FACTORS INFLUENCING PAIN AND ACTIVITY IN RURAL SOUTH AFRICAN WOMEN LIVING WITH HIV

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DECLARATION

I, Andani Ratshinanga, declare that this Thesis/Dissertation/Research Report is my own, unaided work. It is being submitted for the Degree of Master of Science in Medicine at The University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.

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(Signature of candidate)

22____________day of ________July_ 2022__in Johannesburg

Dedication

I dedicate this manuscript to all those I lost during the process of completing my Masters. You are dearly missed Comrades, until we meet again. With love, Andani

Presentations arising from this research project

1. Andani Ratshinanga. “They must know so they can assist me when the pain attacks”. A qualitative study of pain disclosure behaviour in South African women living with HIV. Oral presentation at the first virtual AAPS-PSSA congress, Johannesburg, South Africa. September 2021.
2. Andani Ratshinanga. Pain disclosure behaviour and impact in South African women living with HIV. Oral presentation at the PainSA virtual congress, Johannesburg, South Africa. September 2021.

ABSTRACT

Previous data from South Africa have suggested that people living with HIV (PLWH) and chronic pain remain as physically active as PLWH without pain, possibly due to HIV stigma. Additionally, HIV stigma may motivate PLWH not to disclose their pain, which was hypothesised to reduce the ability of PLWH to recruit social support. This mixed methods study explored factors influencing pain and activity, including pain disclosure and social support, in rural South African women living with HIV (WLWH). Firstly, quantitative methods were used to determine the prevalence and clinical and demographic associations with both pain and pain intensity. The Brief Pain Inventory was used to assess pain prevalence, intensity, and location in 125 women. Pain prevalence was 50% (63/125). HIV status, age, education, employment, current $CD4^+$ T- cell count depressive symptoms were not associated with pain (ps>0.05). Education, employment, and HIV status did not associate with pain intensity. The pain was of moderate to severe intensity (5(4-6)) (median (IQR)). The most common pain sites were the chest (33%) and lumbar spine (24%). Secondly, from the 125 women recruited, twenty WLWH with pain (10) and HIV without pain (10) were recruited for in-depth, semi-structured qualitative interviews to explore beliefs about pain, factors influencing activity, disclosure of pain and social support. Qualitative interviews were transcribed and analysed using thematic analysis. Severe pain episodes caused a high interference with activity in WLWH and pain. Pain disclosure was high (9/10) and motivated by the need for social support. HIV stigma and fear of others' reactions did influence pain disclosure. WLWH did not disclose to everyone (selective disclosure) or did not inform people timeously of painful periods (partial disclosure). Disclosure to health professionals was motivated by the need for pain treatment. Disclosure of pain typically led to increased social support (7/10), such as disclosure targets taking over their duties of daily living. Participants felt liberated after disclosure (6/10), but negative impacts of disclosure included emotional impact (worry, sadness) on those disclosed to (6/10) and participants feeling like a burden (2/10). Results from this first qualitative study on pain in rural South African WLWH and pain elaborate on previous findings. That is, the pain did affect activity in women but only during painful episodes. Women were highly likely to disclose their pain to others and thus were able to recruit social support. There were both positive and negative impacts of disclosing pain, and WLWH tried to prevent negative impacts by selectively or partially disclosing their pain to others.

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Finally, To God and Gospel music. I am here today because I believe You (God) anchored me. When I had no words, I sang praises to You and felt a sense of peace, especially when I was grieving those I lost or a section in my thesis I thought I had completed but the feedback said

"No". Thank you, God, thank you Jesus and all that helped me in this journey which at times I felt would never end.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency syndrome
ART	Antiretroviral therapy
BPI	Brief Pain Inventory
d4T	Stavudine
HAART	Highly active antiretroviral therapy
HIV	Human immunodeficiency virus
HR-QoL	Health related quality of life
MLWH	Men living with HIV
NRTIs	Nucleoside reverse transcriptase inhibitors
PHQ-9	Patient Health Questionnaire-9
PLWH	People living with HIV
PTSD	Post-traumatic stress disorder
WHO	World Health Organization
WLWH	Women living with HIV

INTRODUCTION

In this section, I introduce the literature on pain in people living with HIV (PLWH) including the prevalence, etiology and how pain impacts their lives. I also discuss the under-treatment of pain in PLWH and give an overview of the issue with the treatment of pain in PLWH.

The prevalence of pain in the general population is between 10%-40% with the prevalence of pain being reported to be higher in women compared to men and with the prevalence increasing with age (Breivik *et al.,* 2006; Johannes *et al.,* 2010; Langley, 2011; Jackson *et al.,* 2014; Mansfield *et al.,* 2016). Studies on people living with HIV (PLWH) from developed and developing countries have reported a prevalence of pain in PLWH between 60-80% (Parker, Stein and Jelsma, 2014; Lawson *et al.,* 2015; Sabin *et al.,* 2018; Nkhoma *et al.,* 2019), which is higher than the prevalence of pain in the general population (Breivik *et al.,* 2006; Johannes *et al.,* 2010; Langley, 2011; Jackson *et al.,* 2014; Mansfield *et al.,* 2016). Pain in PLWH has also been reported to be moderate to severe, affecting several anatomical sites (Parker, Stein and Jelsma, 2014; Lawson *et al.,* 2015). -

