Edelman, E., Evangeli, M., Harding, R. and Josh, J. 2021. SPECIAL ISSUE HIV and CHRONIC PAIN (The Global Task Force for Chronic Pain in People with HIV (PWH): Developing a research agenda in an emerging field). *AIDS care*: 1-9.

Mgbemena, O., Westfall, A. O., Ritchie, C. S., Hicks, J., Raper, J. L., Overton, E. T., Norton, W. E. and Merlin, J. S. 2015. Preliminary outcomes of a pilot physical therapy program for HIV-infected patients with chronic pain. *AIDS Care*, 27(2): 244-247.

Miaskowski, C., Penko, J. M., Guzman, D., Mattson, J. E., Bangsberg, D. R. and Kushel, M. B. 2011. Occurrence and Characteristics of chronic pain in a community-based cohort of indigent adults living with HIV infection. *The Journal of Pain*, 12(9): 1004-1016.

Mills, S., Torrance, N. and Smith, B. H. 2016. Identification and Management of Chronic Pain in Primary Care: a Review. *Current Psychiatry Reports*, 18(2): 22.

Modika, M. A. 2020. *Prescription and Vigilance Behaviours of South African Homeopathy, Naturopathy and Phytotherapy Practitioners*. Master's Degree in Homeopathy, University of Johannesburg, South Africa.

Mondal, M. and Shitan, M. 2013. Factors affecting the HIV/AIDS epidemic: an ecological analysis of global data. *African health sciences*, 13(2): 301-310.

Moshabela, M., Zuma, T. and Gaede, B. 2016. Bridging the gap between biomedical and traditional health practitioners in South Africa. *South African Health Review*, 2016(1): 83-92.

Mothibe E, M. and Sibanda, M. 2019. African Traditional Medicine: South African Perspective. In: Traditional and Complementary Medicine. Available: <https://app.dimensions.ai/details/publication/pub.1112110877> (Accessed 2020/03/15).

Mpinga, E. K., Kandolo, T., Verloo, H., Bukonda, N. K. Z., Kandala, N. and Chastonay, P. 2013. Traditional/alternative medicines and the right to health: key elements for a convention on global health. *Health Human Rights*, 15(1): 44-57.

Mudzviti, T., Maponga, C. C., Khoza, S., Ma, Q. and Morse, G. D. 2012. The impact of herbal drug use on adverse drug reaction profiles of patients on antiretroviral therapy in Zimbabwe. *AIDS Research and Treatment*, 2012: Article ID 434171. Available: <https://doi.org/10.1155/2012/434171>

Muraleedharan, K., Dey, S., Prasad, P., Siddiqui, V., Dixit, R., Singh, V. and Nayak, C. 2010. Effectiveness of homoeopathic medicines in HIV patients-A clinical trial. *Indian Journal of Research in Homeopathy*, 4(4): 29-35.

Naif, H. M. 2013. Pathogenesis of HIV infection. *Infectious Disease Reports*, 5(11): 26-30.

Ngcobo, M., Nkala, B., Moodley, I. and Gqaleni, N. 2012. Recommendations for the development of regulatory guidelines for registration of traditional medicines in South Africa. *African Journal of Traditional, Complementary, and Alternative Medicines*, 9(1): 59-66.

Nkhoma, K., Ahmed, A., Alli, Z., Sherr, L. and Harding, R. 2019. Is symptom prevalence and burden associated with HIV treatment status and disease stage among adult HIV outpatients in Kenya? A cross-sectional self-report study. *AIDS Care*, 31(12): 1461-1470.

Nkosi, P. B. and Sibiya, M. N. 2018. Perceptions of traditional health practitioners and radiation oncologists regarding referral of cancer patients in a cooperative practice in KwaZulu-Natal province, South Africa. *International Journal of Africa Nursing Sciences*, 8: 117-121.

Nlooto, M. 2015. Views and experiences of healthcare professionals towards the use of African traditional, complementary and alternative medicines among patients with HIV infection: the case of eThekweni health district, South Africa. *BMC Complementary and Alternative Medicine*, 15(1): 170.

Nlooto, M. and Panjasaram Naidoo, P. 2014. Clinical relevance and use of traditional, complementary and alternative medicines for the management of HIV infection in local African communities, 1989-2014: a review of selected literature. *Journal of African Studies*, 28: 105-116.

Ortblad, K. F., Lozano, R. and Murray, C. J. L. 2013. The burden of HIV: insights from the global burden of disease study 2010. *AIDS* (London, England), 27(13): 2003-2017.

Palaganas, E. C., Sanchez, M. C., Molintas, V. P. and Caricativo, R. D. 2017. Reflexivity in qualitative research: A journey of learning. *Qualitative Report*, 22(2): 426-438.

Parker, R., Stein, D. J. and Jelsma, J. 2014. Pain in people living with HIV/AIDS: A systematic review. *Journal of the International AIDS Society*, 17(1): 18719.

Parker, R., Madden, V. J., Devan, D., Cameron, S., Jackson, K., Kamerman, P., Reardon, C. and Wadley, A. 2019. Barriers to implementing clinical trials on nonpharmacological treatments in developing countries: lessons learnt from addressing pain in HIV. *Pain Reports*, 4(6): e783.

Peltzer, K. 2009. Utilization and practice of traditional/ complementary/ alternative medicine (TM/CAM) in South Africa. *African Journal of Traditional, Complementary and Alternative Medicines*, 6(2): 175-185.

Peltzer, K., Friend-du Preez, N., Ramlagan, S., Fomundam, H. and Anderson, J. 2009. Traditional complementary and alternative medicine and antiretroviral treatment adherence among HIV patients in KwaZulu-Natal, South Africa. *African Journal of Traditional, Complementary and Alternative Medicines*, 7(2): 125-137.

Peltzer, K. and Mngqundaniso, N. 2008. Patients consulting traditional health practioners in the context of HIV/AIDS in urban areas in KwaZulu-Natal, South Africa. *African Journal of Traditional, Complementary, and Alternative Medicines*, 5(4): 370-379.

