FACTORS AFFECTING THE EXPERIENCE OF PAIN, AND PHYSICAL FUNCTION IN SOUTH AFRICAN MALES LIVING WITH HIV.

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A research dissertation submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg in fulfilment of the requirements for the degree of Master of Science in Medicine

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DECLARATION

I, John Mohale, declare that this dissertation is my own work, except where otherwise specified. It is being submitted for the degree of Master of Science in Medicine in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree of examination at this or any other University.

PRESENTATIONS ARISING FROM THIS RESEARCH PROJECT

I presented the preliminary data at the Fourth Annual Brain Function Research Group (BFRG) Research Day.

Date: 20th June 2019

Venue: PVT Boardroom, Ground Floor, Phillip Tobias Building.

ABSTRACT

Background: Preliminary data from South Africa (SA) suggest that people living with HIV (PLWH) and chronic pain may be as active as PLWH without chronic pain. The data also suggest that PLWH and pain in SA may not disclose their pain for fear of HIV stigma.

Aim: To investigate the perceived causes of pain, the impact of chronic pain on physical activity, and factors affecting recruitment of social support in rural South African males living with HIV (MLWH).

Methods: Mixed method, cross-sectional research design was used. The prevalence of pain, factors associated with both pain prevalence and pain intensity using the Brief Pain Inventory (BPI) and participants' medical records were reviewed quantitatively. Chronic pain was defined as pain on most days for at least three months. Eighteen in-depth interviews were then conducted (8 men living with pain, 10 without). Perceptions about pain and factors affecting physical activity, pain status disclosure, and social support were explored. Themes were derived from the research objectives.

Results: Pain prevalence was 28% and HIV prevalence was also 28% in the 124 men recruited. Age (Mann-Whitney test; p= 0.04) and depression (Chi-square test; p= 0.03) associated with pain prevalence. Pain prevalence did not associate with employment status, education level, or HIV status. Pain intensity, however, associated with HIV status (Mann Whitney test; U = 41, p = 0.0004). Participants that were HIV positive reported higher pain intensity (median = 5.9) than the HIV negative participants (median = 4.0). Pain intensity did not associate with depression, employment status, age or education level. Three men (38%, 3/8) believed that their pain came from physical injuries and four (50%, 4/8) did not know what caused it. The men were highly active including those living with pain. All men involuntarily disclosed their pain statuses to some family members because they were living with them. Each of the four men (50%, 4/8) that did not disclose their pain status had their own reason, including avoiding burdening their children (25%, 1/4), lack of trust (25%, 1/4), staying far from the person he did not tell (25%, 1/4), and not yet understanding the pain himself (25%, 1/4).

Conclusion: The prevalence of pain was relatively low in this cohort and pain did not associate with having HIV. Age and depression, however, associated with having pain.

Half of MLWH were unsure of the cause of their pain or they had had physical injuries. All the men managed to recruit social support. These first qualitative data support the idea that South African MLWH and pain are as active as MLWH without pain. In contrast to the previous study, all the men had disclosed their pain to someone, and the reasons for non-disclosure to others did not appear to be because of HIV stigma. Any non or selective disclosure did not interfere with recruiting social support.

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LIST OF ABBREVIATIONS

ART	Antiretroviral therapy
BPI	Brief Pain Inventory
CMP	Chronic musculoskeletal pain
EMRs	Electronical medical records
HIV-SN	HIV-associated sensory neuropathy
HQOL	Health related quality of life
IL9R	Interleukin-9 receptor
MLWH	Males living with HIV
MOS	Medical Outcomes Study
NRC	Ndlovu Research Center
PHQ-9	Patient Health Questionnaire-9
PLWH	People living with HIV
REDCap	Research Electronic Data Capture
SA	South Africa
SD	Standard deviations
TIMP1	Tissue inhibitor of metalloproteinase-1
UK	United Kingdom
US	United states

INTRODUCTION

South Africa (SA) has a highly disproportionate number of people living with HIV (PLWH). Among the general population the prevalence of HIV is 20.4% (UNAIDS data, 2020). Although the prevalence is not the highest in the world, the actual number of PLWH in South Africa is more than any other country in the world; and that number now stands at 7.7 million (UNAIDS data, 2020).

Now that HIV is a chronic disease rather than a terminal illness, medical management of PLWH is about managing symptoms which are common to HIV. These symptoms include pain, which after fatigue is the most common symptom of HIV. There is a paucity of studies reporting chronic pain prevalence in PLWH in SA and at least half of the available data is not recent. The few available studies conducted in South Africa, reported pain prevalence ranging between 52% and 74% (Mphahlele *et al*., 2012; Parker *et al*., 2017), which is much higher than the 18.3% chronic pain prevalence in a nationally representative sample (n=10,336) of South African adults (Kamerman et al., 2020). A systematic review of 61 studies reported a point prevalence of 54% of pain in HIV (Parker et al 2014). Using this figure, would suggest that there could be over 4 million South Africans living with both HIV and pain.

Pain in PLWH can be treated either pharmacologically or non-pharmacologically, although there are few pharmacological options proven to be effective (Merlin *et al.*, 2016). Chronic pain will possibly need both pharmacological and non-pharmacological approaches to treatment (Madden, 2020). Pain management programmes have generally been created in developed countries and moved out to other countries, where they maybe not effective (Parker, 2019). Qualitative studies are needed determine how PLWH in SA are affected by pain socially, emotionally, physically and what their beliefs are in order to develop culturally-relevant pain management programmes.

Problem statement

This research project is a cross-sectional, mixed methods study exploring factors affecting the experience of pain, disclosure of pain and physical function in South African MLWH.

Rationale

Pain is a common problem in PLWH (Parker et al 2014) and reduces health quality of life (HQOL) (Pillay, 2017). Like in other kinds of chronic pain, it is likely that pain management in PLWH will require both pharmacological and non-pharmacological approaches (Madden *et al*., 2020). Non-pharmacological approaches need to be informed by the understanding, beliefs and logistical situation of the target population, otherwise they may fail (Parker *et al*., 2019).

The gaps in the knowledge of South Africans living with HIV and pain include beliefs and behaviour around physical activity, the impact of disclosing pain (or not) and the impact of recruiting social support (or not). Most of the studies completed in South Africans LWH and pain have been quantitative. Quantitative research limits understanding of a topic because answers must fit into pre-conceived questions and answers, and there is not room for new data to emerge. Qualitative studies are needed to understand a topic from the perspective of a different culture.

I decided to conduct a study in South African males only. It is not clear whether sex is associated with pain presence in PLWH because of the limited literature, and the few studies there are, are conflicting ((Hitchcock, Meyer and Gwyther, 2008; Azagew *et al*., 2017; Parker *et al*., 2014). There are other potential differences between the sexes that may affect males' responses to pain including their activity levels (Vancampfort *et al.*, 2018), and disclosure of pain status (Persad *et* al., 2017; Nortjé and Albertyn, 2015). These differences suggest that studying males and females separately would be an advantage. Indeed, anecdotal evidence from the Pain Lab in the School of Physiology at the University of the Witwatersrand suggests that MLWH are hesitant to report pain to female researchers (personal communication with A Wadley and T

Chinaka). This reluctance to disclose pain by MLWH suggests that the sex of the experimenter may affect the level of pain disclosure by PLWH. Therefore, it is necessary to investigate factors affecting the experience of pain, physical function, social support and pain disclosure in MLWH, aided by a male researcher.

The population that was investigated in this study were men involved in a longitudinal research study exploring cardiovascular risk factors in HIV from the Ndlovu Care Group Research Facility, Groblersdal, Limpopo, South Africa. Pain in this rural population involved in a longitudinal study has not been previously investigated or reported and so it was important to describe the pain and associated factors before qualitative interviews were conducted.

Aim of study:

The aim of this study was to investigate factors affecting the experience of pain, disclosure of pain and physical function in South African MLWH.

Objectives:

1. Using quantitative methods, in a cohort of South African men with HIV:
    a. To investigate the prevalence of pain.
    b. To explore the most common pain sites.
    c. To explore the intensity of pain.
    And to explore associating factors of pain prevalence and pain intensity

2. Using qualitative interviews, explore in males:
    a) beliefs about pain,
    b) and factors influencing levels of activity, disclosure of pain, and social support.

CHAPTER ONE
LITERATURE REVIEW

This chapter describes literature on people living with HIV (PLWH), beliefs about pain, pain and physical activity in PLWH, social support and, lastly the impact of disclosure of HIV and pain statuses.

1.1 Pain prevalence in PLWH

Pain in PLWH may occur due to opportunistic infections or other diseases, side effects of antiretroviral therapy (ART), as a symptom of the HIV infection itself (Silva et al., 2017) or as a result of immune dysregulation (Madden, 2020). Pain related to HIV infection is common in PLWH (Mphahlele *et al*., 2015; Parker *et al*., 2014). However, varying pain prevalence ranges have been reported in the literature, ranging from 0% to over 90% (Parker *et al*., 2014).

Tables 1a and 1b show the prevalence of pain reported in studies of PLWH in the last twelve years. To make the tables more manageable, the results have been split into studies from African (Table 1a) and developed (Table 1b) countries. Two things are clear from these tables: firstly, there is a large variability in pain prevalence reported in studies both from developed and developing countries. The large variability may be due to differences in sample sizes, study designs or how pain was measured in each study. Secondly, despite the variability, the prevalence of pain is high in both developed and developing countries. Pain in HIV is therefore an important topic to investigate.

Table 1a: Pain prevalence ranges in PLWH in African countries.

Author	**Study area**	**Number of participants**	**Prevalence of pain (%)**	**Type of study**	**How pain was measured**
Ebirim and Otokwala (2013)	Nigeria	157	**83.7**	Cross-sectional study.	McGill pain questionnaire (short form)
Azagew *et al* (2017)	Ethiopia	422	**51.2**	Cross-sectional study.	BPI (short form)
Parker *et al*. (2017)	South Africa	229	**74.24**	Cross-sectional study.	BPI-Xhosa
Namisango *et al*. (2012)	Uganda	302	**47**	Cross-sectional study.	BPI
Wahab and Salami (2011)	Nigeria	79	**27.8**	Cross-sectional study.	Modified BPI
Mphahlele *et al*. (2012)	South Africa	521	**72*** **56****	Cross-sectional study.	BPI

*Rural cohort

** Metropolitan cohort

BPI = Brief Pain Inventory

Table 1b: Pain prevalence ranges in PLWH in developed countries.

Author	**Study area**	**Number of participants**	**Prevalence of pain (%)**	**Type of study**	**How pain was measured**
Cervia *et al* (2010)	North-eastern U.S.	41	**39.0**	Retrospective data analysis	Self-reported pain scale
Aouizerat *et al* (2010)	San Francisco U.S.	317	**55.0**	Cross-sectional study.	Memorial Symptom Assessment Scale (MSAS)
Lawson *et al* (2015)	United Kingdom (UK)	859	**62.8**	Cross-sectional study.	11-point visual analogue scale (VAS)
Miaskowski *et al* (2011)	San Francisco U.S.	296	**91.2**	Cross-sectional study.	Modified BPI
Lee *et al* (2009)	San Francisco U.S.	317	**55.0**	Cross-sectional study.	Memorial Symptom Assessment Scale (MSAS)
Uebelacker *et al*. (2015)	South-eastern New England	238	**53**	Cross-sectional study.	BPI

BPI = Brief Pain Inventory

1.2 Anatomical sites affected by pain in PLWH

The common sites affected by pain in South African cohorts may include feet (18%-33%), chest (26%-33%), and the head (19%-54%) (Mphahlele *et al.*, 2015; Parker, *et al*., 2017; Mphahlele *et al.*, 2012). Also, in Nigerian PLWH and pain, the major regions affected by pain were the abdomen, chest, head and neck, and lower limbs (Wahab and Salami, 2011; Ebirim and Otokwala, 2013).

Although pain prevalence may be similar in cohorts of PLWH from developed and developing countries, there seems to be a difference in where that pain is felt. For example, a study conducted in 1207 PLWH and HIV negative people from the UK and Ireland, reported that the most common sites affected by pain were the legs, back and shoulders (Jiao *et al.*, 2016). Another study of 638 United States (US) PLWH reported that joint pains, spinal pain and muscle aches were the most common anatomical sites affected by pain (Sabin *et al.*, 2020). Similarly, in a small, qualitative study conducted in 25 PLWH and pain in the US, a wide range of body sites were affected by pain. The most common sites were leg (n=10), back (n=8), shoulder (n=6) and feet (n=8) (Merlin et al., 2015). Thus, the only commonly overlapping site affected by pain in both developed and developing countries seems to be the feet and could be a result of HIV-associated sensory neuropathy (HIV-SN) (Kamerman *et al*., 2012).

1.3 Factors associated with having pain and pain intensity

I am now going to cover the various factors that associate with having pain, and the intensity of that pain, in PLWH.

1.3.1 Sex

The Global Burden of Disease Study 2017 reported that women have a higher burden of disabling conditions, such as most musculoskeletal disorders, than men (GBD 2017 DALYs and HALE Collaborators, 2019). Many musculoskeletal conditions are disabling because they are painful. Indeed, women generally have a higher pain prevalence than men for most conditions (Keogh, 2008; Ruau *et al*.,2012; Racine *et al*., 2012). Literature from a systemic review of 122 studies and a study of electronical medical records (EMRs) captured of more than 11, 000 patients, showed that there is sex difference in pain (Ruau *et al*.,2012; Racine *et al*., 2012). For example, in 11, 000 EMRs analysed in a study, 588 women had osteoarthrosis (67%) compared to 292 men (33%) (Ruau *et al*.,2012). Furthermore, in South Africa, a recent study conducted in a large nationally representative sample of 10 336 people, reported that women

were more likely to have chronic pain (pain for a duration of at least three months) than men (Kamerman *et al*., 2020). The prevalence of chronic pain in women was 20.1% and in men was 15.8%. From this literature it is evident that globally the prevalence of pain is higher in females than in males.

Several reasons are offered for this greater prevalence in females. The variation of sex differences in pain may be caused by health seeking behaviours (women tend to seek health care more than men, subsequently increasing the reported pain prevalence in women) or sex hormones regulating the menstrual cycle, more especially during the reproductive ages (Keogh, 2008). It was suggested that employment status could also influence sex differences in chronic pain prevalence (Wijnhoven, Vet and Picavet, 2006). This is because more women do not have paying jobs than men and not having a paying job is associated with having chronic musculoskeletal pain (CMP). The (epi-) genetics of women may also contribute to sex differences in certain pain conditions (Krasselt, 2017). For example, the X-linked genes, such as tissue inhibitor of metalloproteinase-1 (TIMP1) and interleukin-9 receptor (IL9R), are involved in the female predominance of rheumatic diseases, specifically rheumatoid arthritis (Krasselt, 2017).

Whilst sex differences in pain prevalence are clear, the evidence for sex differences in *pain intensity* seems to be inconsistent but it may depend on the type of pain. Regarding experimental pain, two reviews concluded that women report more experimental pain than men on average (Bartley and Fillingim, 2013; Keogh, 2008). However, a systematic review of 122 experimental studies suggested that there were no sex differences in pain intensity overall (Racine *et al*., 2012).

In clinical pain, sex differences are equivocal (Bartley and Fillingim, 2013; Keogh, 2008). For example, sex differences in pain intensity were reported for medical conditions in a review of 11, 000 electronic patient records. Women reported greater pain intensities than men (Ruau *et al*.,2012). In a brief review of 89 clinical pain studies published in the British Journal of Anaesthesia by two topic experts, however,

conflicting data were presented (Bartley and Fillingim, 2013). It is not clear, therefore, whether there are sex differences in pain intensity in clinical pain conditions.

In people living with HIV (PLWH) the relationship between sex and pain prevalence is inconsistent (Parker *et al*., 2014). Some studies, that evaluated pain prevalence in relation to sex differences in PLWH, found differences while other studies found no differences. For example, being female was associated with a greater prevalence of pain in a study conducted in 422 Ethiopian PLWH (Azagew *et al*., 2017). However, most participants (87.9%) were females in this study and this over representation of females may have affected the observed results favouring the association. Additionally, in a study of 535 black South Africans at risk of HIV (presenting for HIV testing), 59% had experienced pain in the last month, and being female was associated with that pain (Wadley *et al*., 2020). In contrast, a cross-sectional study of neuropathic pain in 354 South African PLWH prior to starting antiretroviral therapy reported that being male was associated with a higher risk of pain (Hitchcock, Meyer and Gwyther, 2008).

Conversely, in other studies, no sex related differences in pain prevalence were found. The first study was conducted in 302 participants at two HIV/AIDS outpatient clinics in Uganda (Namisango *et al*., 2012). The second study was conducted in 79 PLWH (32 males and 47 females) in Nigeria (Wahab and Salami, 2011). The third study finding no association was conducted in 20 men and 21 women living with HIV in North-eastern U.S. (Cervia *et al.,* 2010). There are relatively few studies looking at sex differences in pain in PLWH and some of these studies (like the second and third studies mentioned above) have small sample sizes.

There are few studies investigating sex differences in *pain intensity* in PLWH. In fact, only one cross-sectional study of 302 PLWH conducted in Uganda has reported that sex was not associated with pain intensity (Namisango *et al*., 2012). The associations between sex, and pain prevalence and intensity are unclear in PLWH, but in general populations being female is associated with higher pain prevalence and intensity.

1.3.2 Age

Greater age has consistently associated with the prevalence of chronic pain. A study of 3605 men and women living with chronic pain in Scotland, reported that older age associated with chronic pain (Smith et al., 2001). Similarly, a study of 4000 Norwegian citizens reported that pain prevalence increased with age in their cohort, with the elderly group having the highest chronic pain prevalence. A systematic review and meta-analysis of 25 studies assessing prevalence of chronic widespread pain in general adult populations also reported that chronic pain prevalence increased with age (Mansfield et al., 2016). However, *pain intensity* did not differ with age in the cohort of Norwegian citizens (Rustøen et al., 2005).