There are several reasons why pain may be higher in PLWH: HIV, or the immune response to it, maybe neurotoxic, causing the degeneration and damage of nerve fibres resulting in the development of HIV-associated sensory neuropathy, which is a common complication in PLWH (Kamerman *et al.,* 2012; Wadley, Cherry and Kamerman, 2011). Another reason for the increased pain in HIV may be due to the side effects of antiretroviral therapy (ART) (Maritz *et al.,* 2010; Menezes *et al.,* 2011; Wadley, Cherry and Kamerman, 2011), although less neurotoxic ART combinations are being used since these papers were published (WHO 2010; WHO 2017). Lastly, pain experienced by PLWH may also be due to opportunistic infections, for example, tuberculosis, pneumonia, and cancer, due to the decline of their immune system when HIV is not controlled (Grulich *et al.,* 2007; Benson *et al.,* 2009).

Individuals living with pain and HIV tend to report more than one anatomical pain site (Parker, Stein and Jelsma, 2014), with medians ranging from 1 - 2.5 (Lawson *et al.,* 2015; Uebelacker *et al.,* 2015; Parker, Jelsma and Stein, 2017), with the most reported anatomical pain sites being the head, neck, lower limbs, back pain, shoulder and abdominal pain (Parker, Stein and Jelsma, 2014; Lawson *et al.,* 2015; Uebelacker *et al.,* 2015; Parker, Jelsma and Stein, 2017). Pain in the lower limbs reported by PLWH may be caused by HIV-associated sensory neuropathy (Wadley, Cherry and Kamerman 2011).

Pain in PLWH has been reported to negatively impact all aspects of the health-related quality of life (HR-QoL) of PLWH, including physical activity and mood (Namisango *et al.,* 2012; da Silva *et al.,* 2017; Pillay *et al.,* 2018). Moderate to severe pain intensity in PLWH has also been reported to cause significant interference with activity (Newshan, Bennett and Holman, 2002; Nair *et al.,* 2009; Merlin *et al.,* 2012; Scott *et al.,* 2019). A systematic review from the United Kingdom (UK) also found that pain in PLWH was associated with several psychological disorders like depression, anxiety, and post-traumatic stress disorder (PTSD), with a bidirectional relationship reported by some studies (Scott *et al.,* 2018).

Despite the high prevalence of pain and its impact on PLWH, the systematic review by Parker and colleagues (2014) reported on the undertreatment of pain in PLWH. In both developed and developing countries, only a tiny percentage of PLWH and pain were said to be receiving adequate pain treatment (Breitbart, Rosenfeld, *et al.,* 1996; Nair *et al.,* 2009; Narasimooloo, Naidoo and Gaede, 2011). In contrast, a large percentage of PLWH and pain were receiving analgesics that were inadequate to treat their pain (Parker, Stein and Jelsma, 2014). Part of the problem with the undertreatment of pain may be that there are not many proven effective treatment options for chronic pain in PLWH (Merlin *et al.,* 2016). Furthermore, most research on treating HIV-related pain has focused on neuropathic pain and not on pain of unknown aetiology (Phillips *et al.,* 2010).

Previous studies have explored pharmacological treatments like gabapentin and pregabalin, which are effective in other pain states for treating painful neuropathy in PLWH and found that gabapentin and pregabalin were no more effective than a placebo treatment (Hahn *et al.,* 2004; Simpson *et al.,* 2010). In contrast, some studies investigated non-pharmacological pain treatments like cognitive-behavioural therapy to treat pain in PLWH (Evans *et al.,* 2003; Uebelacker *et al.,* 2016). Both studies reported small improvements in pain in PLWH, but these studies were affected by a high drop-out rate and small sample size (Evans *et al.,* 2003; Uebelacker *et al.,* 2016). Indeed, a preliminary analysis of a six-week peer-led exercise and education intervention using a workbook to manage pain in 27 women living with HIV (WLWH) from South Africa reported improvements in the prevalence of pain, pain intensity and pain interference score (Parker, Jelsma and Stein, 2016).

We need to remember that using non-pharmacological pain treatments may not be easily transferrable between contexts/countries due to the different sociocultural beliefs about pain (Parker, Jelsma and Stein, 2016; Parker *et al.,* 2019). Interventions that are developed in developed countries may need to be performed differently in developing countries. To determine which interventions would be feasible in different cohorts, further studies on non-pharmacological pain treatments need to be done, including feasibility/acceptability studies. Before this process can start, however, qualitative studies are required to describe the pain experienced in the cultural contexts of each country. This dissertation describes a mixed-methods study in a South African cohort of women living with HIV.

CHAPTER 1:

LITERATURE REVIEW

The HIV pandemic has been a threat to global health care for decades. It has caused high mortality and morbidity and threatens public health. Southern Africa has the highest number of individuals living with HIV (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2019). South Africa (SA) has the fourth-highest HIV prevalence in the world and due to the large size of the population, has the highest number of individuals living with HIV (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2019). According to the Centre of Disease Control (CDC) 19.1 % of adults in SA live with HIV (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2019). Approximately 4000 new cases are reported in women aged 14-25 weekly (UNAIDS, 2022), and, in some regions, more than half of the women population is HIV positive (Kim *et al.,* 2021). This shows how much of a burden HIV is on the SA population.