Peltzer, K. and Pengpid, S. 2018. Prevalence and determinants of traditional, complementary and alternative medicine provider use among adults from 32 countries. *Chinese Journal of Integrative Medicine*, 24(8): 584-590.

Peltzer, K., Preez, N. F.-d., Ramlagan, S. and Fomundam, H. 2008. Use of traditional complementary and alternative medicine for HIV patients in KwaZulu-Natal, South Africa. *BMC Public Health*, 8(1): 255.

Peltzer, K., Preez, N. F.-d., Ramlagan, S., Fomundam, H., Anderson, J. and Chanetsa, L. 2011. Antiretrovirals and the use of traditional, complementary and alternative medicine by HIV patients in KwaZulu-Natal, South Africa: A longitudinal study. *African Journal of Traditional, Complementary and Alternative Medicines*, 8(4): 337-345.

Perreau, M., Levy, Y. and Pantaleo, G. 2013. Immune response to HIV. *Current Opinion in HIV and AIDS*, 8(4): 333-340.

Petty, N. J., Thomson, O. P. and Stew, G. 2012. Ready for a paradigm shift? Part 2: Introducing qualitative research methodologies and methods. *Manual Therapy*, 17(5): 378-384.

Phaladze, N. A., Human, S., Dlamini, S. B., Hulela, E. B., Mahlubi Hadebe, I., Sukati, N. A., Makoe, L. N., Seboni, N. M., Moleko, M. and Holzemer, W. L. 2005. Quality of Life and the Concept of "Living Well" With HIV/AIDS in Sub-Saharan Africa. *Journal of Nursing Scholarship*, 37(2): 120-126.

Polit, D. F. and Beck, C. T. 2010. Generalization in quantitative and qualitative research: myths and strategies. *International Journal of Nursing Studies*, 47(11): 1451-1458.

Pope, C., Ziebland, S. and Mays, N. 2000. Analysing qualitative data. *BMJ*, 320(7227): 114-116.

Puhl, A. A., Reinhart, C. J. and Injeyan, H. S. 2015. Diagnostic and treatment methods used by chiropractors: A random sample survey of Canada's English-speaking provinces. *The Journal of the Canadian Chiropractic Association*, 59(3): 279-287.

Pullen, S. 2017. Physical therapy as non-pharmacological chronic pain management of adults living with HIV: self-reported pain scores and analgesic use. *HIV/AIDS (Auckland, N.Z.)*, 9: 177-182.

Pullen, S. D., del Rio, C., Brandon, D., Colonna, A., Denton, M., Ina, M., Lancaster, G., Schmidtke, A.-G. and Marconi, V. C. 2020. Associations between chronic pain, analgesic use and physical therapy among adults living with HIV in Atlanta, Georgia: a retrospective cohort study. *AIDS Care*, 32(1): 65-71.

Puoane, T. R., Hughes, G. D., Uwimana, J., Johnson, Q. and Folk, W. R. 2012. Why HIV positive patients on antiretroviral treatment and/or cotrimoxazole prophylaxis use traditional medicine: perceptions of health workers, traditional healers and patients: a study in two provinces of South Africa. *African Journal of Traditional, Complementary and Alternative Medicines*, 9(4): 495-502.

Rauf, W. N., Meyer, H. P., Marcus, T. S. and Becker, P. J. 2013. Prevalence of chronic pain in patients attending primary healthcare facilities in south-west Tshwane. *South African Family Practice*, 55(1): 85-89.

Reeves, S., Albert, M., Kuper, A. and Hodges, B. D. 2008. Why use theories in qualitative research? *BMJ*, 337: a949.

Reust, C. E. 2011. Common adverse effects of antiretroviral therapy for HIV disease. *American family physician*, 83(12): 1443-1451.

Richter, M. 2003. Traditional medicines and traditional healers in South Africa. *Treatment Action Campaign and AIDS Law Project*, 17: 4-29.

Roberts, K. J. 2002. Physician-patient relationships, patient satisfaction, and antiretroviral medication adherence among HIV-infected adults attending a public health clinic. *AIDS Patient Care and STDs*, 16(1): 43-50.

Robinson-Papp, J. 2016. HIV and chronic pain: musculoskeletal pain. In: Editor(s): Merlin, J. S., Selwyn, P.A., Treisman, G.J., Giovanniello, A.G. eds. *Chronic Pain and HIV: practical approach*. Wiley Online Library, 27-37.

Robinson, O. C. 2014. Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative Research in Psychology*, 11(1): 25-41.

Rocco, T. S. and Plakhotnik, M. S. 2009. Literature reviews, conceptual frameworks, and theoretical frameworks: Terms, functions, and distinctions. *Human Resource Development Review*, 8(1): 120-130.

Rogers, A. H., Bakhshaie, J., Horenstein, A., Brandt, C. P., Heimberg, R. G. and Zvolensky, M. J. 2020. Emotion dysregulation in the experience of pain among persons living with HIV/AIDS. *AIDS Care*, 32(1): 57-64.

Rolfe, G. 2006. Validity, trustworthiness and rigour: Quality and the idea of qualitative research. *Journal of Advanced Nursing*, 53(3): 304-310.

Rutberg, S. and Bouikidis, C. D. 2018. Focusing on the fundamentals: A simplistic differentiation between qualitative and quantitative research. *Nephrology Nursing Journal*, 45(2): 209-213.

Sabin, C. A., Harding, R., Bagkeris, E., Nkhoma, K., Post, F. A., Sachikonye, M., Boffito, M., Anderson, J., Mallon, P. W. G., Williams, I., Vera, J., Johnson, M., Babalis, D. and Winston, A. 2018. Pain in people living with HIV and its association with healthcare resource use, well being and functional status. *AIDS*, 32(18): 2697-2706.

Satoh, S. and Boyer, E. 2019. HIV in South Africa. *The Lancet*, 394(10197): 467.