Much of the pain in HIV literature focused previously on HIV neuropathy, which found consistently that greater age associated with HIV neuropathy (Cherry, 2009; Evans, 2011, Wadley, 2011). There are limited studies exploring the relationship between age and general pain prevalence in HIV, however. One study which categorised individuals into older and younger age groups found that individuals 50 years old or more were more likely to have had aches and pains in the last month than those younger than 50 years (Sabin *et al*., 2018). Other studies which assessed the effect of age as a continuous variable in PLWH, found no association between age and pain prevalence (Cervia *et al.,* 2010; Namisango *et al*., 2012; Wadley *et al.*, 2020) or pain severity (Cervia *et al.,* 2010). There are no studies that have investigated the association between age and the prevalence of chronic pain (pain of greater than three months' duration) in PLWH. As pain reports in the last month may be variable over time (Wadley, 2021), more studies exploring age as a risk factor for chronic pain in PLWH are warranted.

1.3.3 Socio-economic status

Employment and education level are two measures of socioeconomic status (Shavers, 2007). Studies have shown that both employment status and educational level are associated with the experience of pain of an individual. There is some evidence that

unemployed people with lower levels of education are more likely to experience pain as compared to employed people with higher levels of education (Poleshuck and Green, 2008; Parker *et al*., 2014). For example, in a cross-sectional study of 229 amaXhosa women in South Africa, the majority that had pain were unemployed. In addition, the women that experienced pain were also reported to have fewer years of schooling (Parker *et al*., 2017). Similarly, a systematic review of 61 studies of PLWH reported that low levels of education were associated with increased pain prevalence (Parker *et al*., 2014). In contrast, Namisango and colleagues (2012) reported that there was no association between having pain and the highest level of education obtained. In addition, a recent study of 535 black South Africans at risk of HIV, reported that the level of education and the state of employment were not found to be risk factors for pain (Wadley *et al.*, 2020). I have included this study as although, the majority of individuals did not have HIV, participants came from the same socioeconomic environment whether they had HIV or not. The conflicting literature on socioeconomic status and pain has come from single, cross-sectional studies (Namisango *et al.*, 2012; Wadley *et al*., 2020), which by nature of design do not provide information about causality. Review studies provide more reliable conclusions, however, since they summarize data from many studies.

1.3.4 Disease severity

Like age and sex, CD4+ T-cell count has been reported to have an inconsistent relationship with pain prevalence in HIV (Parker *et al*., 2014). Some studies found a higher pain prevalence and pain intensity in participants that had lower CD4+ T-cell counts (Richardson *et al*., 2009; Aouizerat *et al*., 2010). However, other studies found no differences in pain prevalence and pain intensity in relation to CD4+ T-cell count (Wahab and Salami, 2011; Breitbart *et al*., 1996).

Viral load in PLWH has been reported to be positively correlated with *pain sensitivity*, where higher viral load associates with higher pain sensitivity. For example, in a cross-sectional study, the 11/47 PLWH with an undetectable viral load (<50 copies/ml) had a significantly lower pain threshold for mechanical stimuli and lower heat pain

tolerance than PLWH with a detectable viral load (Goodin *et al*., 2017). Two other studies reported that a detectable viral load (>50 copies/ml) was associated with a higher burden of symptoms, including pain (Lee *et al*., 2009; Aouizerat *et al*., 2010). One cross-sectional study reported that increased viral load was not related to pain intensity (Richardson *et al*., 2009). The study explored the experience of pain among 339 women with advanced HIV disease in US. These were cross-sectional studies, however. Cross-sectional studies do not provide information about causality (Mcnair and Mcnair, 2012).

1.3.5 Depression

Depression and pain have been reported as frequent comorbidities in people with chronic pain (Ishak *et al.*, 2018; Williams *et al.*, 2006). A review of 28 studies, indicated that depression and pain are extremely intertwined and may both worsen psychological and physical symptoms (Ishak *et al.*, 2018). Certainly, there is some evidence that depression may predict the development of chronic pain (Uebelacker *et al.*, 2015). Moreover, a longitudinal study, of 423 chronic pain individuals conducted in Israel, reported that depression predicted pain and pain-related disabilities. However, pain and pain-related disabilities did not predict depression (Lerman *et al.*, 2015). The literature strongly suggests that depression may increase the chance of developing chronic pain.

A study of 317 PLWH, conducted in San Francisco, reported depression as one of the symptoms experienced by 45% of the participants that also had pain (Lee *et al.*, 2009). Furthermore, several studies reported that depression may have been associated with increased risk of pain and its severity in populations from both developing and developed countries (Parker *et al*., 2014). A systemic review of 46 studies reported that depression was consistently associated with the presence of pain and *pain intensity* in PLWH (Scott *et al.*, 2018). Another study reported that depression was positively associated with pain intensity (Richardson *et al*., 2009). The evidence clearly points towards an association between depression and greater pain intensity.

1.4 Beliefs about pain and how to self-manage it

Most studies of pain in PLWH have evaluated factors that associate with having pain or how intense that pain is. There is a paucity of studies assessing beliefs about the causes of pain in PLWH, more so in men-only cohorts. It is important to understand South African's beliefs about pain, as this could inform the design of culturally appropriate non-pharmacological interventions for managing chronic pain.

There is only one study conducted so far, to the best of my knowledge, documenting beliefs of the causes of pain in PLWH. The qualitative study investigated the impacts of neuropathic pain and treatment strategies in 26 PLWH and peripheral neuropathic pain symptoms in London, United Kingdom (Scott *et al.*, 2020). Some participants believed that either HIV or specific ART regimens had caused their pain. They based these beliefs on their remembered timeline of events. Other participants described confusion and doubt about the cause of their pain.

Like evidence for beliefs about the causes of pain, there are few studies reporting on how PLWH manage their pain themselves. The few available studies have been conducted in developed countries (Scott et al., 2020; Merlin *et al.*, 2015; Nicholas *et al*., 2007). A study of 26 people (14 men and 12 women) with HIV and peripheral neuropathic pain symptoms, conducted in London, United Kingdom, reported the following self-management strategies: stopping harmful pain management strategies (for example, overdosing pain medication) and/or focusing on their life more broadly (for example, exercising) and most were still in the process of wanting to "try everything," (Scott *et al*., 2020). Another study, conducted in Alabama, United States, in 25 PLWH (20 males and five females) with pain reported the following pain self-management strategies: physical activity; spending time with family and friends and social support; medication-centric pain management; cognitive and spiritual strategies such as positive thinking, relaxation, and prayer; substance use (illegal substances); and avoidance of physical/social activity (Merlin *et al.*, 2015). It is not clear whether the differences in reported self-management strategies were due to cultural differences, as the two studies were conducted in different countries, or possibly due

to sex differences as one study had more males than females (Merlin *et al.*, 2015) whilst the other study had almost equal numbers of males and females (Scott *et al*., 2020).

There is some evidence, from developed countries (US), that socio-demographic variables such as age, sex, and ethnicity of a person may influence the type of self-management strategies for pain that PLWH may adopt (Griswold, Evans and Spielman, 2005). For example, when coping strategies of PLWH with peripheral neuropathy were explored, it was found that younger participants used praying-hoping and catastrophizing, more than older participants, women used more prayer-hoping than men, and also African American participants used prayer-hoping more than Caucasians (Griswold, Evans and Spielman, 2005). Yet, in developing countries, such as South Africa, no studies have been done to determine the self-management strategies for pain used by PLWH. In addition, there has not been a qualitative study exploring the causes of pain and self-management strategies for pain in South African PLWH, and certaintly not in South African males living with HIV (MLWH).

1.5 Pain and physical activity in PLWH

A significant number of PLWH are inadequately physically active (Vancampfort *et al.*, 2017). In fact, a systematic review and meta-analysis showed that the time PLWH spend per day being physically active is lower than in most other populations with other types of chronic diseases globally (Vancampfort *et al.*, 2016). Additionally, the time PLWH spend engaging in sedentary behaviour has been reported to be among the highest levels as compared to other chronic conditions (Vancampfort *et al.*, 2017). Several factors have been reported to be associated with lower physical activity in PLWH, such as: older age, a lower educational level, a lower number of CD4 T-cells/µl, exposure to antiviral therapy, the presence of lipodystrophy, depression, opportunistic infections, and the presence of bodily pain (Vancampfort *et al*., 2017). HIV-related pain may lead to a decrease in physical activity in many PLWH, by restricting their ability to perform basic daily activities such as: working, walking, socialising, etc (Vancampfort *et al*., 2017; Namisango *et al*., 2012; Merlin *et al.*, 2013). In a prospective

cross-sectional study of 1903 US PLWH (430 were female), it was found in multivariable models that pain was independently associated with increased chances of impairment in all three of the domains of physical function that were under study (Merlin *et al.*, 2013). The three domains were: mobility, self-care, and usual activities.

Despite many reports of pain interfering with function from developed countries (Parker et al., 2014; Merlin *et al.*, 2013), there are others indicating a different relationship in African countries (Mphahlele et al., 2012; Wahab et al., 2011). When physical activity levels were measured using the Brief Pain Inventory (BPI) and objectively with accelerometers in South African PLWH, it was found that PLWH with pain may remain as objectively active as PLWH without pain (Wadley et al., 2016). qIn that South African study, it was suggested that factors such as economic stress and HIV stigma in African cohorts may partly explain the difference in activity levels between cohorts from Africa and other parts of the world (Wadley et al., 2016). Additionally, a systematic review of physical activity and HIV in sub-Saharan Africa, reported that the presence of food insecurity was associated with more physical activity in Ethiopian men but not in women (Vancampfort *et al.*, 2018). There is relatively little research exploring the relationship between pain and activity in PLWH, including in a South African context. Additionally, of the few studies to date (Pillay et al., 2017; Wadley et al., 2016), these have been quantitative studies using questionnaires developed in resource-rich countries with different cultural contexts. Only two studies were done using a validated translated tool for pain measurement in South Africans, that is, in amaXhosa women (Parker et al., 2016; Parker et al., 2017). Therefore, qualitative studies are necessary to understand the relationship between pain and activity in PLWH, specifically in the South African context.

1.6 Social support

Social support is defined as the perception and practicality that one is cared for, has available assistance from other people, and is part of a supportive social network (Curtona and Suhr, 1992). There are five general categories of social support, namely: emotional, encouraging self-esteem, informational, social network support (e.g., sense

of belonging), and tangible support (e.g., financial assistance) (Curtona and Suhr, 1992).

Literature from developed countries report that there is an association between social support and health related quality of life (HQOL) in PLWH (Degroote, Vogelaers and Vandijck, 2014). Mental and physical health can contribute to a sense of HQOL. In a narrative review, social support was found to have beneficial effects on mental and physical health of PLWH, and even mental health 12 months later (Degroote, Vogelaers and Vandijck, 2014). A longitudinal study of social support and coping with HIV in 64 PLWH (39 were male) living in the US, suggested that negative health outcomes such as HIV-related health symptoms, may be buffered by social support (Ashton et al., 2005).

Whilst the Ashton study (referred to above) reported on HIV symptoms, which included headaches, joint and muscle pains, there are limited data exploring the association between chronic pain and social support in PLWH. The few available studies suggest that social support may be inversely associated with chronic pain (Crockett and Turan, 2018; Penn *et al.*, 2019). Using an ecological momentary assessment method, the experiences of pain and social support were measured three times a day for seven days in a sample of 109 US MLWH (Crockett and Turan, 2018). It was found that experiences of daily social support (either related to participants' HIV or their feeling more generally accepted and supported) reduced pain intensity later in the day. Pain intensity did not influence social support later in the day, however. Correspondingly, in 60 US PLWH with chronic pain, a significant association was found between perceived injustice and greater pain interference among PLWH with low levels of social support, but not those with intermediate or high levels of social support (Penn *et al.*, 2019). Social support, therefore, seemed to diminish the relationship between perceived injustice and pain.

In South African literature, most studies pertaining to social support in PLWH are over a decade old (Sethosa and Peltzer, 2005; Ncama *et al.*, 2008; McInerney et al., 2008),

and participants were both men and women. In a cohort of 149 (64% females) English and/or isiZulu speaking PLWH in KwaZulu-Natal, South Africa, a moderate social support score was found on the Medical Outcomes Study (MOS) Social Support Survey. Furthermore, a greater sense of social support was significantly correlated with the number of close friends and family (Ncama *et al.*, 2008). When physical functioning was measured using the MOS Short-Form (SF)-36 Health Survey in a study of 149 PLWH conducted in South Africa, it was found that participants who had greater social support had better physical functioning (McInerney *et al.*, 2008). In another study of 55 PLWH (41 women and 14 men) conducted in South Africa, greater social support was significantly associated with disclosure of HIV status (Sethosa and Peltzer, 2005). It is clear from literature that social support has positive outcomes on the HQOL of PLWH. Social support is good for PLWH in multiple ways. Social support may increase the likelihood of disclosing HIV status, high medication adherence and greater physical functioning, which all together contributes to the HQOL of PLWH (McInerney *et al.*, 2008; Ncama *et al.*, 2008). What is not clear is how social support impacts on pain in South Africans living with HIV.

1.7 HIV and pain statuses disclosure

Disclosure of HIV status may have either positive outcomes [increased adherence to anti-retroviral therapy, improved psychological well-being, greater social support] or negative outcomes [exposure to stigma and social rejection, discrimination] (Maman et al., 2014; Smith et al., 2008; Wong et al., 2009; Dessalegn et al., 2019). Some PLWH are reluctant to disclose their HIV status, however, to avoid negative outcomes such as exposure to stigma (Shrestha et al., 2019). In the literature, there are several factors associated with disclosure and non-disclosure of HIV status. I have explored this literature because to understand factors affecting pain status disclosure and its impact on PLWH with chronic pain, it may be necessary to understand and compare the factors affecting the disclosure of HIV and the impact HIV status disclosure has on PLWH.

Disclosure of HIV status to family members/social circle may be influenced by the desire to receive social support, or as a result of trusting the family member (Maman et al., 2014; Shrestha et al., 2019). Desire to encourage a partner to get tested for HIV could influence disclosure to one's partner (Maman et al., 2014). The most common factors motivating non-disclosure of HIV status are fear of stigma and discrimination (Shrestha et al., 2019; Dessalegn et al., 2019; Taylor et al., 2020), fear of blame and accusation by partner (Maeri et al., 2016), concerns that children are too young to understand, fear of increased psychological burden to children, and fear of being stigmatized by children (Zhou, 2012).

The literature suggests that the disclosure of HIV status may have either a positive or a negative impact on PLWH (Maeri et al., 2016; Li et al., 2007). The positive impacts may include partner support for increased care-seeking and medication adherence (Maeri et al., 2016), and higher social support from family members (Maeri et al., 2016; Visser et al., 2008). The negative impacts may include violence, blame (Maeri et al., 2016), feelings of shame, fear and stress by PLWH and their families (Li et al., 2007), and exposure to stigma and social rejection (Maman et al., 2014; Dessalegn et al., 2019). While most studies have investigated the impact of HIV status disclosure on PLWH, there are limited studies evaluating the impact of pain disclosure on PLWH with chronic pain. Therefore, it is unknown whether the disclosure of pain status will have a similar impact as HIV status disclosure or not.

There is some evidence that there are differences in pain disclosure between the sexes. For example, in an experimental study of 207 US adults (18–60 years, mean age = 22.1), it was found that males demonstrated fewer observed pain behaviours compared to female participants (Vigil and Coulombe, 2011). Additionally, when the number of females in an audience observing a male participant increased, the male participants subsequently reported lower levels of pain intensity (Vigil and Coulombe, 2011). In another study of 160 German students, participants tolerated a cold pressor test for longer when the experimenter was of the opposite sex (Kallai, 2004).

Differing pain disclosure between the sexes is evident in South Africa too both in healthy and clinical populations. In a study of healthy South African students, it was found that males of both African and European ancestry, were less willing to express/report pain as compared to females (Persad et al., 2017). When three South African cultures [Sesotho, Sepedi, and Nguni] were studied qualitatively in interviews with 42 participants, sex differences were found in cultural beliefs about reporting and expressing pain (Nortjé and Albertyn, 2015). Both in the Sesotho and Sepedi cultures, it is believed that men should not cry even when they are feeling pain, as crying is seen as a sign of weakness for a man. Women however, are allowed to cry and express their pain so that they can get help (Nortjé and Albertyn, 2015). In the Nguni culture, men are groomed from a young age to handle [suppress] and never cry because of pain (Nortjé and Albertyn, 2015).

There may also be reluctance to disclose pain in PLWH. In one study it was found that a proportion of participants concealed their chronic pain status from their family members and friends, possibly due to fear of being stigmatized about their HIV status (Wadley et al., 2016). In SA there are few data documented on factors influencing disclosure of pain (Wadley et al., 2016), and no data at all exploring the impact of disclosing, or not, or only partially disclosing pain on physical functioning. It is not known if health outcomes resulting from disclosure of HIV-related pain will be similar to the outcomes of HIV status disclosure.

CHAPTER TWO
RESEARCH METHODS

2.1 Introduction

In chapter two, literature pertaining to pain prevalence, pain status disclosure, and physical activity in PLWH was presented. This chapter presents the research methods of the study, including study area, design, population, and ethical consideration.

2.2 Study design

This was a cross-sectional study. A cross-sectional design is a study design in which data are collected at one point in time; sometimes used to infer change over time when data are collected from different age or developmental groups (Pilot and Beck, 2012). Mixed methods were used, i.e., both quantitative and qualitative components were incorporated into the study. Combining both, a quantitative questionnaire and qualitative interviews about pain, ensured that the obtained data were grounded in the experiences of pain by the participants. Mixed methods research is defined as "research that involves collecting, analysing, and interpreting quantitative and qualitative data in a single study or in a series of studies that investigate the same underlying phenomenon" (Creswell and Plano Clark, 2007). Using mixed methods research in this study provided a great opportunity to fully understand the pain experience in MLWH. Whilst the primary purpose of the study was to undertake a qualitative analysis, the rural cohort had never been assessed in terms of pain. It was important to describe the pain quantitatively so that it was clear how this cohort compared to others in the literature.