SA has an extensive ARV treatment programme and so HIV is no longer a terminal illness and people living with HIV (PLWH) now live into old age. Managing HIV is now about managing the comorbidities associated with HIV, such as pain, and this endeavour is key to creating a more sustainable life for people with HIV. This literature review will discuss the prevalence of pain in PLWH and factors associated pain.

1.1The prevalence of pain and pain intensity in PLWH

A systematic review, the highest level of evidence (The Oxford 2011 levels of evidence) by Parker and colleagues (2014), reported on the prevalence of pain from 28 articles representing 6814 PLWH published between March 1982 and March 2012 from both developing and developed countries. The prevalence of pain reported in this review ranged from 54%-point prevalence (at the time of the interview), 55% in a recall period of 1 week, 58% for two weeks, 68% for one month, 83% for three months and 72% for a 6-month recall period. Thus, the pain prevalence rates from the studies included in the systematic review ranged from 53%-83%, and in additional studies (see Table 1 and 2), prevalence rates have gone from 76%-98% (Lawson *et al.,* 2015; Sabin *et al.,* 2018; Nkhoma *et al.,* 2019). There are several potential reasons for this wide range of prevalence rates reported. These include study sample sizes (which range from 41-1325), differing recall periods (including pain on the day of the interview vs one week vs two weeks vs three months vs six months), and the population being studied (differing by sex makeup, age, geographical area), differing severity of HIV, and differing tools for assessing pain (including pain-specific validated questionnaires, pain diaries and interview guides).

Table 1 includes articles from developing countries including those from the Parker *et al,* 2014 review and those published since. Table 2 includes articles from developed countries published since the Parker *et al,* 2014 review.

Table 1: Pain prevalence in PLWH from developing countries

Reference (year)	**Setting**	**Pain prevalence (Recall period)**	**Instrument for measurement**	**Sample size**	**Disease stage (%) (WHO$^{\mu}$) (CDC$^{\infty}$)**	**CD4^{+} T-cell count (cells/mm^{3})**	**ART use (%)**
(Norval, 2004)	South Africa	98% (point prevalence)	Interview	103	AIDS^	missing	3.9
(Mphahlele, Mitchell and Kamerman, 2012)	Urban and rural South Africa	Urban: 56% Rural: 72% (Point prevalence) **and** Urban: 77% Rural: 67% (1 month)	WBPQ*	Urban: 396 Rural:125	Missing	Urban: 200 (99-309) Rural: 199 (120-346)	Urban: 68 Rural: 53
(Narasimooloo *et al.,* 2011)	South Africa	91% (point prevalence)	BPI$^{\#}$	100	Stage II (3%)$^{\mu}$ Stage III (29%)$^{\mu}$ Stage IV (68%)$^{\mu}$	<200 cells/mm^{3} (70)	34
(Wahab and Salami, 2011)	Nigeria	28% (2 weeks)	BPI	79	Stage I (43%)$^{\mu}$ Stage II (35%)$^{\mu}$ Stage III(18%)$^{\mu}$ Stage IV (4%)$^{\mu}$	234.9 ± 218	missing
(Azagew *et al.,* 2017)	Ethiopia	51% (point prevalence)	BPI	422	Stage I/II (81.9%)$^{\mu}$ Stage III/IV(12.1%)$^{\mu}$	≤200 cells/mm^{3} (59)	93
(Nair *et al.,* 2009)	India	In-patients 67% (1 week) Out-patients 25% (1 week)	BPI	42 in-patients 98 out-patients	Stage I (49%)$^{\mu}$ Stage II (16%)$^{\mu}$ Stage III (35%)$^{\mu}$ Stage IV (38%)$^{\mu}$	missing	60
(Nkhoma *et al.,* 2019)	Kenya	61% (1 week)	MSAS-SF	224	Stage I-II (13%) Stage III-IV (87%)$^{\mu}$	349.5 (223.5-519)	92

WBPQ, Wisconsin Brief Pain Questionnaire; MSAS, Memorial Symptom Assessment Scale; BPI**,** Brief Pain Inventory; WHO**,** World Health Organisation; CDC, Centers for Disease Control and Prevention. CDC stages indicate increasing severity, with category one asymptomatic and category 3 being AIDS.

^CDC and AIDS are equivalent.

Articles include those from developing countries included in the Parker, 2014 review and those published since

Table 2: Pain prevalence in PLWH from developed countries

Reference (year)	**Setting**	**Pain prevalence (Recall period)**	**Instrument for measurement**	**Sample size**	**Disease stage (%) (WHO$^{\mu}$) (CDC$^{\infty}$)**	**CD4$^+$ T-cell count (cells/mm^3)**	**ART use (%)**
(Lawson *et al.,* 2015)	United Kingdom	63% (point prevalence)	Validated questionnaire	859	CDC(A) (58%)$^{\infty}$ CDC(B) (23%)$^{\infty}$ CDC(C) (19%)$^{\infty}$	<200 cells/mm^3 (59(7.1)) 200-394 cells/mm^3 (164(19.6) ≥ 350 cells/mm^3 (614(73.4))	76
(Sabin *et al.,* 2018)	United Kingdom & Ireland	Older PLWH: 70% Younger PLWH: 63% (1 month)	Validated questionnaire	1325	Missing	626 (478-810)	98

Articles include those published since the Parker, 2014 review

1.2 Factors associated with pain in PLWH

This section covers the socio-demographic, psychological, clinical and biological factors associated with pain in PLWH. Before I start on the factors related to pain PLWH, I will first cover factors associated with pain in general populations.