Schwandt, T. A., Lincoln, Y. S. and Guba, E. G. 2007. Judging interpretations: But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New Directions for Evaluation*, 2007(114): 11-25.

Scott, W., Del Solar, M. G. C. M., Kemp, H., McCracken, L. M., de C Williams, A. C. and Rice, A. S. 2020. A qualitative study of the experience and impact of neuropathic pain in people living with HIV. *Pain*, 161(5): 970.

Shahmoradi, L., Safadari, R. and Jimma, W. 2017. Knowledge Management Implementation and the Tools Utilized in Healthcare for Evidence-Based Decision Making: A Systematic Review. *Ethiopian journal of health sciences*, 27(5): 541-558.

Shekelle, P. G. 1998. *What role for chiropractic in health care?* *New England Journal of Medicine*, 339(15): 1074-1075.

Shekelle, P. G., Woolf, S. H., Eccles, M. and Grimshaw, J. 1999. Clinical guidelines: developing guidelines. *BMJ (Clinical research ed.)*, 318(7183): 593-596.

Sheppard, H. W., Ascher, M. S., McRae, B., Anderson, R. E., Lang, W. and Allain, J.-P. 1991. The Initial Immune response to HIV and immune system. *Journal of acquired immune deficiency syndromes*, 4(7): 704-712.

Shere-Wolfe, K. D., Tilburt, J. C., D'Adamo, C., Berman, B. and Chesney, M. A. 2013. Infectious Diseases Physicians' Attitudes and Practices Related to Complementary and Integrative Medicine: Results of a National Survey. *Evidence-Based Complementary and Alternative Medicine*, 2013: 294381.

Siering, U., Eikermann, M., Hausner, E., Hoffmann-Eßer, W. and Neugebauer, E. A. 2013. Appraisal Tools for Clinical Practice Guidelines: A Systematic Review. *PLOS ONE*, 8(12): e82915.

Simbayi, L., Zuma, K., Zungu, N., Moyo, S., Marinda, E., Jooste, S., Mabaso, M., Ramlagan, S., North, A. and Van Zyl, J. 2019. *South African national HIV prevalence, incidence, behaviour and communication survey, 2017: Towards achieving the UNAIDS 90-90-90 targets*. Cape Town: HSRC Press.

Simon, V., Ho, D. D. and Abdool Karim, Q. 2006. HIV/AIDS epidemiology, pathogenesis, prevention, and treatment. *The Lancet*, 368(9534): 489-504.

Sparber, A., Wootton, J. C., Bauer, L., Curt, G., Eisenberg, D., Levin, T. and Steinberg, S. M. 2000. Use of complementary medicine by adult patients participating in HIV/AIDS clinical trials. *The Journal of Alternative and Complementary Medicine*, 6(5): 415-422.

Spencer DC, R. T., Krause R, et al. 2018. *Palliative Care Guidelines for the Management of HIV-Infected People in South Africa*, 20(1): 1-26.

Stats SA. 2021. *Mid-year population estimates 2020*. Available: <http://www.statssa.gov.za/publications/P0302/P03022020.pdf> (Accessed 22nd August 2021).

Stecher, C. 2021. Physician network connections to specialists and HIV quality of care. *Health Services Research*, 56(5): 908-918.

Steinberg, W. J., Luyt, D., Pieterse, F., Heever, X. V. d. and Staden, A. V. 2008. SA homeopaths' attitudes towards conventional medicine : scientific letter. *South African Family Practice*, 50(3): 71.

Stevens, L. and Wrenn, C. 2013. Exploratory (qualitative) research. *Concise encyclopedia of church and religious organization marketing*, 53(1): 53-62

Street, R., Falkenberg, T., Sundberg, T., Balakrishna, Y., Abrams, A. and Kredo, T. 2019. Participation of traditional, complementary and alternative health practitioners in conventional health systems in low-and middle-income countries. *Cochrane Database of Systematic Reviews*, (8): CD013391

Swendeman, D., Ingram, B. L. and Rotheram-Borus, M. J. 2009. Common elements in self-management of HIV and other chronic illnesses: an integrative framework. *AIDS Care*, 21(10): 1321-1334.

Tashakkori, A. and Teddlie, C. 2003. Issues and dilemmas in teaching research methods courses in social and behavioural sciences: US perspective. *International Journal of Social Research Methodology*, 6(1): 61-77.

Theofanidis, D. and Fountouki, A. 2018. Limitations and delimitations in the research process. *Perioperative nursing*, 7(3): 155-163.

Treede, R.-D., Rief, W., Barke, A., Aziz, Q., Bennett, M. I., Benoliel, R., Cohen, M., Evers, S., Finnerup, N. B. and First, M. B. 2019. Chronic pain as a symptom or a disease: the IASP Classification of Chronic Pain for the International Classification of Diseases (ICD-11). *Pain*, 160(1): 19-27.

Tsao, J. C. I., Dobalian, A., Myers, C. D. and Zeltzer, L. K. 2005. Pain and use of Complementary and Alternative Medicine in a national sample of persons living with HIV. *Journal of Pain and Symptom Management*, 30(5): 418-432.

Tseng, A., Seet, J. and Phillips, E. J. 2015. The evolution of three decades of antiretroviral therapy: challenges, triumphs and the promise of the future. *British Journal of Clinical Pharmacology*, 79(2): 182-194.

Tshehla, B. 2015. Traditional health practitioners and the authority to issue medical certificates. *SAMJ: South African Medical Journal*, 105(4), 279-280

Uebelacker, L. A., Weisberg, R. B., Herman, D. S., Bailey, G. L., Pinkston-Camp, M. M. and Stein, M. D. 2015. Chronic pain in HIV-Infected patients: Relationship to depression, substance use, and mental health and pain treatment. *Pain Medicine*, 16(10): 1870-1881.

UNAIDS. 2002. *Report on the global HIV/AIDS epidemic*. UNAIDS.