2.3 Study area

The study took place at the Ndlovu Care Group Research Facility, Ndlovu Research Centre (NRC), Elandsdoorn, Limpopo. Ndlovu Research Consortium was founded in 2014 and the research centre was set up in 2017. The Ndlovu Research Consortium

is a research collaboration between the Wits Reproductive Health Institute and Utrecht University in The Netherlands. The Research Consortium has recruited a research cohort of 1928 HIV-positive and HIV-negative individuals from the local area in order to thoroughly explore the long-term effects of HIV infection, its associated chronic diseases and socio-economic problems. The cohort consists of 728 males (210 HIV positive and 518 HIV negative) and 1200 females (510 HIV positive and 690 HIV negative). The Ndlovu Care Group is following up this cohort from 2014 to 2024.

The NRC is located in Elandsdoorn-A, Limpopo province, South Africa. Elandsdoorn is a rural area where majority residents of the community are black South Africans. The languages predominantly spoken are IsiZulu and Sepedi, with some few Xitsonga and Tshivenda speaking people in the area. Elandsdoorn is surrounded predominantly by agricultural activities, farms producing fruits and vegetables in large scales. We chose to recruit at the NRC, because most of the studies exploring pain in PLWH have been done in urban areas. Data collecting at the NRC allowed me to recruit rural males.

2.4 Participants

Participants were recruited in the study for the quantitative component. Some of them participated in the qualitative component (in-depth interview). All participants were black South Africans, with the majority of participants speaking IsiZulu and Sotho. The inclusion and exclusion criteria were as follows.

2.4.1 Inclusion criteria for the quantitative component

Participants had to be male, aged between 18 and 60 years old, know their HIV status, and be in the Ndlovu Care Group longitudinal study cohort and be living in Elandsdoorn. Both HIV positive and HIV negative participants formed part of the study.

2.4.2 Exclusion criteria

Females of all ages and men younger than 18 years and older than 60 years were not included in this study. Females were not included because studies suggested that the sex of the investigator may affect the disclosure of pain. Men may easily disclose pain to a male investigator than a female investigator. Also, men who just got diagnosed with HIV on the day of recruitment were not included.

2.5 Procedure

Data collection for both the quantitative and qualitative components of the study took place from April 2019 to July 2019. At the Ndlovu Research Centre, the researcher was provided with an office opposite the nurse's consultation rooms. Men coming back for their yearly follow up visits for the longitudinal study, were asked by the nurses to go to the researcher's office, one at a time, once they had completed their research visit. In the office, the researcher informed the participants about the study and invited them to participate. The researcher verbally explained the study to the participants and also provided them with the information sheet (Appendix A). The researcher briefly explained the purpose of the study and that there were two parts to the study: 1) a short questionnaire section (10 to15 minutes) and 2) a longer (45 to 60 minutes) interview if they were interested. The interested individuals were asked to read and sign an informed consent form. For those that could not read, the researcher read it to them word by word and explained until they understood. Both parts, the short questionnaire section and the longer interview, had its own informed consent procedure (Appendix B and Appendix C). Consent included request for permission to access clinical information from their Ndlovu study medical records, including their HIV status and CD4 T-cell count. It was explained that the clinical information would only be accessed by the researcher and the staff assisting the in the research.

2.5.1 Quantitative component: questionnaires

Upon the completion of the informed consent for the questionnaire (Appendix B), the men were asked to complete some basic demographic information such as age,

employment status and HIV status. Additional demographic information and some clinical information were obtained from their Ndlovu study medical and baseline questionnaire records.

To determine the presence of pain, men were asked if they had pain using the question from the Brief Pain Inventory (BPI) (Appendix D). The question read as follows: 'Throughout our lives most of us have had pain from time to time (such as minor headaches, sprains, toothaches (Cleeland and Ryan, 1994). Have you had pain other than these everyday kinds of pain during the last month?' Participants that answered that they did have pain were asked to complete a body chart as to where they felt their pain, and also to report the worst, least and average pain intensity. Participants also rated how much pain interfered with several aspects of their day to day lives on an 11-point numerical rating scale from 0 "no pain" to 10 "the worst pain imaginable. The BPI has been used in a South African population before and has also been validated in amaXhosa women LWHV (Parker, 2017). It took eight to 15 minutes to complete the BPI questionnaire.

Information taken from Ndlovu research records

Some of the data were taken from the longitudinal study records. These included CD4 T-cell count (for those participants who indicated they were HIV positive in the BPI questionnaire) and depression scores (Appendix E). The CD4 T-cell count at baseline and the latest CD4 T-cell count at the time data were collected, were obtained from the medical records of the participants. Depression in participants was screened using the Patient Health Questionnaire-9 (PHQ-9) at baseline of the longitudinal study. The PHQ9 is a depression screening tool, and it has been validated and used before in South African people living with- and without HIV (Cholera *et al*., 2014). It has been administered in English, isiZulu, isiXhosa, seSotho and seTswana to men and women in South Africa.

2.5.1.1 Quantitative sample size

In adults, the prevalence of chronic pain is around 33%. A sample size of 125 yielded a population estimate with an 8% margin of error, when assuming a 33% prevalence, and a 95% confidence level.

2.5.1.2 Quantitative data analysis

Data from REDCap were transferred into an excel spreadsheet. GraphPad Prism version 8.0 software was used to analyse the data. Descriptive statistics were used to present the results. Means, standard deviations (SD), percentages (%) and ranges were used to summarize the participants' responses to each item of the BPI scale and to describe demographic data.

Normality of the data was checked before each of the tests were used. A Mann Whitney test was used to determine whether there was statistically significant difference between: 1. ages of participants with and without pain, 2. pain intensity of employed and unemployed participants, and 3. pain intensity of HIV negative and HIV positive participants. A Fisher's exact test was used to determine whether there was statistically significant difference between: 1. the pain statuses of employed and unemployed participants and 2. the pain statuses of HIV negative and HIV positive participants. A Chi-square test was used to determine whether there was statistically significant difference among: 1. the pain statuses of participants that completed primary, secondary or tertiary school and 2. the pain statuses of the participants in the three depression categories of the PHQ-9. The PHQ-9 was already being asked as part of the longitudinal study and the data were taken from the records. Kruskal-Wallis test was used to determine whether there was statistically significant difference among: 1. the pain intensities of participants within the three different depressive symptoms categories and 2. the pain intensities of participants that completed primary, secondary or tertiary school. Spearman correlation test was used to determine correlation between the ages and pain intensities of the participants. P values <0.05 were considered significant.

2.5.2 Qualitative component: in-depth interviews

After the BPI questionnaire was completed in the quantitative section with each participant, they were asked if they were interested in doing an interview. They were informed that the interview section involved questions about living with pain, living with HIV and about their community. For interested participants, the informed consent procedure for the interview was done. For those individuals that could read, they were given an informed consent form to read through, including a separate consent form requesting to audio record the interview. Once they were done reading through the informed consent, any questions they had were answered to their satisfaction and then they signed the informed consent. For those individuals that could not read, each informed consent was read out loud for them and fully explained until they understood and then signed it. Once the informed consent procedure was done, an appointment was arranged for another day to do the interview. For participants willing to do the interview on the same day of recruitment, the interview was done the same day. The sample structure was as follows:

HIV +	With chronic pain N=10
N=20	With no pain N=10

Participants were recruited until data saturation for the majority of themes was reached. Data saturation in qualitative research refers to when participants responses do not yield anymore new information and this can be identified when information provided no longer add to or, does not change the understanding of the phenomenon in question by the investigator (Fusch and Ness, 2015; Tran *et al*., 2017; Nascimento *et al*., 2018). A total of 20 participants were expected, 10 participants per category.

The in-depth interviews were conducted in my office. The door of the office was always closed during the interviews to ensure confidentiality of the participants. I was the interviewer for all the interviews conducted. Interviews were conducted mostly in English, with a few conducted in IsiZulu and Sepedi. Each interview lasted for 40 – 90

minutes. The in-depth interviews were done following a semi-structured interview guide (Appendix F). The guide was designed to be as specific as possible in order that data saturation could be reached with a relatively small sample. A semi-structured interview guide was used because it allowed for questions to be flexible and specific for participants and made it easy to approach questions that may have been too sensitive (Jamshed, 2014). The following are the research questions that were answered with the aid of the interview guide:

- How does chronic pain impact the ability to perform daily activities?
- What are the participants' beliefs about pain?
- How are participants able to disclose their HIV status and chronic pain status to friends, family and health professionals?
- What practical, emotional and social support is available to them as males living with HIV(MLWH)?

The interviews were audio recorded using portable audio recorders. Two audio recorders were used to record each interview at the same time, to ensure that if one recorder malfunctioned the other one continued recording. After each interview, the audio recordings were immediately uploaded to dropbox and deleted from the audio recorders. The audio recordings were then transcribed verbatim. Interviews conducted in IsiZulu, and Sepedi were first transcribed in these African languages, by professional transcribers that fully understand the language used, and then translated into English. All transcripts were sent back to me for review and approval. I double checked if all transcripts were complete by listening to the audio records while reading through the transcripts.

2.5.2.1 Qualitative data analysis

A coding framework was created by one of the supervisors of the researcher using the in-depth interview questions. Analysis of data occurred in two phases. Firstly, three interview transcripts were coded using Microsoft word and then used to make a code book (Appendix G). Each of the three transcripts were coded independently by three analysts (researcher, and two supervisors). Coding was both inductive and deductive.

Pre-existing codes were created based on the interview guide questions and emerging codes were created through a line-by-line reading and coding of each transcript. All categories were derived from the qualitative research objectives. Themes were also derived from the research objectives by the researcher, except for one theme that emerged from the data. Themes were then reviewed by two supervisors and then approved. Finally, the code book was then created by the researcher and reviewed by the two supervisors. The codebook was then used to code the rest of the interview transcripts. Upon completing coding, the interview transcripts, data were compared for any similarities and differences across the interview transcripts.

2.6 Ethical consideration

Ethical approval was granted by the University of the Witwatersrand, Human Research Ethics Committee (Medical), clearance certificate no: M180652 (Appendix H). The Limpopo Department of Health also granted approval of the study.

Upon joining the study, participants were given a study number to avoid a link between the information they provided and their names. The informed consent form had both the study number and participant's names on the signature page. The informed consent forms were kept in separate locked cabinets from the questionnaires and other files with the participant's study numbers to ensure confidentiality. The informed consent forms were paper-pen administered.

The questionnaires were interviewer-administered and captured electronically into REDCap. REDCap (Research Electronic Data Capture) "is a software application and work-flow methodology designed to collect and manage data for research studies". REDCap uses web-based applications to secure study databases and they are easy to create, launch and manage (Harris, 2012).

CHAPTER THREE
QUANTITATIVE RESULTS

In the previous chapter, the study design and methods used to conduct this study were presented. This chapter will describe the quantitative results of the study, which address the first objective: using quantitative methods, report the prevalence, location and intensity of pain, and demographic associations with pain, in a cohort of South African men.

3.1 Study sample

The study took place from March to July 2019. An overview of recruitment and inclusion of participants is illustrated in figure 3.1 below. Three of the participants that refused to participate stated that it was due to their lack of time to participate, and the other two were just not interested.

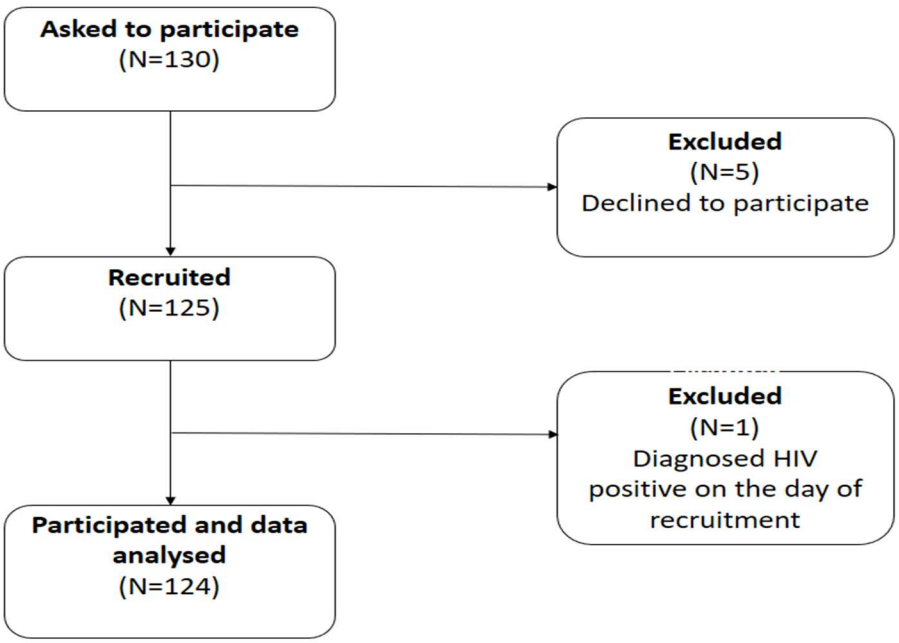


Figure 3.1: Consort flow diagram. Summarises the recruitment and inclusion of all men that participated in the quantitative part of the study.

3.2 Demographic and clinical characteristics of participants

The ages of the participants ranged from 21 to 59 years. The mean CD4 T-cell count of those with HIV was 462 (SD: 232). Table 3.1 summarises the demographic characteristics of the total participants.

Table: 3.1 Demographic and clinical characteristics of the total samples.

Characteristic	**Value (%) (n=124)**
Age (mean, SD)	37 (10)
Primary language spoken.	
IsiZulu	57 (46)
Sesotho*	30 (24)
Setswana	22 (18)
Xitsonga	7 (6)
IsiXhosa	5 (4)
Ndebele	3 (2)
Employment	
Employed	58 (47)
Unemployed	66 (53)
Education**	
No education	1 (1)
Primary	20 (16)
Secondary***	87 (70)
Tertiary****	15 (12)
HIV status	
HIV positive	33 (28)
HIV negative	91 72)

* includes southern and northern Sotho.

** one participant had educational data missing at baseline.

*** included those currently doing matric and those that have completed secondary.

**** included those in college/Technikon or university.

3.3 Pain prevalence and characteristics

The prevalence of chronic pain in this cohort was 28% (35/124). The anatomical sites most affected by pain in study participants are illustrated in Figure 3.2. The characteristics of pain in this cohort are presented in Table 3.2.

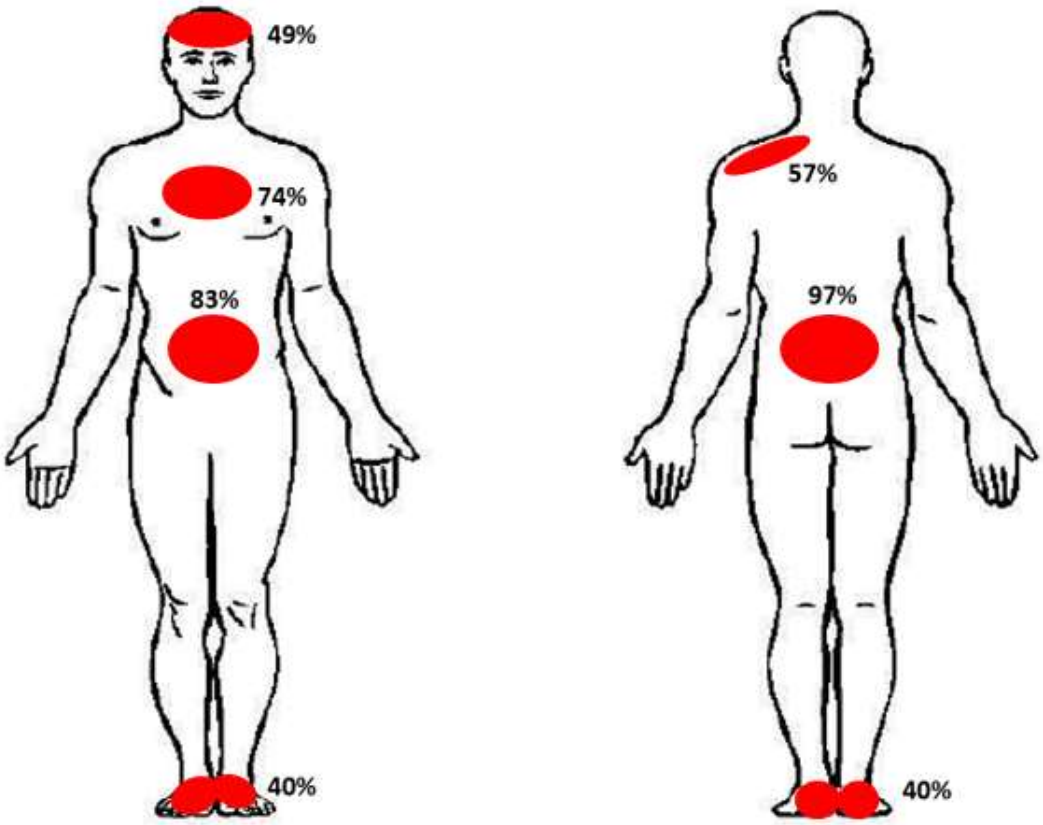


Figure 3.2: Anatomical sites most commonly affected by pain.

Table 3.2: Pain severity and interference scores from the BPI.

Pain	Median (range) (n=35)
Severity*	**5.0** (1.5 - 7.5)
Interference	**4.7** (0.4 - 9.3)

*Calculated as an average of “worst pain”, “least pain”, “average pain” and “pain right now” from the BPI (Cleeland and Ryan, 1994).