Several epidemiology studies have reported on the socio-demographic, psychological, clinical, and biological factors that are risk factors for pain in people living with chronic pain in the general population (Johannes *et al.,* 2010; Van Hecke, Torrance and Smith, 2013; Jackson *et al.,* 2014; Mills, Nicolson and Smith, 2019). Studies have shown that socio-demographic factors associated with pain in the general population have remained constant regardless of the population studied (Johannes *et al.,* 2010; Van Hecke, Torrance and Smith, 2013; Jackson *et al.,* 2014; Mills, Nicolson and Smith, 2019). The most frequently reported socio-demographic factors that are associated with chronic pain in the general population are older age, being female, and a low socio-economic status assessed by employment status, level of education and residential area (Johannes *et al.,* 2010; Van Hecke, Torrance, and Smith, 2013; Jackson *et al.,* 2014; Mills, Nicolson and Smith, 2019). People with lower socioeconomic status tend to have lower income, reduced access to good healthcare or medical aid/health insurance and lack the information or education regarding their pain syndromes and how to treat their pain (Grey and Berger, 2007).

Several psychological factors like anxiety, depression, PTSD, and negative beliefs about pain have been reported to be associated with pain, with several studies reporting the high prevalence of depression, anxiety, PTSD, and other psychological disorders in individuals living with chronic pain (Van Hecke, Torrance and Smith, 2013; Mills, Nicolson and Smith, 2019). The prevalence of pain is also influenced by chronic diseases like cardiovascular disease, musculoskeletal disorders, and cancer (Van Hecke, Torrance and Smith, 2013; Mills, Nicolson and Smith, 2019).

1.2.1 HIV disease

There are two classification systems for HIV disease stages. One is based on the recommendation of the Centres for Disease Control (CDC), which is based on the presence or absence of AIDS-defining illnesses (Appendix 3A) and CD4$^+$ T-cell count, with a CD4$^+$ T-cell count below 500 cells/mm3 indicating disease progression (Appendix 3B) (Castro *et al.,* 1993).

The second classification is The World Health Organization (WHO) HIV disease classification system, which consists of 4 stages (Stage I, II, III, and IV) (Weinberg and Kovarik, 2010). This system uses clinical signs and CD4+ T-cell count to classify into stages (Appendix 3D).

1.2.1.1 The association between pain and CD4$^+$ T-cell count

CD4$^+$ T-cell count is an important marker of immune function in PLWH (Bleesing *et al.,* 2000; Egger *et al.,* 2002; Pattanapanyasat and Thakar, 2005; Phillips and Lundgren, 2006). The depletion of CD4$^+$ T-cells leads to the progression of HIV infection, which may increase the likelihood of opportunistic infection and other clinical events that are associated with HIV (Egger *et al.,* 2002; Pattanapanyasat and Thakar, 2005).

A low CD4$^+$ T-cell count can increase reporting in PLWH, but the data are equivocal (Richardson *et al.,* 2009; Aouizerat *et al.,* 2010). Two studies reporting on the prevalence and intensity of pain and factors associated with pain in PLWH from the USA found that having a CD4$^+$ T-cell count of fewer than 200 cells/mm^3 was associated with reporting pain (Richardson *et al.,* 2009; Aouizerat *et al.,* 2010). In contrast, other studies of PLWH from New York and Canada have found no relationship between pain and CD4$^+$ T-cell count (McCormack *et al.,* 1993; Rotheram-Borus, 2000).