UNAIDS. Global HIV & AIDS Statistics – 2021 Fact Sheet. [cited 2021 Apr 1]. Available from: <https://www.unaids.org/en/resources/fact-sheet> (Accessed 22nd August 2021).

U.S Food Drug Administration. 2021. *FDA approves first extended-release, injectable drug regimen for adults living with HIV*. FDA

Vaismoradi, M., Turunen, H. and Bondas, T. 2013. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & Health Sciences*, 15(3): 398-405.

Vawda, N. 2017. The National Health Insurance and traditional healing in South Africa. *New Agenda: South African Journal of Social and Economic Policy*, 2017(67): 35-38.

Veehof, M. M., Oskam, M.-J., Schreurs, K. M. G. and Bohlmeijer, E. T. 2011. Acceptance-based interventions for the treatment of chronic pain: A systematic review and meta-analysis. *PAIN®*, 152(3): 533-542.

Wadley, A. L., Pincus, T. and Evangeli, M. 2019. A preliminary analysis of the association between perceived stigma and HIV-related pain in South Africans living with HIV. *African Journal of Primary Health Care & Family Medicine*, 11(1): 1-5.

Wadley, A. L., Venter, W. D., Moorhouse, M., Akpomiemie, G., Serenata, C., Hill, A., Sokhela, S., Mqamelo, N. and Kamerman, P. R. 2021. High individual pain variability in people living with HIV: A graphical analysis. *European Journal of Pain*, 25(1): 160-170.

Wahab, K. W. and Salami, A. K. 2011. Pain as a symptom in patients living With HIV/AIDS seen at the outpatient clinic of a Nigerian tertiary hospital. *Journal of the International Association of Physicians in AIDS Care (Chicago, Ill: 2002)*, 10(1): 35-39.

Walker-Bone, K., Doherty, E., Sanyal, K. and Churchill, D. 2016. Assessment and management of musculoskeletal disorders among patients living with HIV. *Rheumatology*, 56(10): 1648-1661.

Walwyn, D. R. and Maitshotlo, B. 2010. The role of South African traditional health practitioners in the treatment of HIV/AIDS; A study of their practices and use of herbal medicines. *South African Journal of HIV Medicine*, 11(2): 11-17.

Wang, H., Wolock, T. M., Carter, A., Nguyen, G., Kyu, H. H., Gakidou, E., Hay, S. I., et al. 2016. Estimates of global, regional, and national incidence, prevalence, and mortality of HIV, 1980–2015: The Global burden of disease study 2015. *The Lancet HIV*, 3(8): e361-e387.

Warnke, D., Barreto, J. and Temesgen, Z. 2007. Antiretroviral Drugs. *The Journal of Clinical Pharmacology*, 47(12): 1570-1579.

Wiese, M., Oster, C. and Pincombe, J. 2010. Understanding the emerging relationship between complementary medicine and mainstream health care: a review of the literature. *Health (London, England : 1997)*, 14(3): 326-342.

Woolf, S., Schünemann, H. J., Eccles, M. P., Grimshaw, J. M. and Shekelle, P. 2012. Developing clinical practice guidelines: types of evidence and outcomes; values and economics, synthesis, grading, and presentation and deriving recommendations. *Implementation Science*, 7(1): 61.

World Health Organization (WHO). 2015. *World health statistics 2015*. World Health Organization.

Yilmaz, K. 2013. Comparison of quantitative and qualitative research traditions: Epistemological, theoretical, and methodological differences. *European Journal of Education*, 48(2): 311-325.

Yong R. J., Mullins, P.M. and Bhattacharyya N. 2021. Prevalence of chronic pain among adults in the United States. *Pain*, 91. Available: <https://doi.org/10.1097/ajp.0000000000000300>

Zietsman, A. 2019. *Differences in Practice Characteristics between Male and Female Chiropractors in South Africa*. M.Tech. University of Johannesburg, South Africa.

APPENDICES

Appendix 1: University Ethics Clearance



Institutional Research Ethics Committee Research and Postgraduate Support Directorate 2nd Floor, Berwyn Court
Gate 1, Steve Biko Campus Durban University of Technology
P O Box 1334, Durban, South Africa, 4001 Tel: 031 373 2375
Email: lavishad@dut.ac.za
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3 June 2020

Dr A. Abdul-Rasheed 74 Vause Road
Unit 8 Talesha Mews Musgrave

Dear Dr Abdul-Rasheed

The management of chronic pain in HIV by Traditional Complementary Alternative Medicine Practitioners: Guidelines for treatment and management

I am pleased to inform you that Full Approval has been granted to your proposal.

The Proposal has been allocated the following Ethical Clearance number **IREC 050/20**. Please use this number in all communication with this office.

Approval has been granted for a period of **ONE YEAR**, before the expiry of which you are required to apply for safety monitoring and annual recertification. Please use the Safety Monitoring and Annual Recertification Report form which can be found in the Standard Operating Procedures [SOP's] of the IREC. This form must be submitted to the IREC at least 3 months before the ethics approval for the study expires.

Any adverse events [serious or minor] which occur in connection with this study and/or which may alter its ethical consideration must be reported to the IREC according to the IREC SOP's.

Please note that any deviations from the approved proposal require the approval of the IREC as outlined in the IREC SOP's.

Yours Sincerely

Professor J K Adam Chairperson: IREC

Appendix 2a: Letter of Information for Interview Participants (English)



Dear participant

Thank you for agreeing to participate in the study.

Title of the Research study: The management of chronic pain in HIV by Traditional Complementary Alternative Medicine Practitioners: Guidelines for treatment and management

Principal Investigator/s/researcher: Dr Ashura Abdul-Rasheed (PhD: Health Sciences Candidate).

Co-Investigator/s/supervisor/s: Supervisor: Prof M.N. Sibiya (D. Tech: Nursing); Co Supervisor: Prof F. Haffeejee (PhD).