3.2.4 Factors associated with having pain

Table 3.3 shows factors tested for association with having pain. There was a statistically significant difference (Mann-Whitney test; p= 0.04) between the ages of people with and without pain. Most people that had pain were older than those without pain. No statistically significant difference (Fisher’s exact test; p= 0.32) in pain status was reported between employed and unemployed participants. There was also no statistically significant difference (Chi-square test; p= 0.79) in pain status among participants that completed primary, secondary or tertiary school. HIV status did not associate with pain status (Fisher’s exact test; p= 0.26). A statistically significant difference (Chi-square test; p= 0.03) in pain status was found amongst the three depression categories on the PHQ-9. participants that had minimal and mild depression tended not to have pain, while participants that had moderate, moderately severe or severe depression were more likely to report having pain.

Table 3.3: Factors associated with having pain.

Factor	Pain N=35	No pain N=89	P value
Age (mean, SD) *	39 (10)	35 (10)	**0.04**
Employment N (%) *			**0.32**
Employed	19 (15)	39 (31)	
Unemployed	16 (13)	50 (40)	
Educational level N (%) **			**0.79**

Primary	7 (6)	13 (11)	
Secondary	24 (20)	63 (52)	
Tertiary	4 (3)	11 (9)	
HIV status N (%) *			**0.26**
HIV positive	12 (10)	21 (17)	
HIV negative	23 (19)	68 (55)	
Depression category N (%) *			**0.03**
Without depression	11 (9)	40 (32)	
Minimal	9 (7)	33 (27)	
Mild	10 (8)	13 (10)	
Moderate/moderately severe/severe depression	5 (4)	3 (2)	

* n=124

** n=122

3.2.5 Factors associated with pain intensity

The In the 35 men with chronic pain, no difference (Kruskal-Wallis test; Kruskal-Wallis statistic= 1.584, p = 0.45) was found in pain intensity among the three depressive symptoms categories [Figure 3.3]. There was no correlation (Spearman; r = -0.18, p = 0.30) between age and pain intensity [Figure 3.4]. No differences in pain intensity were reported between employed and unemployed participants (Mann Whitney test; U = 98.50, p = 0.08) [Figure 3.5]. There were also no differences (Kruskal-Wallis test; Kruskal-Wallis statistic= 0.07, p = 0.96) in pain intensity among participants that completed primary, secondary or tertiary school [Figure 3.6].

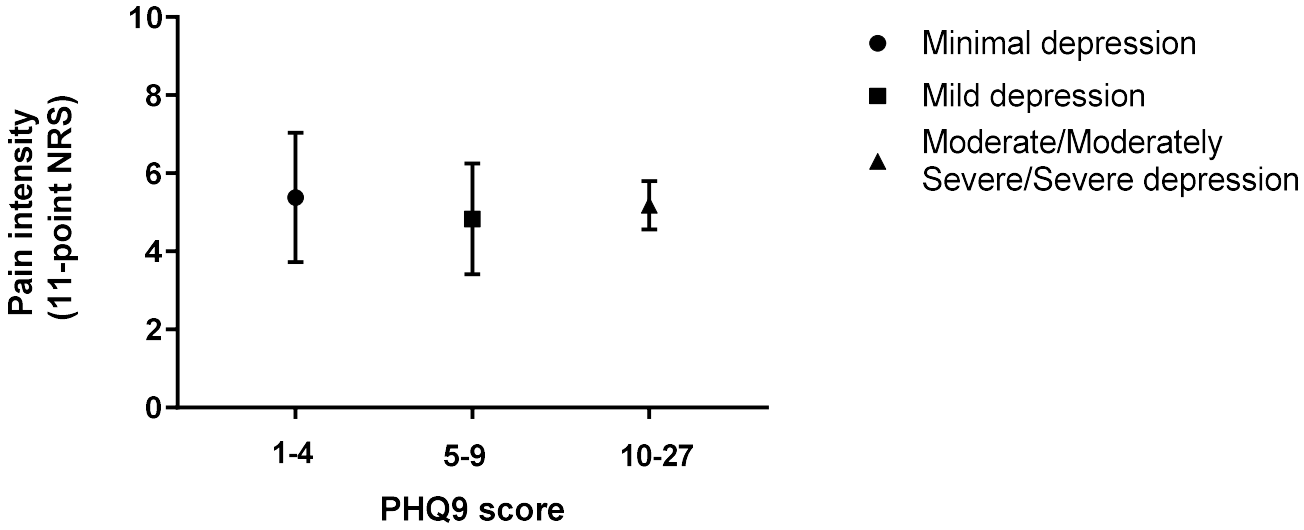


Figure 3.3: Depressive symptoms and pain intensity of participants.

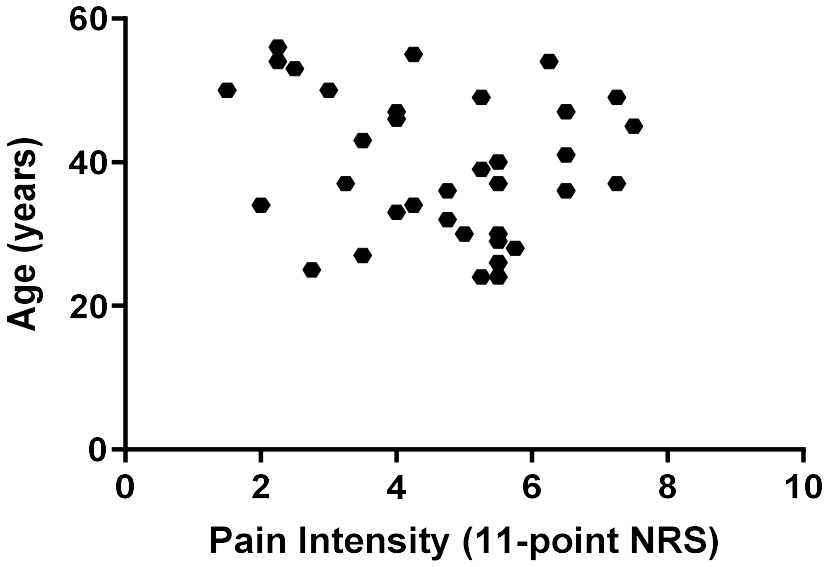


Figure 3.4: Age and pain intensity of individuals with pain

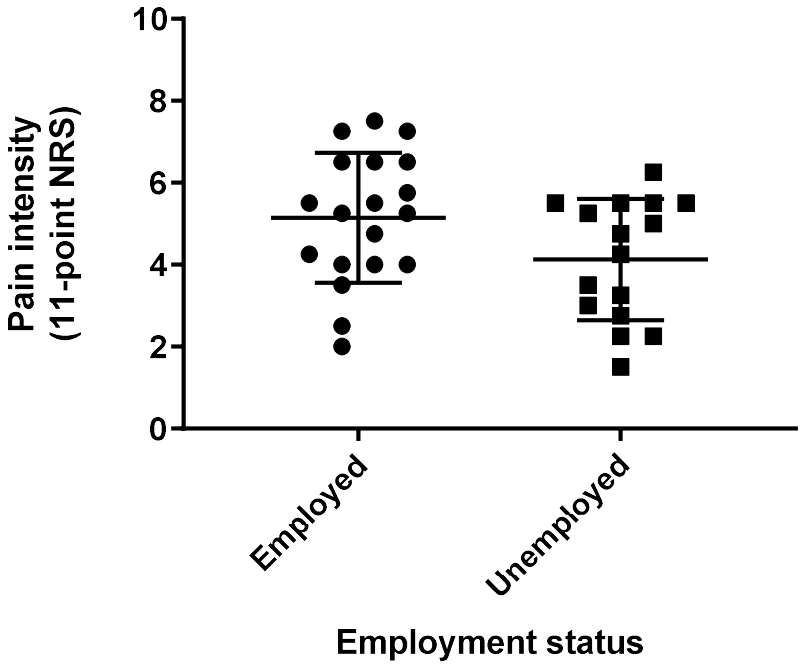


Figure 3.5: Pain intensity in employed and unemployed participants.

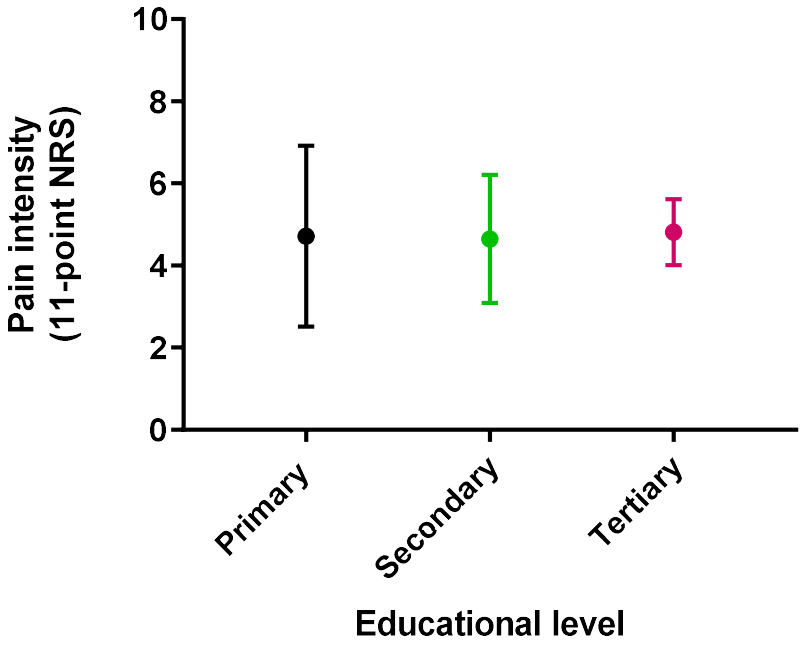


Figure 3.6: Pain intensity and educational levels of participants.

A statistically significant difference (Mann Whitney test; U = 41, p = 0.0004) in pain intensity between HIV negative and HIV positive participants was found [Figure 3.7]. Participants that were HIV positive had higher pain intensity (median = 5.9) than participants that were HIV negative (median = 4.0).

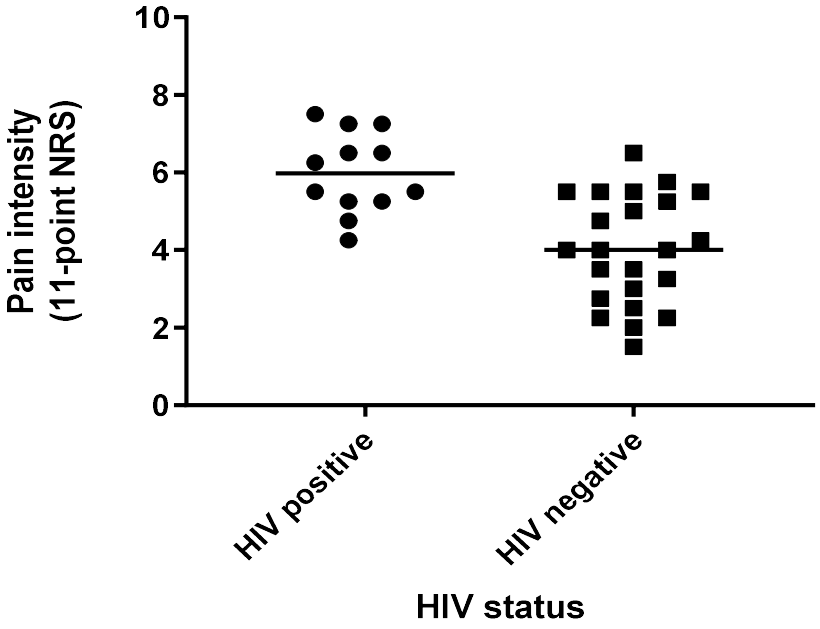


Figure 3.7: Pain intensity of individuals living with HIV and those without HIV.

CHAPTER FOUR
QUALITATIVE RESULTS

This chapter presents the qualitative results of the study, which addressed the second objective: Using qualitative interviews, to determine beliefs about pain, and factors influencing levels of activity, disclosure of pain, and social support in a cohort of South African men.

4.1 Study sample

The in-depth interviews were conducted from March to July 2019. A total of 18 in-depth interviews were conducted with HIV positive participants, with- and without pain. Of the 18 participants interviewed, eight men were living with HIV and physical pain and 10 men were living with HIV and had no physical pain. MLWH both with- and without pain were interviewed, in order to see if there may be any other factors that may influence pain experience from a demographic perspective.

4.2 Demographic characteristics of participants

Table 4.1 shows the demographic characteristics of the sample. The ages of the participants ranged from 27 to 55 years with a median age of 37. There was no difference in age, employment or educational level of those with and without pain.

Table 4.1: Demographic characteristics of the 18 interviewed participants.

Characteristic	**Whole group (n=18)**	**Those with pain (n=8)**	**Those without pain (n=10)**	**P value**
Age (mean, SD)	40 (7.4)	43 (8.4)	38 (6.0)	**0.16**

Primary language spoken, n (%)				
IsiZulu	9 (50)	5 (63)	4 (40)	
Sesotho*	5 (27)	2 (25)	3 (30)	
Setswana	1 (6)	0 (0)	1 (10)	
Xitsonga	2 (11)	1 (12)	1 (10)	
IsiXhosa	1(6)	0 (0)	1 (10)	
Employment, n (%)				**1.00**
Employed	8 (44)	4 (50)	4 (40)	
Unemployed	10 (56)	4 (50)	6 (60)	
Education, n (%)				**0.36**
Primary	1 (6)	1 (12)	0 (0)	
Secondary**	16 (88)	7 (88)	9 (90)	
Tertiary***	1 (6)	0 (0)	1 (10)	

* includes southern and northern Sotho.

** included those currently doing matric and those that have completed secondary.

*** included those in college/Technikon or university.

Four themes and 14 subthemes were derived from the research objectives and the interview data of this study (Appendix I), as shown in table 4.2 below.

Table 4.2: Themes and subthemes derived from the research objectives and the interview data.

Theme	**Subtheme**
The experiences of living with pain among MLWH and pain.	• Perceptions of living with pain in MLWH. • Perceived causes of pain in MLWH. • Pain management in MLWH.
	• Physical activity of MLWH on a typical day.

How living with chronic pain affect daily activity in MLWH.	• Physical activity of MLWH on a busy day. • Pain interference with daily activities in MLWH.
Disclosure of pain in MLWH.	• Reasons for disclosing pain status to family members. • Reason for disclosing HIV positive status. • Voluntary disclosure of HIV status. • Involuntary disclosure of HIV status. • Reasons for not disclosing pain status.
Social support for MLWH.	• Emotional support. • Financial support from friends. • Being able to ask for help during pain.

4.3 Theme 1: Experiences of living with pain among MLWH and pain

This theme describes how MLWH in this study perceived living with pain, what were their believed causes of pain and the methods of pain management they used.

4.3.1 Perceptions of living with pain in MLWH

Of the eight MLWH and pain, only five participants were able to provide complete data about living with both pain and HIV, due to time constrains (exceeded the time limit for the interviews). The majority of participants perceived living with pain as being worse than living with HIV. They believed that living with HIV was better because they had accepted their HIV status and on treatment for HIV. Their perceptions about pain reflected, their experience of pain as interfering physically and emotionally with their daily lives. Participant J018-LWPH-37-years-old reported:

> *"I've accepted my status [HIV status] the way it is. So, it's not something that bothers me anymore, but the pain it's unbearable because it's something that reminds me every now and then. Even if I don't want to think about it [the pain],*

it just comes and says, "Don't forget that I'm still here". Then yes, it's the one [the pain] that's giving me a hard time but combining both of them [HIV and pain] or comparing, no the status [HIV] doesn't have any impact on me, no. But, the pain, it does because it affects my daily duties, you know right? If I have to work, if I have to lift something up, then it [the pain] does affect me doing that."

Similarly, participant J097-LWPH-55-years-old, also commented that living with HIV was not bothering him but the pain was. In his statement he said:

"HIV I just live with it, but it is not a problem at all, just the pain I have on my back but nothing in connection to HIV, just the pain in my back nothing else."

Whilst some MLWH and pain were only bothered by their pain and not HIV status, one participant perceived living with both pain and HIV as a 'bad thing'. He explained that pain was bothering him emotionally and physically. Also, it seemed like he had not accepted his HIV status, and this made him to be unhappy. Participant J030-LWPH-54-years-old said:

"It's bad it's not good. You feel pain every day, it's not good. You can't stay nicely with no problem, the pains stay with you, now I feel those pains now my mind changes now I'm not happy and here this pain, when thinking about this pain and is inside I can't see it, but it is moving inside, so the freedom of the soul isn't there. I am not happy about it because I was not born with these things [pain and HIV], I found them here on earth that is why it would've been better had I not known. So, I know my life here on earth, it doesn't sit well with me."

4.3.2 Perceived causes of pain in MLWH

Half of MLWH and pain believed their pain was idiopathic and three reported that their pain was caused by physical injury.

Idiopathic pain (The cause of pain is unknown). From all MLWH and pain, about half of them reported that they don't know what caused their pain. All responded with a brief "*I don't know*". While one of the participants further assumed that his pain could be cause by cold weather. He said: *"Eish I don't know what is causing it now or it's the cold or what I don't know."* J064-LWPH-47 years old.

Pain caused by physical injury. Physical injury was reported by almost half of MLWH as the cause of pain they experienced. They described the different physical injury incidents they believed were the cause of their pain. Participant J018-LWPH-37-years-old believed that his pain was caused by a car accident. He mentioned a specific day he had a car accident as the day he began feeling pain. He stated:

> *"I started experiencing the pain on the 27th of May last year, that's when I got an accident [car accident]."*

Participant J097-LWPH-55-years-old, also attributed his pain to a car accident. Unlike participant J018-LWPH-37-years-old, Participant J097-LWPH-55-years-old sounded a little unsure of the cause of his pain in his explanation. In his statement he said, *"I'm thinking maybe because I once had an accident on the road and I rolled and landed on my back, maybe that is the cause."*

Participant J013-LWPH-37-years-old attributed his pain to physical injury without a doubt. He stated, *"My pain it started … I got injured, I don't remember which year I fell; I was working on the scaffolding."*

Pain caused by thinking and working too much. One man thought his pain was caused by thinking and working too much. Participant J108-LWPH-32 years old, said, *"think that it's caused mostly by thinking too much. Thinking and working, working hard. Here by my heart, sometimes by my head, mostly headaches and mostly if I work too much, I feel it in my body, I get headaches, here my feet, you see."*

It is interesting to note that all MLWH and pain did not associate their pain with HIV.