1.2.1.2 The association between pain and HIV disease stage

Several studies have reported on the association between HIV disease stage and pain in PLWH (Martin *et al.,* 1999; Dobalian, Tsao and Duncan, 2004; Norval, 2004; Nair *et al.,* 2009; Azagew *et al.,* 2017). A study reporting the prevalence of pain between inpatients with advanced HIV disease and ambulatory outpatients from India found that the inpatients reported a higher pain prevalence than the outpatients (Nair *et al.,* 2009). Seventy-nine percent of the patients who reported pain were in WHO HIV clinical stage III and IV, with the in-patients with advanced HIV disease (stage IV) making up almost 90% of patients in this stage of the disease (Nair *et al.,* 2009). This suggests that pain may increase as HIV disease progresses. Indeed, a cross-sectional study looking at the prevalence of pain in PLWH from Ethiopia found an association between having pain and WHO HIV clinical stage II, III and IV (Azagew *et al.,* 2017). There are two studies that have found no difference between the prevalence of pain and the HIV disease stage. These include a study of 79 PLWH from Nigeria, which found no significant association between the presence of pain and HIV disease stage (Wahab and Salami, 2011), as did another study of 153 PLWH from Rome (Del Borgo *et al.,* 2001). These results need to be interpreted with caution. Wahab and colleagues (2011) participants were in WHO stage I and II, while Del Borgo and colleagues (2001) reported on the lack of heterogeneity in the cohort regarding the HIV disease stage of participants. Therefore, there might be an association between the presence of pain and the HIV disease stage. Only a few studies have reported on the association between disease stage and the number and location of anatomical pain sites in PLWH. One study reported the prevalence of pain in 211 PLWHs from Sweden (Martin *et al.,* 1999). A strong positive correlation was found between the CDC disease stage and the number of anatomical pain sites reported by PLWH (Martin *et al.,* 1999). As the HIV disease stage advanced, the number of anatomical sites reported by PLWH increased (Martin *et al.,* 1999). A two-year longitudinal study on men living with HIV in the USA found that the mean number of pain sites reported by this cohort increased with the progression of the disease (Singer *et al.,* 1993). A study of 103 people living with end-stage HIV infection (AIDS), however, had a similar number of pain sites as studies containing PLWH with a variety of disease stages (Norval, 2004). These data combined suggest that the relationship between the disease stage and the number of pain sites is equivocal.

As demonstrated above, the relationship between CD4$^+$ T-cell count, disease stage and pain prevalence is unclear. One of the reasons that have been suggested regarding this uncertainty may be the variable access to and use of antiretroviral therapy (ART). In a healthy cohort with well-maintained CD4$^+$ T-cell counts (>200 cells/mm^3), the pain did not associate with CD4$^+$ T-cell count, and this was accounted for by the use of ART(Cervia *et al.,* 2010). The authors suggested that with the effective use of ART, CD4$^+$ T-cell count can be maintained, and disease progression stalled, leading to decreased pain prevalence in PLWH. Recent studies of PLWH on ART with well-maintained CD4$^+$ T-cell counts still report a high prevalence of pain, however (Merlin *et al.,* 2012; Lawson *et al.,* 2015; Sabin *et al.,* 2018; Nkhoma *et al.,* 2019) suggest that ART alone are not sufficient to control pain in HIV.

1.2.2 The association between pain and antiretroviral therapy (ART) use

The widespread introduction of ART in the last decades has decreased many HIV-related illnesses and deaths worldwide (Volberding and Deeks, 2010; Smit *et al.,* 2015). ART slows the progression of HIV to AIDS by suppressing the HIV replication process (Hogg *et al.,* 1999; Smit *et al.,* 2015; Martinez-Picado and Deeks, 2016). The widespread use of ART has changed HIV infection from a deadly virus to a manageable chronic disease requiring long-term treatment (Hogg *et al.,* 1999; Volberding and Deeks, 2010; Smit *et al.,* 2015).

Despite the numerous benefits that ART offers, multiple side effects have been reported by PLWH on ART (Volberding and Deeks, 2010; Chen *et al.,* 2013; Moketla *et al.,* 2018). The results are conflicting on whether ART use is associated with pain. Some studies have found no association between ART use by PLWH and the presence of pain or other symptoms (Richardson *et al.,* 2009; Harding *et al.,* 2012), but others have found an association. In a study looking at the prevalence of various symptoms, their burden and association with the use of ART in 347 gay men living with HIV from the United Kingdom (UK), men who were currently on ART reported a significantly higher prevalence of symptoms compared to men who were not on ART (Harding *et al.,* 2006). The most reported symptom was pain, with ART users reporting a pain prevalence of 51.2% compared to 32.2% reported by men who were not on ART. Results from this cohort need to be interpreted with caution because the sample receiving ART were within the range of WHO advanced HIV disease ($CD4^+$ T-cell count <200 cells/mm3), and pain has been reported to be associated with HIV disease stage in PLWH (Norval, 2004; Nair *et al.,* 2009). In another study from the UK looking at the prevalence and risk factors for pain in a cohort of 859 PLWH, the prevalence of pain was more prevalent in participants who had ever been on ART, were currently on ART, and those on protease inhibitors (Lawson *et al.,* 2015).

In contrast, other studies have found the exact opposite: ART is associated with reduced pain prevalence. For example, a cross-sectional study reporting on the prevalence of pain in ambulatory urban and rural South African PLWH found that in their rural cohort, ART use was associated with a lower chance of having pain (Mphahlele, Mitchell and Kamerman, 2012). A longitudinal study found that over five years, decreasing pain was associated with the use of ART in a cohort of 357 PLWH from Colorado (Koeppe *et al.,* 2012). Another longitudinal study of 97 PLWH from Uganda found that in the first year of ART initiation, there was a decrease in the prevalence of individuals' symptoms. One of the symptoms that decreased in prevalence was pain, which dropped from 79% to 60% (Wakeham *et al.,* 2017). However, results from this study need to be interpreted with caution because even though there was a decrease in the prevalence of pain in this cohort, the prevalence of pain remained high, and 25% of participants reported pain causing high distress (Wakeham *et al.,* 2017). So, although the association between pain and exposure to ART is not clear, pain in HIV remains prevalent, affects mental health (as we will see in the next section) and affects adherence to ART (Wasti *et al.,* 2012; Al-Dakkak *et al.,*2013; Achappa *et al.,* 2013).