Brief Introduction and Purpose of the Study: Treatment and management of chronic pain in HIV is varied due to the pain experience being highly subjective, which can be challenging for practitioners. Infected individuals explore both pharmacological and non-pharmacological interventions for chronic pain in HIV. The aim of the study is to explore the treatment and management practices for chronic pain in HIV by selected TCAM practitioners and thereby develop TCAM practitioner guidelines for HIV palliative care.

Outline of the Procedures: You are invited to participate on a one-on-one interview that will take approximately 30-45 minutes. Interviews will be held to ascertain your treatment and

management approaches for chronic pain in HIV patients. I will facilitate the interview discussion. For record purposes, I kindly request to audio-record the interview discussion.

Risks or Discomforts to the Participant: There are no anticipated risks or discomforts for participating in this study.

Benefits: The study will stimulate thought processes on treatment and management protocols for chronic pain in HIV. Further from this, guidelines on TCAM approaches will be developed.

Reason/s why the Participant May Be Withdrawn from the Study: You may withdraw from the study at any time of the study. There will be no adverse consequences should you choose to withdraw from the study.

Remuneration: There is no remuneration for participating in this study.

Costs of the Study: You will not be required to pay any costs towards the study.

Confidentiality: Your name will not appear in the research documents including the interview guide. Codes instead of your name will appear in the research documents.

Research-related Injury: There is no anticipated research-related injury that is associated with this study.

Persons to Contact in the Event of Any Problems or Queries: Please contact the researcher on 076 114 4203 or my supervisor, Prof M.N. Sibiya on 031-373 2704 or the Institutional Research Ethics Administrator on 031-373 2375. Complaints can be reported to the DVC: Research, Innovation and Engagement Prof S. Moyo on 031-373 2577 or moyos@dut.ac.za

Isithasiselo Sesi-2b: Incwadi Yolwazi Yalabo Abazobe Behlonywa Imibuzo



Mbambiqhaza othandekayo.

Ngiyabonga ngokuvuma kwakho ukuthi ubambe iqhaza kulolu cwaningo.

Isihloko socwaningo/ sophenyo: Ukwelashwa okanye ukudambiswa kwezinhlungu ezikuphatha njalonjalo/ esezibekhona isikhathi eside kulabo abaphila negciwane lesandulela ngculazi, okwenziwa abasebenzisi bemithi okanye abelaphi bendabuko noma bamakhambi: Izinkombandlela/ imihlahlandlela yokwelashwa noma yokudambisa izinhlungu.

Umphenyi/ umcwaningi omkhulu: UDkt. Ashura Abdul-Rasheed (Umfundi weziqu zobudokotela kumkhakha wezempilo).

Abaphathi/ ababhekeleli bocwaningo: USolwazi M.N. Sibiya (Iziqu zobudokotela kumkhakha wobuhlengikazi), uSolwazi F. Haffejee (Iziqu zobudokotela).

Isingeniso kafushane kanye nenhloso yocwaningo/ yophenyo: Izindlela zokwelapha nokuphatha izinhlungu ezingapheli/ ezihlezi zikhona kulabo abaphila negciwane lesandulela ngculazi ziyehluka ngenxa yokuthi indlela umuntu nomuntu azizwela ngayo izinhlungu iyashiyana, lokho ke kuyaba inkinga kubelaphi/ kodokotela. Iziguli eziphila nesandulela ngculazi ziyaye zisebenzise imithi yesilungu kanye nemithi yesintu/ yendabuko ukulwa nezinhlungu

ezingapheliyo ezibangelwa igciwane lesandulela ngculazi. Inhloso yalolu cwaningo ukuhlola izindlela zokwelapha nokuphatha izinhlungu ezingapheli kulabo abaphila negciwane lesandulela ngculazi ezenziwa yilabo balaphi besintu/ abaphathimakhambi abakhethiweyo. Ukuze kudlondlobaliswe/ kuthuthukiswe izinga lokunakekelwa nokwelashwa ngokwesintu/ ngokwamakhambi kwalabo abaphila negciwane lesandulela ngculazi.

Uhlaka lwenqubo yocwaningo/ yophenyo: Uyamenywa ukuthi uhlangenyele ocwaningweni oluyingxoxo oluzathatha imizuzu engama-30 kuya kuma-45. Kuzobanjwa lezi zingxoxo ukuze kutholakale ukuthi yiziphi izindlela ozisebenzisayo ukwelapha/ ukulawula izinhlungu ezingapheliyo kwiziguli eziphila negciwane lesandulela ngculazi. Ngizobe ngilawula futhi ngihola lezi zingxoxo ukuze zibe lula. Ngezinhlalo zobufakazi, ngiyaxusa ngomusa ukuthi ungiphe imvume yokuthi ngiyiqophe lengxoxiswano.

Ubungozi noma Ukuphazamiseka kukambambiqhaza: Abukho ubungozi noma izinkinga ongaba nazo wena ngenxa yokuhlanganyela noma yokubamba iqhaza kulolu cwaningo.

Inzuzo: Lolu cwaningo luzothuthukisa okanye lugqogquzele inqubo/ indlela yokucabanga mayelana nezindlela zokwelapha kanye nokubhekana nobuhlungu obungapheliyo kulabo abaphila negciwane lesandulela ngculazi. Ngaphezu kwalokhu, kuzobe sekusungulwa futhi kuthuthukiswe imihlahlandlela yezindlela zokunakekela nokwelapha ngokwesintu/ ngokwamakhambi.

Izizathu ezingenza ukuthi umbambiqhaza ahoxiswe ekubambeni iqhaza kulolu phenyo: Unemvume kanye nenkululeko yokuhoxa ekuhlanganyeleni/ ekubambeni iqhaza kulolu cwaningo nganoma yisiphi isikhathi. Ukuhoxa kwakho ekubambeni iqhaza kulolu cwaningo angeke kuze kube nomthelela noma nomphumela omubi kuwe okanye kukudalele izinkinga.

Umholo: Angeke kube khona mholo okanye imali ozoyinikezwa ngokubamba iqhaza kulolu cwaningo.