4.3.3 Pain management in MLWH

MLWH in this study used multiple ways to manage their pain. Some of them relied on pharmacological methods while others were more non-pharmacological and perhaps remedial in nature.

Pharmacological management and resting. The majority of MLWH reported that they used medication (pain killers) and/or relaxation (sitting/resting) to alleviate their pain. Participant J097-LWPH-55-years-old, relied on taking medication for pain (pain blocks) and resting a bit. He said:

"I will have to rest a bit when it is really painful, or maybe take the pain blocks."

Likewise, participant J013-LWPH-37-years-old, also relied on medication and relaxing.

'I have to relax eh, maybe drink some pain killers."

Remarkably, while participant J018-LWPH-37-years-old, initially also relied on taking medication for pain, he was also concerned about the adverse effects of pain medication on his health, such as addiction. He reported that he had stopped taking medication for pain. *"I've been taking medication for the pain because I've been taking pain killers ever since, but uh it came to a point where, I realized that I need to stop taking the pain killers because I'll end up being addicted to them."*
However, he did not report alternative methods of pain relief.

Non-pharmacological management. Non-pharmacological methods related to remedial techniques for pain relief which included: adjusting seating positions (2 participants), dipping the painful body parts in warm water (1 participant), sleeping (4 participants), taking a walk (1 participant).

Participant J115-LWPH-45-years-old reported that he had to bend his back to relieve pain. He reported, *"Yeah. Sometimes I, I will bend myself. Sometimes when I'm at work I have to bend because there is no bed there (chuckles), so I have to bend."*

Participant, J030-LWPH-54-years-old, reported that he dipped his legs in water to relieve pain. He stated, *"This pain sometimes when I feel as if its [the pain] strong, I put these legs in water, in water that is a bit low [not hot/warm]."*

Participant J115-LWPH-45-years-old, also explained that he sleeps to ease the pain. He said, *"Uh when I'm sleeping like, I ease it a little but it's still there."*

Participant J108-LWPH-32-years-old, who believed that his pain was caused by thinking and working too much, reported that he takes a walk to relieve his pain. He reported, *"I take a walk, just get out and walk. Just walk, maybe a distance and go to the mall, or just go out and then it [the pain] becomes a little better."*

None of the participants reported accessing the health system for pain relief, talking to health professionals for help and exploring medical examination for pain.

4.4 Theme 2: How living with chronic pain affect daily activity in MLWH

This theme describes how living with chronic pain affected the daily activities of MLWH in this study. Participants described the physical activities they did, first on a typical day, and then on a busy day.

4.4.1 Physical activity of MLWH on a typical day

All of the participants without pain, reported that they were physically active daily. Nevertheless, some participants were more active than others. Participants J051-LWH-40-years-old and J056-LWH-27-years-old, in particular, both stated that they were actively playing soccer weekly. Participant J051-LWH-40-years-old stated that, "*I'm still playing soccer. So, I know that every day by 5 o'clock I have to be at the [soccer] practice."* Similarly, participant J056-LWH-27-years-old stated that in a day he plays soccer, "*once or twice, I stay closer to the sports ground*."

In contrast to participants J051-LWH-40-years-old and J056-LWH-27-years-old, Participant J068-LWH-35-years-old was a tuberculosis (TB) researcher and he traveled a lot. Participant J068-LWH-35-years-old stated that his job requires him to travel from one health institution to another most of the time. In his interview he said:

> *"I'm not sitting most of the time. Most of the time, I'll be going visiting health institutions. Yes, checking all the TB patients that did they got eh TB treatment on time. Did they uhm, uhm, uhm, uhm, uhm take their treatment? Did they take whatever that they are supposed to take? So, norm … normally as I said that I'll be driving around. Maybe by a day, maybe I'll see five or six health institutes."*

All participants with pain, described their typical days as always involving some physical activity. Participant J018-LWPH-37-years-old, who is self-employed, reported, "*Uh, I do work, it only depends on what kind of a job do I have that particular day, as I said I'm in construction. I don't leave anything behind I do everything like bricklaying, plastering, painting, roofing, ceiling, tiling, plumbing*." Participant J013-LWPH-37-years-old, who is unemployed and spends more time at home, stated, "*Let me just say, every time I wake up. I'm thinking of fixing something. I always fix some things in my house."*

Similarly, participant J030-LWPH-54-years-old, who is unemployed and spends more time at home also, reported that he was active daily. *"I just do work at home, just*

cleaning, clean the floor, put polish and do anything at home is very nice to do. Fetch some water, everything. Do some garden, wash my clothes and my things so that I can feel at home.",

Participant J097-LWPH-55-years-old, also unemployed, described his typical day by saying, *"when I wake up usually, I clean the yard, as I have a garden, I will be busy with it and as I usually work with wood material and stuff, I will be using those wood to work on the yard."* Furthermore, he stated, *"If I am not going anywhere, I would be working there for about three, four or five hours in a day. I will just be keeping myself busy with that, and if I still have time I will be working with my wooden stuff and maybe making a seating bench or something like that, as I like to keep myself busy with those types of things."*

Overall, all the participants, both with and without pain, reported that they were physically active daily. There did not appear to be any differences with regards to daily physical activity levels between the participants with pain and those without pain.

4.4.2 Physical activity of MLWH on a busy day

Participant J029-LWH-33-years-old, who is a general worker at a borehole company, reported that his busy day is when, "*We are digging many holes, maybe they are digging 12 holes. Yes, for me it's difficult there [busier than normal]."* Participant J027-LWH-42-years-old, unemployed and usually at home most of the time, stated, "*I will be maybe … let's say I will go to town.*" when describing his busy day. While all participants reported having a busy day, one participant admitted to never being busy at all, "*Ahh not busy that…I'm not busy all the time*.", said participant J025-LWH-44-years-old.

During the description of their busy days, all participants with pain reported that they got busier than during their typical days. All participants described doing physically

demanding activities that they infrequently did for extended periods of time as being busy.

The levels of busyness varied among the participants. For example, participant J115-LWPH-45-years-old, works as a security officer and explained that his busiest day is when he is cleaning his room. *"Cleaning my room and then, all that stuff that day, yeah. Cleaning my room, that keeps me busy because security, I don't think it's difficult because you are always sitting."* However, participant J030-LWPH-54-years-old, stated that his busiest day is when he is doing a part time job of building houses. Participant J030-LWPH-54-years-old, stated, *"When I'm building yes. I have, I work because I do many jobs, I mix, I dig, I put some brick, bring some water, anything that's shorting [In short supply/not enough available] I want to put the things so when I do work sometimes, we start to build, and I have to build for the whole day."*

Overall, all participants living with pain and nine participants living without pain reported having busy days. There seems to be no differences in physical activity levels between the participants with and without pain. Only one participant, living without pain, reported that he was not busy at all.

4.4.3 Pain interference with daily activities in MLWH

Despite the fact that men with pain are still active, there was pain interference with daily activities. The majority of the participants living with pain, reported that the pain they were experiencing interfered with their day-to-day activities. Regarding pain interference with his daily activities, participant J115-LWPH-45-years-old, said, *"Yeah, most of the days, when it is very much painful, I can't do anything."* Participant J013-LWPH-37-years-old, also stated, *"I can bend, but I can't bend for too long."* Furthermore, participant J018-LWPH-37-years-old, who was a construction worker, stated:

> *"Bricklaying, that's the hardest job (laughs). I hate that one, I don't like it, I just do it for a living, but I don't like it's very hard. It's heavy, but since uhm I've*

started having pains, I can't do it anymore because once I do it, eish it's going to be hectic. It's going to be hectic there's no rest after that one."

Participant J030-LWPH-54-years-old, explained how the pain interfered with his daily activities when it was bad. He said, *"There is nothing I can do because it starts in the foot and then when it pains, I can't move because that pain is very hot [painful] I must stay and feel it until it stops."* In addition to interfering with his daily activities, participant J030-LWPH-54-years-old, reported that pain also interfered with his sleep. In his interview, he reported, *"Hmm yesterday it was there too much [the pain] and it made me not to sleep nicely."*

Participant J097-LWPH-55-years-old, explained that the pain bothered him every time when he was doing his job. He worked as a security officer, and he was required to work standing the whole time. He described how much pain interfered with his work by saying:

"*You see when I am seating down, I would say it [the pain] seats down as well [becomes less painful/stops], so when I am standing up it [the pain] stand as well [becomes painful] and after a while I can feel it. So, when I am sleeping it as well is very rare that I can feel it, but when I am standing, I'm provoking it and it hinders me from doing my job as I have to do it while standing.*"

Participant J097-LWPH-55-years-old, added that he ended up resigning from his job because of the pain:

"*I: Okay so just for the record you were working in security department.*

Yes, we were standing you never sit down… I had to resign because of the pain, they didn't fire me because of the pain. When you are working you wouldn't be allowed to sit because you are having pain. So, I resigned and explained why I was doing that and told them that it was because of the pain caused by the accident."

4.5 Theme 3: Disclosure of pain in MLWH

This theme describes pain status disclosure in MLWH. The reasons why MLWH did and did not disclose their pain status to certain people are described.

4.5.1 Reasons for disclosing pain status to family members

All participants with pain, reported that they had disclosed their pain status to their families. The participants disclosed their status only to people they spent most of their time with i.e., family. One participant stated that his family just noticed that he was in pain rather than him explicitly disclosing his pain. Participant J013-LWPH-37-years-old, said, *"They do, they do know about this [pain]. They found out… they always see me when I'm busy. Yes, it could be me complaining about my back, but they don't think it's something that they take it serious."*

Participant J018-LWPH-37-years-old, stated that everyone knew about his pain because they all knew that he had a car accident. His exact words were:

> *"Mmh, as I said I've been involved in an accident so since from hospital they've been… monitoring my health every day. They [my family?] keep on asking me; "today how are you feeling, is there any changes?" I keep them updated, but recently we don't talk about it that much because I only complain about it if I work hard or lift something heavy, then that's when it strikes even worse, then I have to complain about it because I'll be sitting still not moving."*

One participant, J024-LWH-39-years-old, mentioned that he had only disclosed his pain status to his wife and his wife disclosed to their children.

Several reasons emerged as to why participants disclosed their pain status to different people. It seemed like all participants involuntarily disclosed their pain statuses to

some of their family members. With regards to pain status disclosure to their wives, three participants (J030-LWPH-54-years-old, J064-LWPH-47-years-old and J097-LWPH-55-years-old) mentioned that it was because they stayed together [married] and they could not keep it a secret. Participant J064-LWPH-47-years-old, stated, *"because we live together. I don't hide anything from her. I want her to know so that even when she wakes up and I have passed on, when they ask her, she can say I told her about the pain."* Participant J108-LWPH-32-years-old, reported that the reason he disclosed his pain status to his mother was because he spent most of his time with her. *"Yes, because mostly I stay with her when I'm at home. About the pain I tell her.",* said participant J108-LWPH-32-years-old. He added by saying that when his pain gets worse, that causes him to disclose his pain status too:

> *"When I feel pain, this makes me to end up telling them that no, I'm not okay, you see. It means that if it's not this pain, it's little pain, obviously it becomes worse, there now I talk that no I'm not alright, when I see it's just a small thing, maybe it can be pain, it can end just now, maybe 2 minutes then it's gone. But if is this pain that takes the whole day, already 5, 5 hours there I talk now, that I'm not alright."*

Half of the participants (J013-LWPH-37-years-old, J115-LWPH-45-years-old and J024-LWH-39-years-old), stated that some people found out about their pain statuses through observing them in pain or taking medication. Participant J024-LWPH-39-years-old, reported, *"since I stay with all of my children in this household, you see they can also see since in most cases when they go to school, I usually accompany them so when I am sick [suffering with pain] they can see that actually, I am very sick, I will not take them, they will need to go on their own.*

Participant J018-LWPH-37-years-old, said in his interview that he did not have to disclose his pain status as all his family members already knew he had pain from his car accident. Participant J064-LWPH-47-years-old, added by saying that he disclosed his status to his father while asking for assistance with medication. Participant J064-LWPH-47-years-old, stated, *"I saw him [my father] drinking pills and I asked if he has pills for pain. I have this pain here you see.*

In order to understand pain status disclosure, it is important to also understand HIV status disclosure. It allows comparison between the two disclosures.

4.5.2 Reason for disclosing HIV positive status

To understand pain status disclosure, it is important to also understand HIV status disclosure. It allows comparison between the two disclosures.

All participants with pain reported that they had disclosed their HIV status to one or more people. Participants had various reasons for disclosing their HIV statuses. The reasons varied depending on the person they were disclosing their HIV status to. Participants gave reasons such as: we stay together [sharing of details with someone you live with] (1 participant), I got sick (1 participant) and partner tested HIV positive (3 participants), for disclosing HIV statuses to their wives or partners.

With regards to other family members, participants gave a number of reasons for disclosing their HIV status to them. These included: trusting the family member, wanting to feel free, because of spending more time together, the family member saw the HIV treatment, participant got sick, and advising family members to protect themselves from HIV. It seems like participants only disclosed their HIV statuses to family members and some of their friends that they trusted the most. It also seems like some participants, disclosed their HIV statuses voluntarily while others were forced to involuntarily disclose by their circumstances.

Voluntary disclosure of HIV status. Almost all participants living without pain disclosed and gave reasons for disclosing their HIV statuses. There was not a common reason among all nine participants, for disclosing their HIV statuses. However, almost half of

the participants said that they disclosed their HIV statuses because they trusted the person they were confiding to. Participant J025-LWH-44-years-old, for example:

> *"Oh, okay so uhm let's talk about your friends. You mentioned you have two. Do they know your status?*
> *It's only one person (one of the two friends) who knows. That one is the one I trust the most"*

Similar to participant J025-LWH-44-years-old, participant J096-LWH-37-years-old, mentioned that he had disclosed his HIV status to his cousin and his mother because he trusts them.

Few of the participants; J051-LWH-40 years old, J084-LWH-45-years-old and J005-LWH-45-years-old, mentioned that they disclosed their HIV statuses to educate either their family or friends (people that the participants spent a lot of time with) about HIV. Participant J051-LWH-40-years-old, said, *"So, I told them … I told them my status that I'm HIV positive. Please uh, teach these kids when they get to that stage. Tell them everything, tell them about HIV, tell them about sex so that they should know."*

Involuntary disclosure of HIV status. Some men involuntarily disclosed their HIV statuses because of their circumstances. Participant J030-LWPH-54-years-old, stated:

> *"I realized that it wouldn't help hiding it from her, because now you see having this skin rash here, I want to go to the hospital, it hurts here I have to go [to] hospital. So that caused me to tell her straight. You see, she must know what's happening. So, I told her straight I didn't hide it from her."*

Participant J096-LWH-37-year-old gave the following reason for disclosing his HIV status to his wife, *"She wanted a child with me then I decided to tell her"*.

There were other numerous reasons given by the participants. These included: just feeling ready to share their HIV statuses, needing support from the family members or friends, to feel free around another person, and to alert a romantic partner so they can get tested. Similar to the participants living with HIV and pain, it also seems like some men disclosed their HIV statuses voluntarily while others involuntarily disclosed due to their circumstances.

These data show that there are some common reasons for disclosing both HIV and pain status to family members, avoiding keeping a secret, trust and being forced by circumstance (family seeing HIV treatment or the man's pain behaviours).

4.5.3 Reasons for not disclosing pain status

In this study, all participants living with pain had selectively disclosed their pain status to most of their families, some friends and health care providers. They did not disclose their pain to all people, but they all disclosed to someone. Some chose to not disclose to certain people such as some friends, their own children and co-workers. The choice for non-disclosure ranged from distrust and the need to protect from causing pain. Half of the participants (J013-LWPH-37-years-old, J030-LWPH-54-years-old, J115-LWPH-45-years-old and J097-LWPH-55-years-old) living with pain, reported that they did not disclose their pain statuses to some people. Each one of the four participants had a personal reason for not disclosing their pain status.

Participant J013-LWPH-37-years-old, mentioned that he only disclosed his pain status to one of his friends. He stated that lack of trust among the other friends was the root cause for not disclosing his pain status. *"You see, it's like they are my friends but there are things I won't be able to share with them. Like I share with this guy [the trusted friend], that's how it is. You won't trust all your friends."*

In contrast, participant J115-LWPH-45-years-old's reason for not disclosing his pain status to his friend was a distance barrier. When asked why he didn't disclose his pain status to his friend, he mentioned it was because they were staying apart from each other.

Participant J030-LWPH-54-years-old, said his reason for not disclosing his pain status was that he did not understand the pain yet himself. While participant J097-LWPH-55-years-old, said he did not want to burden his children by disclosing his pain status to them. Participant J097-LWPH-55-years-old, stated, *"Eish my brother, you know as a man, I don't want my kids coming and saying my dad is sick and all of that, I know they are still young and weak hearted. So, I don't want that to happen to them, so I want them to be happy when they see me, and I get happy as well."* It seems like participants did not disclose their pain statuses, mainly to the people they did not spend a lot of time with and did not trust.

4.6 Theme 4: Social support for MLWH

This theme describes recruitment of support by the study participants. Participants reported different types of support they received from their family members, friends and health care workers which included: emotional and financial support.