1.2.3 Psychological factors

Pain in the general population has been associated with the presence of psychological disorders such as depression, anxiety, post-traumatic stress disorder (PTSD), mood disorders, and negative beliefs about the pain such as pain catastrophizing and the fear of pain (van Hecke, Torrance and Smith, 2013; Mills, Nicolson and Smith, 2019). The intensity of pain has also been reported to be influenced by these psychological disorders (van Hecke, Torrance and Smith, 2013; Mills, Nicolson and Smith, 2019). Therefore, we might expect similar associations between PLWH and pain with the presence of psychological disorders like depression and anxiety influencing the prevalence and intensity of pain.

Indeed, a systematic review with a meta-analysis (of 46 studies and 37 studies, respectively) on the psychosocial factors associated with chronic pain in PLWH found that psychological factors like depression, anxiety, and PTSD were prevalent in PLWH and were indeed related to chronic pain (Scott *et al.,* 2018). The systematic review also found that psychological factors like depression, anxiety, and PTSD were associated with greater pain intensity and more anatomical pain sites reported by PLWH (Scott *et al.,* 2018).

Pain catastrophizing, where individuals with pain interpret the pain as highly threatening, may result in fear-avoidance, where individuals reduce or avoid physical activity for fear of making the pain worse (Leeuw *et al.,* 2007; Crombez *et al.,* 2012). Greater pain catastrophizing and fear avoidance have been associated with the increased presence of pain and pain intensity in the general population (van Hecke, Torrance and Smith, 2013; Mills, Nicolson and Smith, 2019), and similar associations have been seen in PLWH and pain.

Two studies of PLWH from the USA and London found that greater pain catastrophizing was associated with increased pain intensity in PLWH and neuropathic pain (Lucey *et al.,* 2011; Phillips *et al.,* 2014). Although a South African study found that pain catastrophizing did not associate with pain intensity in painful sensory neuropathy, the authors suggested that the lack of association may be because pain catastrophizing was so high, making an association difficult to detect (Pillay *et al.,* 2017). The South African cohort consisted of 83% (149/179) of women, and the high prevalence of pain catastrophizing may be due to the high number of women in the study, as women have been reported to engage in pain catastrophizing more than men (Sullivan, Tripp and Santor, 2000; Keogh and Eccleston, 2006; Fillingim *et al.,* 2009; Bartley and Fillingim, 2013). Not many studies have investigated the association between negative beliefs about pain, like pain catastrophizing and fear avoidance in PLWH and pain. Therefore, more studies on the impact of negative thoughts about pain need to be done (Scott *et al.,* 2018).

Indeed, there have been few studies on beliefs about pain, positive or negative, in South African PLWH.

1.2.4 Socioeconomic status and pain

Low socioeconomic status (typically assessed through employment status and education level) has been reported to be a risk factor for pain in general populations (van Hecke, Torrance and Smith, 2013; Macfarlane *et al.,* 2015; Mills, Nicolson, and Smith, 2019). Reasons for an association may be that: People with a low socioeconomic status have reduced access to health care, which results in the undertreatment of pain (Miaskowski *et al.,* 2011; Dorner *et al.,* 2011), and people with lower education are more likely to do manual work, which is associated with greater pain (Meucci, Fassa and Xavier Faria, 2015; Mills, Nicolson and Smith, 2019) and conversely, people with chronic pain are more likely to be unemployed as a result of their pain. In addition to the socioeconomic status being associated with pain, it is expected that it may be related to PLWH too. Indeed, a study looking at pain and the use of outpatient services by PLWH from the USA found that in their cohort of 2267 PLWH, the individuals that reported a higher prevalence of pain were intravenous drug-using females, the unemployed and people with a lower level of education (Dobalian *et al.,* 2004). People with lower levels of education also reported higher pain intensity levels than those with higher education levels (Dobalian *et al.,* 2004).

1.3 Sex

1.3.1 Sex differences in pain

In population-based epidemiological studies, women have a higher prevalence of painful conditions than their male counterparts (Levine and De Simone, 1991; Fillingim *et al.,* 2009; Van Hecke, Torrance and Smith, 2013; Mills, Nicolson and Smith, 2019). Many studies look at sex differences in different pain conditions like musculoskeletal pain (Fillingim *et al.,* 2009; Gerdle *et al.,* 2008; Rollman and Lautenbacher, 2001), fibromyalgia (Bartley and Fillingim, 2013; Fillingim *et al.,* 2009), neuropathic pain (Hall *et al.,* 2006; de Mos *et al.,* 2007; Fillingim *et al.,* 2009), migraine(Bartley and Fillingim, 2013; Schwartz *et al.,* 1998), and irritable bowel syndrome (Bartley and Fillingim, 2013; Fillingim *et al.,* 2009) have found that women have a higher prevalence of pain compared to men and that women report a higher number of anatomical pain sites compared to men (Rollman and Lautenbacher, 2001; Gerdle *et al.,* 2008; Fillingim *et al.,* 2009). A recent South African study reporting on the prevalence of pain and its associate reported that women were more likely than men to report a higher prevalence of discomfort, with women reporting a prevalence of 20.1% while men reported a prevalence of pain of 15.8% (Kamerman *et al.,* 2020)

In addition to a greater burden of pain in population-based epidemiological studies, women have displayed greater pain sensitivity to some experimental pain modalities than men(Fillingim *et al.,* 2009; Racine *et al.,* 2012). A systematic review of sex differences in the perception of experimental pain found that women had a lower pain tolerance for thermal pain (heat/cold) and lower pain threshold for pressure pain than men (Racine *et al.,* 2012). No significant sex differences in pain threshold or pain tolerance were found for ischemic pain, electrical pain, muscle pain and visceral pain, however (Racine *et al.,* 2012).