Inani elikhokhwa umbambiqhaza wocwaningo/ wophenyo: Ayikho imali ozoyikhokha ngokuhlanganyela okanye ngokubamba kwakho iqhaza kulolu cwaningo.

Ubumfihlo: Igama lakho angeke livele kumbhalo walolu cwaningo, ngisho nakumhlahlandlela wengxoxo. Esikhundleni segama lakho kuzobhalwa amakhodi/ izinombolo kumadokhumenti/ kumbiko walolu cwaningo.

Ukulimala okuphathelele nocwaningo/ nophenyo: Akukho ukulimala okubonakala kungase kwenzeke ngenxa noma okumayelana nalolu cwaningo.

Abantu ongaxhumana nabo uma unezinkinga okanye imibuzo: Uyacelwa ukuthi uxhumane nomcwaningi ku 076 114 4203 noma umphathi wami, uSolwazi M.N. Sibiya ku 031-373 2704 noma Umlawuli wezimiso zokuhle kwezocwaningo weSikhungo ku 031 373 2375. Izikhalazo zingabikwa kwa kuSekela Mphathi Wesikhungo: Wezocwaningo, Nokusungula kanye Nezokuxhumana, uSolwazi S. Moyo kule nombolo 031-373 2577 noma moyos@dut.ac.za

Appendix 3a: Consent



Statement of Agreement to Participate in the Research Study:

- I hereby confirm that I have been informed by the researcher, Dr Ashura Abdul-Rasheed about the nature, conduct, benefits and risks of this study - Research Ethics Clearance Number: _____,
- I have also received, read and understood the above written information (Participant Letter of Information) regarding the study.
- I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by the researcher.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.
- I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me.

_____	_____	_____	_____
Full Name of Participant	Date	Time	Signature / Right Thumbprint

I, Dr Ashura Abdul-Rasheed herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

_____	_____	_____
Full Name of Researcher	Date	Signature

_____	_____	_____
Full Name of Witness (If applicable)	Date	Signature

_____	_____	_____
Full Name of Legal Guardian (If applicable)	Date	Signature

Isithasiselo Sesi-3b: Isivumelwano Esicatshangisiwe



Isitatimende semvumelwano yokubamba iqhaza kucwaningo/ kuphenyo:

- Mina ngiyaqinisekisa ukuthi umcwaningi, uDkt. Ashura Abdul-Rasheed ungazisile ngenkambo, uhlobo, inzuzo kanye nobungozi balolu cwaningo- Inombolo yezimiso zokuhle yocwaningo: _____
- Ulwazi kanye nencazelo emayelana nalolu cwaningo ebhalwe lapha ngenhla (Incwadi Yolwazi kaMbambiqhaza) nayo ngiyitholile, ngayifunda futhi ngayiqondisa
- Ngiaqonda ukuthi imiphumela yocwaningo, okubala imininingwane yami yobulili, iminyaka, usuku lokuzalwa, ama-inishiyali nokuthi ngiphethwe yini kuzosetshenziswa ngokungaziwa/ ngobumfihlo ukuze kwenziwe umbiko wocwaningo.
- Ngokubona izidingo zocwaningo, mina ngiyavuma ukuthi imininingwane yami etholakale kulolu cwaningo isetshenziswe ngu mcwaningi ohlelweni lwekhompiyutha.
- Ngingakwazi, kunoma yisiphi isigaba, ukuthi ngihoxise imvume nokubamba kwami iqhaza kulolu cwaningo ngale kwengcindezi.
- Ngibe nethuba elanele lokubuza imibuzo futhi (ngokuzikhethela/ ngokuzithandela kwami) ngiyafunga ukuthi ngikulungele ukubamba iqhaza kulolu cwaningo.
- Ngiaqonda ukuthi lolo lwazi olusha, olubalulekile futhi oluthintana nokubamba kwami iqhaza ngenkathi kwenziwa lolu cwaningo ngizovumeleka ukulazi.

Igama eliphelele loMbambiqhaza Usuku Isikhathi Isiginisha / Isithupha sakwisandla sokudla

Mina, uDkt. Ashura Abdul-Rasheed ngiyaqinisekisa ukuthi lo mbambiqhaza ongenhla uchazeliwe kabanzi ngohlobo, inkambo kanye nobungozi balolu cwaningo olungenhla.

Igama eliphelele loMcwaningi Usuku Isiginisha

Igama eliphelele likaFakazi (Uma kufanelekile) Usuku Isiginisha

Igama eliphelele loMnakekeli Osemthethweni Usuku Isiginisha (Uma kufanelekile)

Appendix 4a: Demographic Data of the Participants (English)

Section A: Demographic data

Participant number:

Date: _____

Age: _____

Gender: _____

Race: _____

Discipline of practice: _____

Number of years in practice: _____

**Isithasiselo Sesi-4b: Imininingwane Yabantu Okanye Ye-Demografiksi
Yabahlanganyeli/ Yababambiqhaza**

Isigaba A: Imininingwane yabantu

Inombolo yombambiqhaza/ yomhlanganyeli:

Usuku: _____

Iminyaka yobudala: _____

Ubulili: _____

Ubuhlanga/ ibala: _____

Uhlobo lomsebenzi: _____

Inani leminyaka osuyichithile kulolu hlobo lomsebenzi: _____

Appendix 5: Interview Guide for Chiropractors

SECTION B: INTERVIEW QUESTIONS

Main Questions:

1. What are the primary areas of complaint of chronic pain in HIV patients that present at your practice?
2. What is your treatment protocol/s that you utilise for chronic pain in an HIV patient?
3. Explain your management approaches for chronic pain in an HIV patient.
4. What are the barriers and challenges you experience in your treatment and management approaches when dealing with an HIV patient?
5. Briefly tell me how these barriers and challenge have affected or influenced your treatment regimens.
6. What are your recommendations for managing an HIV patient with chronic pain?