4.6.1 Emotional support

Participants in this study identified three groups of sources of support which included friends, family and healthcare workers. Emotional support was in relation to being able to talk to a family member or a friend.

Emotional support from friends. Participant J029-LWH-33-years-old, stated that he talks to his friend about his personal business. *"I have only one friend who can … I*

can tell him about my personal things, yes. He is the one who can help me. He helps me because uh, when something is wrong, I talk to him. Like he's my brother."

Emotional support from family members. Less than half of the participants stated that they were receiving emotional support from some of their family members. Participant J029-LWH-33-years-old, stated that he speaks to his grandmother about personal things in his life, including his HIV status. Participant J005 also mentioned that he could talk to members of his family when he needed help.

Participant J024-LWPH-39-years-old, explained how he felt when his family was supporting him when he was in pain. *"Yes, they indeed help me in the household because they make food for me, they just bring everything that I need, they are able to bring to me."*, said participant J024-LWH-39-years-old.

Emotional support from health care workers. One participant also explained that he relied on health care workers for support. Participant J018-LWPH-37-years-old, said this:

"I: Where, where would you ask for help from, if you needed help?
P: No, I think the medical center it's the best one.
I: Okay.
P: Either I will go to the clinic, the hospital wherever I can find a doctor."

4.6.2 Financial support

Only friends were identified as sources of financial support for MLWH in this study.

Participant J064-LWPH-47-years-old, reported that he was receiving support financially from this friend. Participant J064-LWPH-47-years-old, stated, "*No he is the one my friend whom even if he has money he sends me and ask if I'm alright, do I have apples eh he supports me with that, if I don't have maize meal or I have a little*

left he can call at his home and tell them to buy for me and say I will pay back when I come back end of the month. He is the one who helps me a lot."

Participant J115-LWPH-45-years-old, explained how his friend supports him financially. He said, *"Most of the time uhm that … that friend of mine is the one maybe like I'm struggling financially is the one who's assisting me."*

4.6.3 Being able to ask for help during pain

Half of the participants living with pain, were able to recall times where they asked for help during the experience of pain. In his statement, participant J018-LWPH-37-years-old, stated, *"Yes, when I'm working or maybe when I'm fetching water. I … there's this guy that I normally ask for help from him, that he can help me carry those buckets maybe if we have to carry them off the bakkie and put it in a tank and put them back again. Yes, there's one guy that I ask."*

Participant J024-LWH-39-years-old, who works as an undertaker, also reported that he has asked for help from a neighbor during a pain experience. *"Actually, when they are bad, since my neighbor works at the chemist, I end up calling him and he just brings the injection."*, said participant J024-LWH-39-years-old. Likewise, both participants J013-LWPH-37-years-old and J115-LWPH-45-years-old reported that they had previously asked for help during pain experience.

Conversely, two participants (J030-LWPH-54-years-old and J097-LWPH-55-years-old) reported that they never asked for help during a pain experience. Participant J030-LWPH-54-years-old stated, *"No I have not asked someone.",* and he did not give a reason why. Participant J097-LWPH-55-years-old said, *"I never really ask help from anyone when I feel that it is really bad, I just make a plan to get to the clinic."* He added that the following was his reason for not asking for help:

> *"As you know at the clinic, they are professionals they went to school so that they can deal with a human being and they know which medication to give you, if you ask someone for help, they can give you traditional medication which*

might not go well with your body, the other could give you a tablet that your treatment doesn't want or advice, so I just avoid all those things and go to the clinic."

CHAPTER FIVE
DISCUSSION, LIMITATIONS AND CONCLUSION.

5.1 Introduction

Chapter four presented the qualitative results. This chapter will present the discussion of the results and concludes the study.

5.2 Discussion

This is the first study to qualitatively investigate the factors affecting the experience of pain and physical functioning in MLWH. I investigated beliefs about pain, and factors affecting physical activity, disclosure of pain and social support in 124 males living with HIV (MLWH) and without HIV from the Ndlovu Care Group Research Facility in Groblersdal, South Africa. This was achieved, firstly, by using quantitative methods to characterise the pain in the cohort. The pain was characterised by describing the prevalence, location and intensity of pain, and demographic associations with pain in MLWH and without pain. Pain had never been characterised before in this cohort, despite the men being in a longitudinal study. When PLWH with pain are under study, their pain may reduce as they receive medical, and even just general, attention (Parker, Jelsma and Stein, 2016; Kemp *et al*., 2020; Dinat *et al*., 2015).

This cohort of 124 of men with an HIV prevalence of 28% had a pain prevalence of 28%. The factors that associated with pain prevalence were age and depression. Pain prevalence did not associate with employment status, education level, or HIV status. Pain intensity associated with HIV status. Some men believed that their pain came from physical injuries, but most did not know where it came from. Men in this study were highly active. They also disclosed their pain statuses to their family members and closest friends. Reasons why each of the four men did not disclose their statuses to some people included avoiding burdening his children, lack of trust, staying far from the person he did not tell, and not yet understanding the pain himself. Despite the four

men not disclosing their pain status to some people, all men in this study managed recruit the support they needed.

5.2.2 Pain prevalence and characteristics

There was a spate of papers published on the topic of pain prevalence and factors associating with that pain between 2009-2013 (Tables 1a and 1b in the literature review) and only very few since. There has been a recent call by clinicians, researchers and patients in the field of HIV and pain for more studies including large, well-funded studies to understand the problem better (Madden *et al*., 2020; Merlin *et al*., 2021). My data contribute to this call.

The prevalence of pain in this cohort was low compared to other cohorts living with HIV, with 28% of the participants reporting having pain at the time the data were collected. Whilst this pain prevalence is within the ranges reported in a systemic review paper (Parker *et al*., 2014), it is on the lower end of the range. The point average of pain in the systematic review was 54%. The pain prevalence of this study is also consistent with that of a study conducted in 79 PLWH, 32 (40.5%) males and 47 (59.5%) females, in Nigeria where they found a pain prevalence of 27.8% using a similar tool to my study (Wahab and Salami, 2011). The low pain prevalence may be due to the fact that only males were assessed, and men experience less pain than women (Kamerman *et al*., 2020; Ruau *et al*., 2012).

The top seven anatomical sites commonly affected by pain in my study included: lower back (97%), abdomen (83%), chest (74%), shoulders (57%), the head (49%), feet (40%). Lower back pain prevalence was much higher in this study as compared to other studies in SA (Wadley *et al*., 2021 under review). I also found a slightly higher prevalence of feet and chest pain in this cohort than the other studies (Mphahlele et al., 2015; Parker, et al., 2017; Mphahlele et al., 2012). The prevalence of chest and abdominal pain was different from that of studies conducted in developed countries (Merlin et al., 2015; Jiao *et al.*, 2016). Studies conducted in developed countries did

not report chest and abdominal pain. My findings are in agreement with the findings in other SA studies on PLWH, except for lower back pain, it was extremely high in my study (Mphahlele et al., 2015; Parker, et al., 2017; Mphahlele et al., 2012).

5.2.3 Factors associated with pain prevalence and intensity

To my knowledge, this is the first study to investigate the association between age and the prevalence of chronic pain (pain of greater than three months' duration) in MLWH. There was a significant difference in ages of men with and without pain. Men that had pain were older than those without pain. Sabin and colleagues (2018) reported similar findings in PLWH, despite them assessing acute pain rather than chronic pain. However, no correlation was found between pain intensity and age of the participants. Depression and pain have been reported as frequent comorbidities in people with chronic pain (Ishak *et al.*, 2018). A statistically significant difference in pain prevalence was found amongst the three depression categories on the PHQ-9 scale. Participants that had minimal and mild depression tended to have no pain, while participants that had moderate, moderately severe or severe depression were more likely to report having pain. These results are in agreement with several studies that reported that depression may be associated with higher pain prevalence in PLWH in two systemic reviews (Parker et al., 2014; Scott et al., 2018). While literature reports that depression and pain are extremely intertwined and may both worsen psychological and physical symptoms (Ishak *et al.*, 2018), contrasting results were found in this cohort. Whilst depression was associated with the prevalence of pain, there was no statistically significant difference in pain intensity between participants in the three depressive symptoms categories.

Employment status and educational level were found to have no association with pain prevalence or intensity in this cohort. These findings are similar to those of Namisango and colleagues (2012). Additionally, a study of 535 black South Africans at risk of HIV, with a HIV prevalence of 13%, reported similar results, with the level of education and the state of employment not found to be risk factors for pain (Wadley *et al.*, 2020). Contrasting to my findings, in a cross-sectional study of 229 amaXhosa women in

South Africa, the majority that had pain were unemployed and had fewer years of schooling (Parker et al., 2017). The reason for the lack of differences in socio-economic status as pain risk factor is unclear.

HIV status did not associate with the pain status of the participants. These results are unexpected given that previous studies reported pain prevalence to be higher in PLWH (Parker *et al*., 2014). It is also noteworthy to point that only men who volunteered to participate from the ongoing longitudinal study were included in this study. More MLWH could have volunteered to participate than those with HIV and pain.
Until now, it has not been easy to get HIV negative cohorts (certainly in SA) because it was difficult to recruit people to HIV negative and HIV positive arms without asking them. Some big observational and longitudinal studies have now allowed this (Wadley *et al.*, 2020a; Wadley *et al.*, 2020b). The lack of association between pain and HIV may be because the participants were under study for a longer period. It may be that their pain may reduce as they receive medical, and even just general attention (Parker, Jelsma and Stein, 2016; Kemp *et al*., 2020; Dinat *et al*., 2015).

In contrast, a statistically significant difference in pain intensity between HIV negative and HIV positive participants was found in this study. Participants that were HIV positive had higher pain intensity (median = 5.9) than participants that were HIV negative (median = 4.0). There are few studies reporting on the differences in pain intensity between HIV negative and HIV positive people. However, it has been suggested that HIV causes immune dysregulation, and the resultant inflammation may increase pain intensity in PLWH (Madden *et al*., 2020).

Until now, everything that was discussed was about quantitatively characterizing pain in the research cohort. Now the qualitative data will be discussed. Four themes were derived from the research objectives.

5.2.4 Theme 1: Experiences of living with pain among MLWH and pain

Causes of pain in MLWH

From the 18 participants interviewed, only eight of them had pain at the time they were interviewed. Half of MLWH and pain believe that living with pain is worse than living with HIV, whilst one man believed that it was worse living with both HIV and pain. Regarding the participants' beliefs about their pain, two ideas emerged: three had had a physical injury and the pain had not resolved. The other half (4/8) stated that they did not know what caused their pain. There is only one study that has reported the beliefs of the causes of pain in PLWH, conducted in London, United Kingdom (UK) (Scott *et al.*, 2020). On the one hand, participants in the UK study did not report physical injury as one of the believed causes of their pain. Rather they believed it was due to HIV or specific ART regimens (Scott *et al.*, 2020). There was a proportion of participants, however, who, similarly to this study, reported the cause of their pain to be unknown. Thus, it may be important to include some education about chronic pain in any pain management programme developed for PLWH. This may assist PLWH and pain to better characterize and understand their pain. A study conducted in SA also reported about believed causes of pain but not in PLWH (Nortjé and Albertyn, 2015). Many rural people in that study believed that when a person has pain is bewitched. In addition, in the seSotho culture they believed that experiencing severe physical pain was caused by ancestors punishing someone for wrongdoing or for not responding to a "calling". In contrast to findings by Nortjé and Albertyn (2015), in this study there were no beliefs about pain related to witchcraft or ancestors. This could be because the interview questions for this study did not probe much about cultural or ancestral beliefs about pain.

Pain management in MLWH and pain

Participants used several methods to manage their pain, including pharmacological management, resting, adjusting seating positions, dipping the painful body parts in warm water, sleeping, taking a walk or exercising. Some of these pain management strategies, pharmacological management and exercising, were reported by Merlin and colleagues (2015). Merlin and colleagues (2015) reported that in their predominantly

male African American sample, self-medication with illicit drugs was common. In contrast, illicit drugs were not reported as one of the pain management strategies in this study. This may be due to the fact that this study was conducted in a rural area where most people may not have easy access to illicit drugs (Hautala *et al*., 2017), compared to the urban cohort in Merlin and colleagues (2015). Unlike the report by Griswold, Evans and Spielman (2005), that African American participants used prayer-hoping more than Caucasians; prayer-hoping was not used by the black South African men in this study. (Griswold, Evans and Spielman, 2005). Despite some of them being religious, men in my study did not mention ever using prayer-hoping for pain management (Griswold, Evans and Spielman, 2005).

5.2.5 Theme 2: How living with chronic pain affect daily activity in MLWH

Participants in this study, both, men living with- and without chronic pain reported no differences in physical activity. They all reported that they were physically active daily, and there seemed to be no difference in their levels of activity. The findings of my study support previous findings that South African PLWH with pain may remain as active as PLWH without pain (Wadley et al., 2016). Indeed, the whole cohort interviewed seemed to be a physically active cohort in general. These results conflict the reports from a systemic review of six studies, that a significant number of PLWH are inadequately physically active (Vancampfort *et al.*, 2017). The systemic review included only one African study and five American studies, however, and the analysis did not include a cultural comparison in activity levels. Furthermore, only two of the six studies objectively measured activity. Higher levels of sedentary behaviour tended to occur more in self-report measures than in objective measures and so the review may have presented data that under-report activity levels (Vancampfort *et al.*, 2017).

Despite their reportedly high activity levels, the men with pain also reported that pain was interfering with their daily activities, as previously reported in other studies (Vancampfort *et al*., 2017; Namisango *et al*., 2012; Merlin *et al.*, 2013). HIV-related pain may lead to a decrease in physical activity in many PLWH, by restricting their ability to perform basic daily activities such as: working, walking, socialising, etc

(Vancampfort *et al*., 2017; Namisango *et al*., 2012; Merlin *et al.*, 2013). Despite many reports of pain interfering with function from developed countries (Parker et al., 2014; Merlin *et al.*, 2013), there are others indicating a different relationship in African countries (Mphahlele et al., 2012; Wahab et al., 2011). Pain seems not to interfere with function in African cohorts (Mphahlele et al., 2012; Wahab et al., 2011). Similarly, in this study some of the participants living with pain persisted through the pain. Persistence is defined as enduring pain for a longer than usual time a person is expected to (Hasenbring *et al*., 2012). Some participants in this study reported some level of persistence with regard to the pain they had by continuing with physical work-related activities despite feeling the pain.

Economic stress (for example, the need to work for money) may contribute to the highly active behaviour reported by men in this study. It was reported that the presence of food insecurity was associated with more physical activity in Ethiopian men, further supporting economic stress as the major contributor to the highly active behaviour in African men (Vancampfort *et al.*, 2018). Secondly, the need to just stay active was another factor contributing to the highly active behaviour in this cohort. Economic stress has been previously suggested as a reason for South African PLWH with pain to remain as objectively active as PLWH without pain (Vancampfort *et al.*, 2018; Wadley et al., 2016). It seems that for men in this study, keeping active is more about keeping working than avoiding revealing their HIV status.

5.2.6 Theme 3: Disclosure of pain in MLWH

Reasons for disclosing pain status to family members

Several reasons emerged as to why participants disclosed their pain status to different family members. Overall, it seemed like most participants involuntarily disclosed their pain statuses to their family members, except for a few. Also, participants preferred to disclose first to the people they lived with and spend most time with. There are some similarities between reasons for disclosing pain and HIV statuses in the cohort for this study. The most common reason for disclosure of both HIV and pain was that they

lived with those individuals. As a result, they could not hide either their HIV status or pain status and they also wanted the other people to know in case they got worse and needed support. These reasons for disclosure of pain status are similar to the ones reported by Maman and colleagues (2014) and Shrestha and colleagues (2019) for HIV status disclosure. The findings of this study contradict the findings of Wadley and colleagues (2016), that SA PLWH often didn't disclose their pain to their close family and friends. However, in this study some men with pain only told their partners that they had HIV when their partners tested positive for HIV. This really supports the idea that men did not disclose their pain unless they had to, by obligation.

Reasons for not disclosing pain status

About four participants in this study did not disclose their pain status for reasons such as: lack of trust, distant relationships, they did not understand the pain yet themself, and did not want to burden children. These results are different from the one by Nortjé and Albertyn (2015), where a cultural reason was given. Both in the Sesotho and Sepedi cultures, it is believed that men should not cry even when they are feeling pain, as crying is seen as a sign of weakness for a man. One reason for not disclosing pain status to children in this study, has been reported for not disclosing HIV status to children in another study. Avoiding burdening children was similarly reported by men in my study as was reported by some parents in a Chinese cohort (Zhou, 2012). Although stigma was the suspected reason for non-disclosure prior (Wadley *et al*., 2016), currently being a burden is more likely the reason for non-disclosure of pain.

5.2.7 Theme 4: Social support for MLWH

Types of support available as perceived by MLWH

All participants reported that they were able to recruit emotional and financial support from friends and family members. None of the eight participants with pain reported not receiving some form of support, despite that some did not disclose their pain to some people. It seems like, those who did not disclose their pain to some people, concealed their pain from people who were not necessarily their first line of support. Therefore,

not disclosing pain did not stop men this study from getting the support they need. Four of the eight participants reported that when their pain was at its worst in the past, they had asked for help. Social support was reported to have beneficial effects on mental and physical health of PLWH (Degroote, Vogelaers and Vandijck, 2014). A longitudinal study of social support and coping with HIV in 64 PLWH (39 were male) living in the US, suggested that negative health outcomes such as HIV-related health symptoms, may be buffered by social support (Ashton et al., 2005). In this study, it is not completely clear what impact social support had on pain. The impact of social support on pain in MLWH needs to be explored further.

5.3 Strengths, limitations, and recommendations

This was a mixed methods research design. Combining both, a quantitative questionnaire and qualitative interviews about pain, may have increased a chance of obtaining data that are grounded in the experiences of pain by the participants.