Studies looking at sex differences in pain severity in clinical and experimental pain have shown contradicting results, with some studies reporting greater pain severity in women than men, and some studies have found no sex differences (Bartley and Fillingim, 2013; Fillingim *et al.,* 2009; Racine *et al.,* 2012). For example, a systematic review looking at sex differences in pain intensity and location of pain in inflammatory arthritis found that women reported higher pain intensity levels than men (Barnabe *et al.,* 2012). Furthermore, a study of 240 people from the United States of America with chronic back pain also found that women reported greater pain intensity than men (Fillingim *et al.,* 2003). In contrast, no sex differences in pain intensity were found in 187 American individuals with cancer pain (Edrington *et al.,* 2004; Gerdle *et al.,* 2008; Fillingim *et al.,* 2009). In a systematic review of experimental studies, there were no significant sex differences in pain intensity for pressure pain, cold pain, ischemic pain, or chemical pain. However, women reported significantly more intense pain for electrical pain than (Racine *et al.,* 2012). Although extensive research has been carried out on sex differences in pain severity in people living with chronic pain, it is not clear if there is a sex difference.

1.3.2 Sex differences in HIV-related pain

As mentioned above, the prevalence of many chronic pain conditions is generally higher in women; therefore, the prevalence of pain may be higher in women living with HIV compared to men living with HIV. The prevalence of pain has been reported to be higher in studies focusing on women living with HIV and pain compared to the general population (Richardson *et al.,* 2009; Parker, Jelsma and Stein, 2017). For example, a study looking at the prevalence of pain in 229 amaXhosa women living with HIV/AIDS from South Africa reported a 74% chronic pain prevalence (Parker, Jelsma and Stein, 2017). While a study looking at the experience of pain in 339 women living with advanced AIDS from the USA reported a prevalence of 84% in the last six months before the study (Richardson *et al.,* 2009). Indeed, the prevalence of pain in WLWH is high. However, the prevalence of pain in WLWH still falls within the pain prevalence ranges reported in Tables 1 and 2 for male and female PLWH.

Studies reporting on sex differences in the prevalence of pain in PLWH report contradicting results, whilst some studies have found no association between pain and sex in PLWH (Breitbart *et al.,* 1996; Aouizerat *et al.,* 2010; Vogl *et al.,* 1999), others have reported a higher prevalence of pain and higher pain intensity in WLWH compared to men living with HIV (MLWH) (da Silva *et al.,* 2017; Dobalian *et al.,* 2004; Nkhoma *et al.,* 2019; Sabin *et al.,* 2018). One study that found a difference was in 859 PLWH from the United Kingdom, where women were more likely to report the presence of pain than men of all ages (45% for women vs 39% for men) (Lawson *et al.,* 2015). The differences in the prevalence of pain in this cohort may be statistically significant. However, the difference may not be clinically meaningful. In contrast, a study on 354 PLWH/AIDS from South Africa found that neuropathic pain was more prevalent in men than women (Hitchcock, Meyer and Gwyther, 2008). Results from this study need to be interpreted with caution as people who were unable or unwilling to use ART therapy were excluded and people who were unable to attend the clinic because of disability or socio-economic factors were also excluded (Hitchcock, Meyer and Gwyther, 2008). Women tend to be affected more by barriers to healthcare due to a lack of knowledge and lower socioeconomic status compared to men (Gray and Berger, 2007). Therefore, excluding these individuals (who may be more likely to be women) may have affected the association with sex in this cohort.

With women being more sensitive to clinical pain conditions and some experimental pain modalities compared to men, WLWH may also experience greater pain severity. In a variety of studies looking at PLWH, sex has been reported to be associated with pain intensity, with WLWH reporting higher pain severity levels compared to MLWH (Breitbart W, McDonald, MV, Rosenfeld, 1996; Miaskowski *et al.,* 2011; da Silva *et al.,* 2017). These studies included individuals from developed and developing countries, individuals with different socioeconomic statuses, employed and unemployed, and educated and uneducated individuals (Breitbart, McDonald, Rosenfeld,1996; Tsao, Stein and Dobalian, 2010; da Silva *et al.,* 2017). The relationship between pain severity and female sex has also been shown in a longitudinal study of 2267 PLWH from the USA, where women reported higher pain severity than their male counterparts at baseline and one year later (Tsao *et al.,* 2010).