Probing questions

1. What are the specific treatment options and modalities that you employ in your treatment for chronic pain in an HIV patient?
2. Elaborate on why you chose the specific treatment protocol used for chronic pain in HIV patient?
3. What are the management protocols (referral, multi-disciplinary approach, combination treatment, prescription of vitamins/minerals, dietary advice etc) that you address in practice when dealing with chronic pain in an HIV patient?
4. What are the challenges in treating chronic pain in an HIV patient?
5. How do such challenges affect your treatment modality of choice?
6. How do such barriers impede on managing your patient?

Appendix 6: Interview Guide for Homoeopaths

SECTION B: INTERVIEW QUESTIONS

Main Questions:

1. What are the primary areas of complaint of chronic pain in HIV patients that present at your practice?
2. What is your treatment protocol/s that you utilise for chronic pain in an HIV patient?
3. Explain your management approaches for chronic pain in an HIV patient.
4. What are the barriers and challenges you experience in your treatment and management approaches when dealing with an HIV patient?
5. Briefly tell me how these barriers and challenge have affected or influenced your treatment regimens.
6. What are your recommendations for managing an HIV patient with chronic pain?

Probing questions

7. What are the specific herbs/remedies/tinctures or treatment modalities that you employ in your treatment for chronic pain in an HIV patient?
8. Elaborate on why you choose the specific herb/remedy/tincture and treatment protocol used for chronic pain in HIV patient?
9. What are the management protocols (referral, multi-disciplinary approach, combination treatment) that you address in practice when dealing with chronic pain in an HIV patient?
10. What are the challenges in treating chronic pain in an HIV patient?
11. How do such challenges affect your treatment modality or herb of choice?
12. How such barriers impede on managing your patient?

Appendix 7a: Interview Guide for Traditional Health Practitioners (English)

SECTION B: INTERVIEW QUESTIONS

Main Questions:

1. What are the primary areas of complaint of chronic pain in HIV patients that present at your practice?
2. What is your treatment protocol/s that you utilise for chronic pain in an HIV patient?
3. Explain your management approaches for chronic pain in an HIV patient.
4. What are the barriers and challenges you experience in your treatment and management approaches when dealing with an HIV patient?
5. Briefly tell me how these barriers and challenge have affected or influenced your treatment regimens.
6. What are your recommendations for managing an HIV patient with chronic pain?

Probing questions

7. What are the specific herbs or treatment modalities that you employ in your treatment for chronic pain in an HIV patient?
8. Elaborate on why you choose the specific herb or treatment protocol used for chronic pain in HIV patient?
9. What are the management protocols (referral, multi-disciplinary approach, combination treatment) that you address in practice when dealing with chronic pain in an HIV patient?
10. What are the challenges in treating chronic pain in an HIV patient?
11. How do such challenges affect your treatment modality or herb of choice?
12. How such barriers impede on managing your patient?

Isithasiselo Sesi-7b: Umhlahlandlela Wokuxoxisana Nabalaphi Bendabuko/ Bamakhambi

INGXENYE B: IMIBUZO YOMHLAHLANDLELA

Imibuzo eyingqayizivele/ ebalulekile:

1. Yiziphi izindawo zokuqala emzimbeni eziwayele ukuthi labo abaphila nesandulela ngculazi bakhalaze okanye bakubikele ngazo uma bezofuna usizo kuwe?
2. Iyiphi inqubo yakho yokwelapha oyisebenzisayo uma welapha ubuhlungu obungapheli/ obuhlezi bukhona kwisiguli esiphila nesandulela ngculazi?
3. Chaza ukuthi uyaye uzihlasele noma uzelaphe kanjani izinhlungu ezingapheli eziphatha isiguli esiphila negciwane lesandulela ngculazi?
4. Yiziphi izithiyo, izingqinamba nezinselelo ohlangabezana nazo ezindleleni zokwelapha kwakho nasezindleleni zakho zokubhekana okanye zokuphatha isiguli esiphila nesandulela ngculazi?
5. Ake ungitshele kafushane ukuthi lezi zingqinamba nezinselelo ziyithinte/ ziyithikameze kanjani indlela yakho yokwelapha.
6. Yimiphi imibono okanye iziqondiso zakho onazo mayelana nokwelapha noma ukuphatha isiguli esihlushwa izinhlungu ezingapheliyo kanti futhi esiphila nesandulela ngculazi?

Imibuzo yenqubo

7. Yimaphi amakhambi noma izindlela zokwelapha ezithize ozisebenzisayo ekulapheni izinhlungu ezingapheli/ zanjalonjalo esigulini esiphila nesandulela ngculazi?
8. Chaza kabanzi ukuthi kwenziwa yini ukuthi usebenzise lolo hlobo lwekhambi noma lokwelapha olusebenzisayo uma welapha izinhlungu ezingapheliyo eziphatha isiguli esiphila nesandulela ngculazi?
9. Yiziphi izindlela/ izimiso zakuphatha noma zokwelapha (izindlela zokwelapha ezifana nokudlulisela, ukubambisana, nokuhlanganyela nabanye abalaphi) ozisebenzisayo esigodlweni noma endaweni yakho olaphela kuyo uma ubhekene nesiguli esihlushwa izinhlungu ezingapheliyo futhi esiphila nesandulela ngculazi?
10. Yiziphi izingqinamba ezikhona uma welapha izinhlungu ezingapheliyo kwisiguli esiphila negciwane lesandulela ngculazi?
11. Ingabe lezizingqinamba/ zithiyo ziyithinta noma ziyithikameza kanjani indlela yakho yokwelapha okanye uhlobo lwamakhambi okhetha ukulisebenzisa?
12. Ingabe lezizithiyo ziyikhinyabeza kanjani indlela onakekela ngayo noma owelapha ngayo iziguli zakho?

Appendix 8: Sample of a Transcript

Section A: Demographic data

Participant number: 13

Date: 30 March 2021

Age: 52

Gender: Female

Race: Indian

Discipline of practice: Homeopath

Number of years in practice: 23 years

Interviewer: Hi Dr, so good to see you

Participant: Hi Ashura, how's things going, so glad you are doing your PhD, well done

Interviewer: Thank you, and thanks for taking the time to partake in this study, I am certain with your years of experience, the information you provide will be great and enriched.