In my literature review, I identified a wide range of pain prevalence estimates. Accurate estimates are important for people designing health programmes to be cognisant of when identifying if pain is actually a problem and designing interventions. Over/under reports will lead to the wrong decisions. To assist with accuracy, I used a frequently used tool, the BPI, to assess pain prevalence. An appropriate sample size was determined through sample size calculation, so the pain prevalence is likely to reflect that of the larger population in the area. I have added data to the literature from a rural population, whereas most studies are from urban areas, and in men, whereas most pain prevalence studies from SA recruit more women (Parker *et al*., 2017; Wadley *et al*., 2016).

There was a high response rate for this study. This implies that the data presented may be a good representation of the study cohort. Data of men who may have had HIV for different lengths of time were collected at same time. These different durations of HIV for participants may have affected the experiences of MLWH for example. This

is because they have different experiences with regard to the time they have been living with HIV. Some have lived with HIV longer than others. The main language used to interview the men was English, despite it not being their first language. This may have affected the results, as some men may have not been able to fully understand the questions or express themselves in English. Although additional data on HIV negative men have been collected, it did not form part of the MSc. This resulted in a lack of comparison between HIV positive and HIV negative cohorts in terms of themes in the qualitative component of this study.

Future studies should interview participants in their first language. Also, men in this study were in a long-term study, and may have been on ART treatment and have received psychological support from the project. This support may have affected their experience of pain. Future studies should recruit participants from a population not under study. Also, future studies may explore the impact of being in a long-term study on pain. About half of the participants in this study did not know what caused their pain, thus more studies and health programmes are required to fully understand the aetiology of pain in PLWH. Despite reporting the use of pharmacological pain management strategies, MLWH and pain never accessed the health system for pain relief, talking to health professionals for help and exploring medical examination for pain. Therefore, there should be routine questions about pain in history taking of patients at health centres. Also, health care givers need to have knowledge about HIV and pain so that they can give better care to PLWH and pain. Since men in this study seemed comfortable to disclose their pain to the male researcher, it is recommended that, whenever possible, MLWH and pain are assessed for pain by male health care givers. Also, an educational program about HIV and pain should be provided for patients to improve their understanding of pain. However, this study provides the baseline of studies in MLWH.

5.5 Conclusion

The prevalence of pain was relatively low in this cohort of rural South African men involved in a longitudinal research study, and pain did not associate with having HIV.

Age and depression, however, associated with having pain. To my knowledge this is the first male-only study to investigate pain in MLWH using mixed methods.

There were no culturally-specific beliefs about pain but rather MLWH were unsure of the cause, or they had had physical injuries. Like objective data that have been published, there were similar reports of activity between men living with- and without chronic pain. Despite their high activity levels, the men with pain also reported that pain was interfering with their daily physical activities, but they persisted through the pain. Economic stress may be the reason for South African MLWH with pain to remain as active as MLWH without pain.

MLWH in this study disclosed their pain status mostly involuntarily to family members. Fear of being stigmatised did not seem to be a reason they did not disclose. MLWH may have concealed their pain because they were avoiding burdening their children. All MLWH in this study were receiving social support despite some of them not disclosing their pain status to some people.

This study provides the first data on pain beliefs, and factors affecting physical activity, pain disclosure and recruiting social support in South African MLWH. Previous studies have been limited by a reluctance of South African MLWH to report pain to a female researcher. A real strength of this study was having a male researcher to interview the men. These data are the next step in understanding the experience of pain in South Africans so that culturally-appropriate pain management strategies and programmes can be designed.

APPENDIX A

INFORMATION SHEET

Information sheet

Good day. My name is John Mohale. I am a student at the University of the Witwatersrand, Johannesburg. I would like you to participate in a research study to find out about pain and its effect on activity in people living with HIV

Why is the study being done?

The purpose of this study is to determine the factors influencing pain and activity in males living with HIV.

We are doing this study to:

- determine the prevalence of pain and quality of life of males living with HIV through questionnaires
- determine beliefs about pain, factors influencing the quality of life and experience of pain through In-Depth interviews.

Where will the study be done?

If you agree to be part of the study, your interview will be done in a private room right here at the Ndlovu Care Group Research Facility. It will be quiet and no-one will be listening to our conversation.

How long is this study?

The total amount of time required for your participation in this study (questionnaires and In-Depth interview section) is approximately 15 minutes for the questionnaire section of the study and approximately 45minutes for the In-Depth interview section of the study.

What do I have to do if I am in this study?

There are **2 parts of this study**: **1)** The short questionnaire section and **2)** The longer interview section (If you are interested in doing this section).

There will be separate informed consent procedures for each component. After the informed consent procedure you will be asked to do the following:

1. Questionnaire section
    - You will complete a basic demographic information form asking you some basic information about yourself.
    - You will complete the Euroqol-5D, this form measures health-related quality of life.

- To determine if you have pain, you will be asked to fill in the Brief Pain Inventory (BPI). It assesses pain intensity and how pain affects your daily activities.

2. The longer interview section

   This section is available if you are willing to talk about your experiences.

   - The interview will be audio-recorded for transcription, with your permission and then transcribed by trained transcribers.
   - During the interview, an interview-guide will be used to answer the following research questions: How does HIV and/or chronic pain, impact on your quality of life, and ability to perform daily activities? What are your beliefs regarding the cause of pain? How able are you to disclose your HIV and/or pain status to family, friends and the community? What practical, social and emotional support is available for you for living with HIV and/or pain?

What are the benefits of being in this study?

There are no benefits to you for participating in this study. But if you join the study you will help us in understanding the effects of pain on activity on people living with HIV, and hopefully manage the pain better in the future.

What are the risks of being in this study?

There are no risks for taking part in this study. However, some of the questions we ask may be about sensitive topics. If you start to feel uncomfortable, we can stop the discussion. You are allowed to withdraw from the study at any time.

What are your rights?

- You can decide not to be part of this study. The doctors and nurses will still help you even if you decide not to be part of this study
- If you decide to be part of the study, you can withdraw from the study at any time without stating any reason.
- If you decide to withdraw from the study the doctors and nurses will still help you.

Withdrawal from the study

As mentioned above, you can withdraw from the study at anytime without stating any reason. This will not affect your relationship with the doctors and nurses. If you decide

to withdraw from the study just tell me and the people assisting me in this project. Your participation in this study is appreciated and your information will be helpful in this study. The researcher is allowed to withdraw you from the study if the study causes you emotional distress (anxiety or stress), if your information may affect the validity of the study (If you are intoxicated or under the influence of drugs) and if you are disrupting the other participants or the research stuff.

Confidentiality

All your information will be kept a secret and will only be available to me and the research stuff assisting me. The information will not be available to your doctors and nurses. When you become part of the study, we will give you a study number, like a PIN number, so that the information you give us may not be linked to your name. All the information we collect for this study will be stored away safely. After the study, all the information we collect in this study will be combined and then the results presented to doctors and nurses.

What do I have to do if I have any questions or problems?

Before you agree to be part of the study and sign the consent forms, I want you to feel free to ask me any questions about the study. If you have any problems that you think may be related to being part of the study please contact me [Cell: 072 488 2834 or Email: johnjeymohale@gmail.com].

Study approval

A group of staff at the Ndlovu Care Group Research Facility and the University of Witwatersrand who look after patient's rights have checked my study to make sure it is fair and treats patients well. If you have any questions regarding the approval of my study please contact [011 717 1000].

APPENDIX B

INFORMED CONSENT FORM FOR QUANTITATIVE PART

Participant study ID no

CONSENT FORM

A study to investigate factors affecting the experience of pain and physical function in South African male living with HIV.

Part 1: Questionnaires

I, _____, have been told about the research that is trying to find out more about pain and its effect on activity in males living with HIV.

I understand that I will be asked about my pain and how it affects my daily activities.

I agree to take part in this research study by answering questions. I know that nobody is forcing me to do this and I can withdraw from this study at anytime without stating a reason.

I understand everything that has been explained to me and that I can ask questions about the study anytime.

Signed (subject) Date

Signed (researcher) Date

APPENDIX C

INFORMED CONSENT FORM FOR QUALITATIVE PART

Participant study ID no_____

CONSENT FORM

A study to investigate factors affecting the experience of pain and physical function in South African male living with HIV.

Part 2: Interview

I, _____, I have been told about the research study trying to find out more about pain and its effect on activity on males living with HIV through an In-Depth interview.

I understand that I do not have to take part in this section of the study if I am not comfortable with sharing my experiences about pain and HIV.

I understand the interview will be done in a quiet private room. Only the researcher and/or research stuff will be present during my interview.

I understand that my interview will be audio recorded with my permission and then transcribed.

I know I can withdraw from the study at any time without stating a reason.

_____

Signed (subject) Date

Signed (researcher) Date

APPENDIX D

BRIEF PAIN INVENTORY (BPI) SCALE

Appendix D: Brief Pain Inventory interference scale

Questionnaire

A. Pain

Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches).

Have you had pain other than these everyday kinds of pain for the last month?

Yes ☐ No ☐

Have you had pain most days for the last three months?

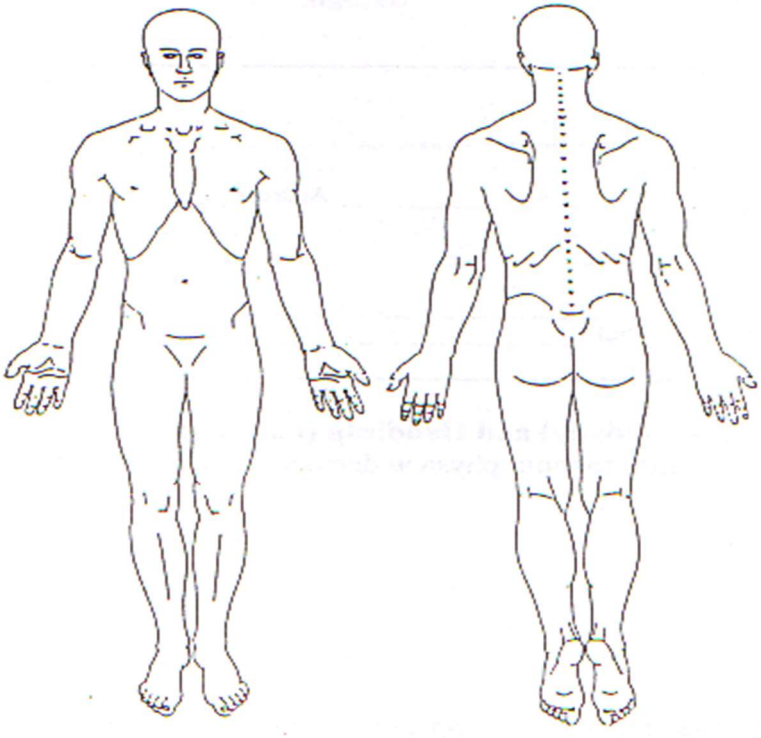
Yes ☐ No ☐

If yes to both, continue with B.

If no, continue to C.

B. Brief Pain Inventory

1. On the diagram, shade in the areas where you feel pain. Put an **X** on the area that hurts



the most.

2. Please rate your pain by circling the one number that best describes your pain at its ***worst*** in the last week.

0 1 2 3 4 5 6 7 8 9 10

No pain Pain as bad as you can imagine

3. Please rate your pain by circling the one number that best describes your pain at its ***least*** in the last week.

0 1 2 3 4 5 6 7 8 9 10

No pain Pain as bad as you can imagine

4. Please rate your pain by circling the one number that best describes your ***average*** pain in the last week.

0 1 2 3 4 5 6 7 8 9 10

No pain Pain as bad as you can imagine

6. Please rate your pain by circling the one number that tells how much pain you have ***right now.***

0 1 2 3 4 5 6 7 8 9 10

No pain — Pain as bad as you can imagine

7. Circle the one number that describes how much, during the past week, **pain** has ***interfered with*** your:

A. ***General Activity***

0 1 2 3 4 5 6 7 8 9 10

Does not interfere — Completely interferes

B. Mood

0 1 2 3 4 5 6 7 8 9 10

Does not interfere — Completely interferes

king Ability

0 1 2 3 4 5 6 7 8 9 10

Does not interfere — Completely interferes

nal Work (includes both work outside the home and housework)

0 1 2 3 4 5 6 7 8 9 10

Does not interfere — Completely interferes

E. ***Relations with other people***

0 1 2 3 4 5 6 7 8 9 10

Does not interfere — Completely interferes

ep

0 1 2 3 4 5 6 7 8 9 10

Does not interfere — Completely interferes

G. *Enjoyment of life*

0 1 2 3 4 5 6 7 8 9 10

Does not interfere — Completely interferes

C. Are you living with HIV?

Yes ☐ No ☐

APPENDIX E

DATA SHEET FROM THE NDLOVU RECORDS

See the attached excel spread sheet.

APPENDIX F

QUALITATIVE INTERVIEW GUIDE

Interview guide

The following interview guide, drawn from grounded theory, will guide the interview: Different sections will be asked depending on whether the individual has HIV and/or pain.

For all:

1. How long have you been living here?
2. What is it like to live in this community?
    a. Are there jobs?
    b. Do you have friends here?
    c. Will people help if things are difficult?
    d. What is the health care like?
3. Could you describe a typical day?
    a. What would you do on a normal day? How busy is it?
4. Using the EQ5D VAS for health-related quality of life (see end of document). Ask them to score how good or bad their perceived health is and ask why they gave that score.

    Why not higher?
    Why not lower?

For those with pain

1. Tell me about your pain?
    a. When did it start?
    b. What does it feel like?
        i. How would you describe it?
        ii. Is it there all the time? Does it come and go?
2. Why do you think you have pain?/What do you think is the cause of your pain?
3. Is there anything you do that relieves the pain? e.g. medications, activities/rest.

4. When the pain is bad:
    a. What are you still able to do?
    b. What activities can't you do?
    c. Are you able to ask for help? And if so, from whom?
5. Have you told your family/spouse/partner about your pain?
    a. If yes, how did they react when you told them about your pain?
        i. How did it feel to tell them?
    b. If no, can you tell me why you didn't tell them?
        i. How did it feel to not be able to tell them?
6. Have you told a doctor or nurse about your pain?
    a. If yes, can you tell me how that went?
        i. Were they able to help?
    b. If no, can you tell me why you didn't tell them?

For those with HIV

1. Would you tell me about your HIV?
    a. When did you find out you had it?
    b. How has life been since then?
    c. How does your HIV affect you? Does it stop you from doing anything?
2. How does it feel to be someone who has HIV in this community?
3. Have you told your family/spouse/partner about your HIV?
    a. If yes, how did they react when you told them about it?
    b. If no, can you tell me why you didn't tell them?
4. Can you ask for help if you need it? Is there support available?
    a. What kind?

For those with HIV *and* pain

1. How is it to have both HIV and pain?
2. Is there support available? Can you ask for help?
    a. What kind of support is there?
    b. Do you know of other people with both HIV and pain?

APPENDIX G

QUALITATIVE CODE BOOK

Community information section

Perceptions about community living in

- Perception of the community
  - I like living in this community
    - *"Most of the people who live here, they usually spend their time drinking. Things like that, you see? That's what they are doing, but I think it's a nice community from my side."* - IDI-Pain-J013-37-RP.
- Years of residence in the community
    - *"I think it's about 9 years now."* - IDI-Pain-J013-37-RP.

Job prospects

- Availability of jobs
  - No job opportunities in the community
    - *"Yes. It's difficult, even if … actually, if you don't have matric around here at home. You can … you won't work, if you want to work, you must go to …maybe Loskop dam."*- IDI-Pain-J011-36-P.
  - Types of jobs available in the community
    - ✓ Retail jobs
      - *"There's a mall there, there are lots of shops, that's retail. You can go there, maybe you will be lucky to find a job. But like working … let's say like for a big company or like a big firm. The opportunities are very low because there are … there's nothing, there's nothing. It's only that mall that side. That's all"*- IDI-Pain-J013-37-RP.
- Employment status
  - Unemployed
    - *"I: Okay. So just to remind, remind myself again. You said, that you are unemployed?*

      P: Yes, right now."- IDI-Pain-J013-37-RP.
  - Occupation
    - *"Uh, I do work it only depends what kind of job do I have that particular day as I said I'm in construction. I don't leave anything behind I do everything like bricklaying, plastering, painting, roofing, ceiling, tiling, plumbing"* - IDI-Pain-J018-37-RP.

Perceptions about friends

- Perception of friendship
  - Acquaintances
    - *"Yes. So if, if I'm saying I'm your friend (Clears throat) that means I will be there for you through thick and thin you know, I'd be supporting you every step of the way. Whatever it comes towards your way, whatever it comes towards my way then we will be there for each other. That's what I call friendship but knowing someone (clears throat) sorry, it is a friendship, yes but not that kind of friendship. So I wouldn't exactly say friends, I would say people I know."* - IDI-Pain-J018-37-RP.
- Friends are supportive
  - *"And, there was this other guy, who was sitting to next to me. The tall one, but he left now. He's one of my best friend. By the time he eh, I find out that, I was HIV; he was the first person that I talked to. And he was supportive too until today, you see. That's what I can tell you. They are supportive. And, they …there are people who like to go out, unlike me. I don't have that time; I don't go out … go every month. Like this month I'm going out, next week I'm going out eh, eh!"* - IDI-Pain-J013-37-RP.
- Self-perception since HIV diagnosis
  - Less social
    - *"I don't have that time; I don't go out … go every month. Like this month I'm going out, next week I'm going out eh, eh! I can't do that. I only go out maybe once after two months, that's when I go out."* - IDI-Pain-J013-37-RP.
- Number of friends
  - *"So, now I have only two friends."* - IDI-Pain-J011-36-P.
- Frequency of meeting with friends
  - *"Mm. Let me just say. We, we always see each other, every weekend actually."* - IDI-Pain-J013-37-RP.
- Topics discussed with friends
  - *"Eh. We usually talk about life. What maybe something that I want to do in life. How to get a job. Things like that. That's what we talk about."* - IDI-Pain-J013-37-RP.

Social support in the community

- Perception of social support in the community
  - *"(0.4) honestly, no one helps."* - IDI-Pain-J018-37-RP.
- Asking for help from community members
  - Change in social identity from one generation another
    - *"You say mostly like. Let's say, our parents, they did not grow up like us. They would be able to go to a neighbour and ask for sugar, you see. Ask for something, Me, I can't talk to my neighbour and ask for a cup of sugar."* - IDI-Pain-J013-37-RP.
- Reasons for avoiding asking for help from community
  - Gossip
    - *"There's no need going out and ask from other people because you don't know when you going out, what they are saying behind your back."* - IDI-Pain-J013-37-RP.

Health systems

- Perception of the community health care system
  - Positive perception about the clinic
    - *"Okay, there's one clinic that I always go to which is Kwarelagte uh, the staff there it's friendly, they treat us equally, they don't give us hassles you know, so I wouldn't complain about it. I don't know the other ones because I've never been there, so normally if my child comes down with something that need some medical attention. I take them to Kwarelagte because it's the one that I prefer."* - IDI-Pain-J018-37-RP.
  - Negative perception about the clinic
    - *"They are too slow, too slow. You can arrive at 6 in the morning. They open at 8, when they open at 8, you will be out there plus minus 1 to 2 o'clock, you see?"* - IDI-Pain-J011-36-P.
  - Positive perception about the hospital
    - *"Okay we have Philadelphia hospital uh, it's also good because my wife has been in and out there uh, having sickness that needed uh medical attention and they helped her uh the way they can. So at least now she's better, much, much better. So, I wouldn't complain that much about it, no."* - IDI-Pain-J018-37-RP.
  - Negative perception about the hospital

- *"At the end they will tell you, that they don't have any medication. And you came in there what time, about 6 o'clock you were still, you were there to …waiting for them to open. You will stay there until 4 o'clock. They will tell you there's no medication. That's bad. And if you go to these general hospitals, (0.4) they are not clean. If you go to these … to their holi … to these wards. you'll see, it's not clean. It's too dirty. But there are people who are working there. What are they doing?".* - IDI-Pain-J013-37-RP.

- Opinion about health care staff members
  - Positive perceptions about nurses
    - "Okay, there's one clinic that I always go to which is *Kwarelagte* uh, the staff there it's friendly, they treat us equally, they don't give us hassles you know,." - IDI-Pain-J018-37-RP.
  - Negative perceptions about nurses
    - *"You see, because they are not like the older ones, the older ones they would have time for you. These younger ones they don't have that time. They don't have … they are not even patient with anyone. And, they are very rude, that's my problem. But, these older one who came in before these younger ones are they … are the ones that I prefer. Unfortunately, they are too old, they can't work until that long. But, they are the ones that I prefer."* - IDI-Pain-J013-37-RP.
  - Positive perceptions about doctors
    - *"Doctors are very good; doctors are very, very good."* - IDI-Pain-J051-40-R.

<u>Everyday activities</u>

- Description of a typical day
  - *"Let me just say, every time I wake up. I'm thinking of fixing something. I always fix some things in my house"* - IDI-Pain-J013-37-RP.
- Types of activities done on a typical day
  - *"At my job, I don't work hard, I wake up … I work hard, if I go to the mountain and dig up some medicines, you see. But when I'm turn back there …maybe I go Monday and maybe I'm going to crush those medicines, maybe Wednesday. Uh, it's not a hard job"* - IDI-Pain-J011-36-P.

- Description of a busy day
  - *"Eh. Let me just put it like this. Like last week I was busy. And I was busy with the … I was busy cutting the trees. I spent almost the whole day because I have a lot of trees in my yard. I was busy cutting trees almost from 7 o'clock until late, until 5 o'clock I think, busy cutting the trees. That was … I think that was my busy day."* - IDI-Pain-J013-37-RP.
- Types of activities done on a busy day
  - *"Eh. Let me just put it like this. Like last week I was busy. I was busy cutting the trees. I spent almost the whole day because I have a lot of trees in my yard. I was busy cutting trees almost from 7 o'clock [am] until late, until 5 o'clock[pm] I think, busy cutting the trees. That was … I think that was my busy day."* - IDI-Pain-J013-37-RP.

Living with HIV Section

Experience of living with HIV

- Perception of living with HIV
  - The same as living without HIV
    - *"Eh. What I can say for my side. I won't talk about anyone else. From my side, I think it's like the same as with a person who is HIV negative. I think it's the same because what you can do I can still do it, you see. I don't see any difference, as long I can take my medication, that's all. I don't see any difference because if you can ride a bike, I can also ride a bike. If you can jog, I can also jog, you see still the same. Nothing changes, it's only the negative and the positive [HIV status]."* - IDI-Pain-J013-37-RP.
- Year of diagnosis
  - *"Mmh, I think it was early 2014, I think."* - IDI-Pain-J018-37-RP
- How the diagnosis came about?
  - *"I got sick neh? After I got sick, I heard about this Ndlovu centre think and I did come here with my wife. Did test, we find out that we are positive."* - IDI-Pain-J013-37-RP.

Disclosure of HIV status

- Who you told
  - Family
    - *"We had to go to Witbank, me and my wife. (Chair movement) Eh, I think it was on Friday, yes, it was on Friday. On Friday, I then told my mom, to call my sisters because they are not staying with them. They also have their own places. Then they called them, [they] did come. Then I put them all, sat them down then I decided to tell them. Hey guys, it's like this, like this, like this, you see?"* - IDI-Pain-J013-37-RP.
  - Friends
    - *"I: Okay cool. So I just want to know uhm, with your friends? Do they know your status?*

      P: Yeah. He's the only one who knows. I think this one and the other one in Witbank there's only two of them who knows about my status." - IDI-Pain-J013-37-RP.
- Order of status disclosure
  - *"Yes. I started with my family. And the person who told my kids, it was my wife if I remember correctly, because I was not around."* - IDI-Pain-J013-37-RP.
- Reason for disclosing HIV positive status
  - A trusted friend
    - *"He's one of my best friends. By the time he eh, I find out that, I was HIV; he was the first person that I talked to. And he was supportive too until today, you see."* - IDI-Pain-J013-37-RP.
  - Encouraged by his wife
    - *"But my wife decided, no it's best if we tell them. What if something happened to us? They won't know what happened, you see?"* - IDI-Pain-J013-37-RP.
- Feeling after disclosure of HIV positive status
  - *"Eh. After talking about … eh after talking with my parents actually, I felt okay. And I was happy that they did support me. They did give me that support; you see? I felt happy."* - IDI-Pain-J013-37-RP.
- Reaction to HIV positive status disclosure
  - Shocked but supportive
    - *"Yes, they [Parents] did become shocked. But after, after, after I told them, they were supportive."* - IDI-Pain-J013-37-RP.

- Didn't disclose HIV status at work
  - *"I: Negative? Uhm, okay so at work does anyone know about your status? P: No, no."* - IDI-Pain-J013-37-RP.
- Reason for not disclosing HIV positive status
  - Fear of being judged
  - *"Yeah, I don't hide, it's just that in the community you know, people judge one another. So, if maybe your neighbour knows your status then they going to start spreading the news and the people will be saying vile words. The next thing you get angry then you start hating people and you start causing fights, you know, something that is not necessary to you."* - IDI-Pain-J013-37-RP.
  - Fear of his own response to others' reactions
    - *"Yeah, I don't hide, it's just that in the community you know, people judge one another. So, if maybe your neighbour knows your status then they going to start spreading the news and the people will be saying vile words. The next thing you get angry then you start hating people and you start causing fights, you know, something that is not necessary to you."* - IDI-Pain-J013-37-RP.
  - Avoiding burdening family members
    - *"So I don't want to stress my children, no."* - IDI-Pain-J018-37-RP.
  - Stigma

<u>Effect of living with HIV</u>

- How living with HIV affected the relationship
  - Didn't affect my relationship with my spouse
    - *"It never did, you know what I can say neh, you see that eh woman I'm staying with for my side I always tell her, even my parents I always say; I think for me, she was a gift from God. Why I'm saying that because even if I did finally find out okay, we were HIV positive things like that. She never judged me even once."* - IDI-Pain-J013-37-RP.

- Effect of living with HIV on work
  - No effect on the participant's job

- *"It didn't, it didn't because it's not something that I always put it on my mind. Like I say I am just the same as you I don't put it on my mind. I don't stress about it."* IDI-Pain-J013-37-RP.

- Physical effect of living with HIV
  - No physical change after taking treatment
    - *"I was getting tired, sleeping a lot uh, losing weight but as soon as I started taking treatment then everything went back to normal. I got that energy that I lost, it was back then I didn't sleep that much. I was sleeping normally like everybody does. So (.) physically it hasn't uh, uh changed anything, no."* - IDI-Pain-J018-37-RP.
- Emotional effect of living with HIV
  - Not affected emotionally
    - "*Then that's when I got tested then I knew my status, then I accepted immediately."* - IDI-Pain-J018-37-RP.
- Social effect of living with HIV
  - No effect on social life
    - *"I: Okay and then socially?*
      P: Uh, no." - IDI-Pain-J018-37-RP.
- Sexual effect of living with HIV

<u>Social support</u>

- Source of support
  - Health care workers
    - *"So, if I need help I go to the clinic then explain my problem. You know I've been facing these difficulties 1, 2,3 - 1,2,3 you understand. Then the doctor, she's trained for that, you understand? Then he will know what to say to me, if he can't then he will refer me to relevant person right now. If you go to that door you'll find someone there who's going to help you with your problem, then that's why I go there."* - IDI-Pain-J018-37-RP.
- Type of social support
  - Emotional support
    - *"In the community eh, in the community think I rather maybe come here [Ndlovu Research Center], because there is someone, maybe a social worker."* - IDI-Pain-J013-37-RP.

Living with pain section

- Perception of living with pain
-
- Experience with Pain
  - *"P: Yes actually. I've been experiencing this pain for more than a year now.*
    I: Okay?
    P: Yes. So every day that passes by the pain it's getting worse, uh okay." - IDI-Pain-J018-37-RP.
- Date began feeling pain
  - *"(Clears throat) eish my brother, that one it's a tough one okay uh, I started experiencing the pain on the 27th of May last year"* - IDI-Pain-J018-37-RP.
- Frequency of pain

"I: Okay. And then let's say in a week, how often do you feel the pain?
P: Mmh, let's say eh, I can say maybe, I can feel it for 4 days sometimes." - IDI-Pain-J013-37-RP.

- Causes of pain
  - Car accident
    - *"I think the accident is the one that caused the pain."* - IDI-Pain-J018-37-RP.
  - Injured while working
    - *"I fell from the top of the scaffold, I hit my back. That's when it started." - IDI-Pain-J013-37-RP.*
  - Unknown cause
    - *"P: Yes. The one in the back just happened naturally. It's just a pain that I have.*
      I: Mmh.
      P: I don't know what caused it, because it can't be the accident, no." - IDI-Pain-J018-37-RP.
- Dealing with the pain
  - Hitting the body against the wall
    - *"When that pain starts, I go to the wall and beat the wall with my back"* - IDI-Pain-J011-36-P.
  - Medication

- *"When I drink eh, some eh, pain killers, it [pain] stops"* - IDI-Pain-J011-36-P.

  - Relaxing
  - *"I have to relax until I fall asleep then when I wake up in the morning it would be much better."* - IDI-Pain-J018-37-RP.

- Pain interference with Daily Activities
  - Persistence
    - ✓ Reasons for working despite the pain
  - *"Let's say I'm busy with something and I want to finish (0.4) I cannot let that pain stop me when I am … I would just keep doing what I want to do until I'm done."* - IDI-Pain-J013-37-RP.
- Asking for help during pain experience
  - *"I think; it was here in my house. Yes, it was here in my house. I was asleep, it was in the morning, Yes. I was asleep. My wife already woke up, I had … I was supposed to work afternoon. It just hit me like something was pulling my back. I couldn't wake up there. I had to call my wife from outside, using my phone. Lucky enough she had her phone with her … to come and help me."* - IDI-Pain-J013-37-RP.

<u>Pain status disclosure</u>

- Who you told
  - Family
    - *"I: Your wife?*
      P: Yes, she does know about it.
      I: She knows? Okay, and then your children?
      P: They know about it." - IDI-Pain-J018-37-RP.
  - Other
    - *"I: Uhm, okay. So with your friends, do they know about your pain?*
      P: It's only this guy who was here because I used to work with him." - IDI-Pain-J013-37-RP.
- Severity of pain
  - *"I'm still trying to understand it because it just comes. It comes very bad because it hits me hard, that it's even hard for me to breathe."* - IDI-Pain-J018-37-RP.
- Reaction after pain status disclosure

- Family member's reaction
  - ✓ Sad
    - ➢ Children wanting to take responsibility
      - *"I: Okay. So. How, how did your son react when he found out that you have the pain?*

        P: Ah! It was sad, it was sad. He said that when he grows up he will take me to a special doctor, you see. I said; "No my boy, just go to school and read maybe you will be a doctor, one of the good days. Maybe you will help me". - IDI-Pain-J011-36-P.
- Other
  - ✓ Good reaction
    - *"No, he [participant's friend] never gave me any bad reaction. Because even him, he also told me the same advice my parents told me. That you must go to the doctor, things like that."* - IDI-Pain-J013-37-RP.

- Participant's feeling after disclosing pain status
  - After disclosing to family members
    - ✓ Feels comfortable
      - *"I feel comfortable when I tell her [his wife] about my pains. Because, when I tell her at least there is someone I can talk to about my problems, you see."* - IDI-Pain-J011-36-P.
- Reasons for disclosing pain status
  - Disclosure to family members
    - ✓ Pain got worse
      - *"Because I was suffering with that pain. It was getting worse, it was getting worse, it was getting worse."* - IDI-Pain-J011-36-P.
  - *Disclosure to others*
    - ✓ *Through work*
      - *"At work, because we were … we used to work together."* - IDI-Pain-J013-37-RP.
- Reasons for not disclosing pain status
  - Lack of trust for some people
    - *"You see, it's like they are my friends but there are things I won't be able to share with them. Like I share with this guy [best friend], that's how it is. You won't trust all your friends."* - IDI-Pain-J011-36-P.

Experience of living with both HIV & pain

- Perception of living with HIV and pain
  - Only the pain bothers me and not HIV
    - *"I've accepted my status the way it is. So it's not something that bothers me anymore, but the pain it's unbearable because it's something that reminds you every now and then. Even if you don't want to think about it, it just comes and says; "Don't forget that I'm still here". it's [pain] the one that's giving me a hard time but combining both of them or comparing uh-uh the status doesn't have any impact on me, uh-uh."* - IDI-Pain-J018-37-RP.
  - *It is stressful*
    - *"It's stressful. It's, it's too much stress cause remember like I'm living with HIV, I have to drink my medication every night. On the other side when this pain comes … maybe I had that pain for a week. That means I have to drink that medication for HIV, I have to drink the pain killers for a week, you see? For me it becomes stressful because my body … that medicine too much eh, let me say like pills in my body … like when I'm going to the toilet. Maybe to pee you will hear that no this guy drinks too much pills. You see for me it becomes too stressful."* - IDI-Pain-J013-37-RP.
- People you know who live with both HIV and pain
  - Knowing someone living with HIV and Pain
  - How you found out about them?
  - How do you feel knowing others living with both HIV and Pain?

APPENDIX H

ETHICS CERTIFICATE

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

R14/49 Dr Antonia Wadley et al

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M180652

NAME: (Principal Investigator)	Dr Antonia Wadley et al
DEPARTMENT:	School of Physiology Ndlovu Care Group Research Facility Elandsdooren, Limpopo
PROJECT TITLE:	Investigation of factors influencing the experience and disclosure of pain, and daily activity in rural South Africans living with and without HIV
DATE CONSIDERED:	29/06/2018
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	
APPROVED BY:	Professor CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	20/08/2018

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the Third Floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in June and will therefore be due in the month of June each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG	HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

06/01/2021

Dr A Wadley, et al
School of Physiology
Medical School
University

Sent by e-mail to: Antonia.Wadley@wits.ac.za

Dear Dr Wadley

Re: **Protocol Ref No: M180652**
Protocol Title: *Investigation of factors influencing the experience and disclosure of pain and daily activity in rural South Africans living with and without HIV*
Principal Investigator: Dr A Wadley, et al

I refer to our recent discussions and write to confirm that as Mr J Mohale (s/n 2056645) and Ms A Ratshinanga (s/n 588238) were listed as co-investigators on your original ethics application, the clear implication on the Clearance Certificate was that they were covered under "*et al.*"

I see no real need to issue separate Certificates in their names and indeed we cannot do so, as we do not issue retrospective approvals.

Yours Sincerely

I. Burns

.....
Mr I Burns
For the Human Research Ethics Committee (Medical)

.....
Dr N Naran, Co-Chairperson, Human Research Ethics Committee (Medical)

APPENDIX I

THEMES AND SUBTHEMES TABLE

Theme 1: Experiences of living with pain among MLWH and pain

- *Perceptions of living with pain in MLWH*
- *Perceived causes of pain in MLWH*
- *Pain management in MLWH*

Theme 2: How living with chronic pain affect daily activity in MLWH

- *Physical activity of MLWH on a typical day*
- *Physical activity of MLWH on a busy day*
- *Pain interference with daily activities in MLWH*

Theme 3: Disclosure of pain in MLWH

- *Reasons for disclosing pain status to family members*
- *Reason for disclosing HIV positive status.*
- Voluntary disclosure of HIV status
- Involuntary disclosure of HIV status
- *Reasons for not disclosing pain status*

Theme 4: Social support for MLWH

- *Emotional support*
    - *Emotional support from family*
    - *Emotional support from friends*
    - *Emotional support from health care worker*
- *Financial support from friends*
- *Being able to ask for help during pain*

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