Participant: Thanks for contacting me, anything for research.

Interviewer: Please note that this will be recorded, your details will be kept confidential as you have read in letter of info and informed consent. This is purely for research purposes, so feel free to express your honest thoughts and experiences. I just want to reiterate, that since we dealing with HIV which can be sensitive for some, you will by no way reveal any details of any patient. This is purely practitioner based. When you are ready I will begin

Participant: I fully understand, we can go ahead.

Interviewer: Just to ensure you fulfil the criteria for this study, have you ever treated an HIV patient for CP as a primary complaint presenting to your practice?

Participant: Oh yes definitely, that is a prominent thing that is by far the most common thing I treat in HIV patients. I mean they are experiencing chronic inflammation and with all the side effects of the AZT, it is a never ending lucky packet of pain.

Interviewer: Okay great, I will proceed to ask you about your treatments etc, feel free to jump in and talk freely.

SECTION B: INTERVIEW QUESTIONS

Main Questions:

Interviewer: What are the primary areas of complaint of chronic pain in HIV patients that present at your practice?

Participant: You know just to break it down simply, it is not very easy for me to provide you with a list of areas, just off pat before explaining. When dealing with chronic pain in HIV, I can say everywhere, but I need to tell you with homeopathy we need to understand the disease process, have a solid background knowledge and understanding. [\[Theme 1: knowledge and understanding\]](#)

We need to also understand the patient mentally, physically, emotionally as all these can contribute to the primary areas of pain. Homeopathy is much individualised and we use a holistic approach based on this individuality. I mean with HIV and CP the body is undergoing changes non-stop, hence the primary areas can be physical- most common feet, back, big joints like pelvis and knees and almost 110% headaches- I mean its viral, anything viral gives you pain (LAUGHS). [\[Theme 2: Principles and Practice of CP in HIV\]](#).

Also with CP understand that these patients are on ARV-those have side effects, some come to me with an entire bowel of meds. [\[Theme 1\]](#)

Interviewer: But if you have think of all the patients you see, what areas were common (probe)

Participant: Headaches, foot pain and burning, low back pain

Interviewee: What is your treatment protocol/s that you utilise for chronic pain in an HIV patient?

Participant: Diagnosis first – that is key. I need to know what it is I am dealing with. HIV is not easy. A work up is key and essential Ashura, I mean before I even think of remedies I take a lot into consideration: I send for bloods, urine, x-rays if I must. CD4+ is key. [Theme 2- principles and practice]. My case history, physical exam and a good chat to the patient on their mental health is essential for me. I use a holistic system [Theme 2]. It's only after this, I work on the homeopathic aspect, I establish a simillima which guides me to which remedies, herbs etc. I need to prescribe.

Interviewer: I see this is good information, but can you tell me more about the remedies, simillimum?

Participant: Remedies are given based on simillima, for pain arnica, if localised muscles/joints etc. Traumeel injectable, if pain is from overloaded toxin liver from all the other meds I utilise nux vomica. Magnesium tissue salts and curcumin I provide-muscle rejuvenation and anti-inflammatory.

With this chronicity I also need to note the level of chronicity to determine dosage, number of times per day etc. It is really holistic and individualised. I sometimes use herbal tinctures too, these are more potent, and can be used in more acute exacerbations of chronic conditions [Theme 2- principles and practice].

Interviewer: Explain your management approaches for chronic pain in an HIV patient.

Participant: CP patients are hard to treat, they give up easily, there is no compliance makes it worse. They are tired of doctors [Theme 3 and 4]

I refer – I work well with chiropractors, gps, you have to learn that you don't own a patient and work in a team, I have confidence in what I do, but I also know when I need the help of a colleague. I even refer to counselling psychologists [Theme 3]

Interviewee: Do you do anything to change treatments? (Probe)

Participant: Uhm I also e-evaluate my patients and treatment over time, even though a simmilla is established sometimes a patient body is stubborn, they need multiple remedies [Theme 3]

Interviewee: What are the barriers and challenges you experience in your treatment and management approaches when dealing with an HIV patient?

Participant: Patient compliance, they are taking so many drugs and I add mine in, so it takes convincing.

Patient mind-set, depression is a real thing in someone who is in pain all the time, sometimes I get a happy patient, at the follow up they are miserable

No faith from other mainstream doctors- I don't want to say who, but people shun people form homeopathy

No recognition- patients sometimes say my GP said this is hocus pocus, it's like drinking water. This is a great challenge to have your profession questioned. [Theme 4- Challenges and Barriers]

Interviewee: Briefly tell me how these barriers and challenge have affected or influenced your treatment regimens.

Participant: Well not really my regimens, as I said I re-evaluate patients so if I have to switch it up I do

Interviewee: What are your recommendations for managing an HIV patient with chronic pain?

Participant: Understand the patient. Work as a team, we need to be incorporated because patients come to us, we have a place, maybe abit of education on what we do so that people have acknowledge base. [Theme 4]

Appendix 9: Letter from a professional editor



Helen Bond

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1 December 2021

CERTIFICATE

Dr Ashura Abdul-Rasheed

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Dear Ashura

Thank you for using Impela Editing Services to review your PhD thesis entitled **“THE MANAGEMENT OF CHRONIC PAIN IN HIV BY TRADITIONAL COMPLEMENTARY ALTERNATIVE MEDICINE PRACTITIONERS: GUIDELINES FOR TREATMENT AND MANAGEMENT”**.

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I wish you the very best in your submission and in your career.

Kind regards

Helen Bond (Bachelor of Arts, HDE)

Appendix 10: Turnitin report

THE MANAGEMENT OF CHRONIC PAIN IN HIV BY TRADITIONAL COMPLEMENTARY ALTERNATIVE MEDICINE PRACTITIONERS: GUIDELINES FOR TREATMENT AND MANAGEMENT

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