It has been suggested that several factors may be associated with sex differences in pain (Fillingim *et al.,* 2009; Racine *et al.,* 2012; Bartley and Fillingim, 2013; van Hecke, Torrance and Smith, 2013; Mills, Nicolson and Smith, 2019). For example, several studies have reported on socio-demographic factors that may influence sex differences in people living with pain (van Hecke, Torrance and Smith, 2013; Macfarlane *et al.,* 2015; Mills, Nicolson and Smith, 2019). Socio-demographic factors and their association with pain will now be discussed.

1.3.3 Sex and socioeconomic status

Socio-economic status has been reported to be a risk factor for the presence of pain in PLWH (Dobalian *et al.,* 2004; Miaskowski *et al.,* 2011), and women's socio-economic status has been reported to be lower than men's (Rosenfeld *et al.,* 1996; Gray and Berger, 2007). Women tend to be less educated, more frequently unemployed and lack access to a proper health care system (Grey and Berger, 2007). Therefore, poor socioeconomic status may lead to higher pain prevalence and intensity in WLWH than in MLWH. It seems WLWH may have a lower socioeconomic status, and socio-economic status has been reported to be associated with poor health outcomes in many chronic diseases, including metabolic disorders (Suwannaphant *et al.,* 2017; Bird *et al.,* 2020), cardiovascular diseases (Woodward *et al.,* 2015; Rosengren *et al.,* 2019), and psychological disorders (Maselko *et al.,* 2018).

1.3.4 Sex, psychological factors, and pain

Studies show that psychological factors like depression, anxiety and PTSD are associated with having or developing chronic pain (Van Hecke, Torrance and Smith, 2013; Macfarlane *et al.,* 2015). Psychological factors have also been reported to affect pain severity in individuals with pain (Mills, Nicolson and Smith, 2019). Women experience psychological factors like depression, anxiety, and post-traumatic stress more severely than men (Fillingim *et al.,* 2009; Leben, 2018). The high prevalence of psychological disorders in women may contribute to the increased pain reported by women and WLWH compared to men. Indeed, several studies looking at PLWH have reported more significant depressive symptoms and psychological disorders in women than men (Brandt, 2009; Aljassem *et al.,* 2016).

Sex differences in the experience of pain may also be caused by different pain coping strategies used by women and men in pain (Bartley and Fillingim, 2013; Mills, Nicolson and Smith, 2019). Women have been reported to use social support networks, positive self-statements, and emotion-focused techniques to cope with pain (Racine *et al.,* 2012; Van Hecke, Torrance and Smith, 2013). Women have also been reported to engage in pain catastrophizing more than men (Bartley and Fillingim, 2013; Fillingim *et al.,* 2009; Keogh and Eccleston, 2006; Sullivan *et al.,* 2000). By engaging in pain behaviours and verbalizing their catastrophic thoughts, women receive social support from individuals close to them (Sullivan, Tripp and Santor, 2000; Sullivan *et al.,* 2006). Men, however, have been reported to use behavioural distraction and problem-focus strategies instead to manage their pain (Bartley and Fillingim, 2013).

Social gender roles have been associated with how individuals express or respond to pain (Fillingim *et al.,* 2009; Racine *et al.,* 2012; Bartley and Fillingim, 2013). Pain expression has been reported to be more socially acceptable in women compared to men, while men may be expected to be more stoical (Bartley and Fillingim, 2013; Fillingim *et al.,* 2009; Racine *et al.,* 2012). Studies have shown that both women and men believe that women are more sensitive to pain, endure less pain and are more willing to report pain compared to men (Robinson *et al.,* 2001; Wise *et al.,* 2002; Robinson and Wise, 2003).

1.3.5 Sex and health-related quality of life

Health-related quality of life (HR-QOL) refers to the quality of life resulting from general health, psychological health and level of functional independence (Karimi and Brazier, 2016). As mentioned above, women tend to present with more chronic pain conditions, experience more psychological health problems and have lower socioeconomic status than men. It follows, therefore, that several studies have found that women reported a poorer HRQoL compared to men in several different chronic pain conditions (Linzer *et al.,* 1996; Mrus *et al.,* 2005; Orfila *et al.,* 2006; Douglas, 2007) and this same pattern may exist in WLWH. Indeed, studies reporting on the HR-QOL in PLWH from different countries, including Africa, have found that women report a poorer HR-QOL than men (Vigneshwaran *et al.,* 2013; Tesfay *et al.,* 2015; Gebremichael *et al.,* 2018; Fumaz *et al.,* 2019). Women in these studies were reported to experience worse psychological distress, had a lower socioeconomic status, reported low energy, a lack of social support and also reported a higher pain prevalence than men (Tesfay *et al.,* 2015; Gebremichael *et al.,* 2018; Fumaz *et al.,* 2019).

1.3.6 Culture and Demographic areas

Studies reporting pain-related pain-related factors in PLWH have tended to be quantitative, with very few qualitative studies. This lack of qualitative studies on PLWH and pain has led to a lack of data on how culture influences the experience of pain in PLWH. In this section, I will discuss how culture generally influences beliefs about pain and how traditional gender roles affect the reporting and disclosure of pain in people living with pain. I will also discuss how demographic areas may impact pain in the general population and PLWH.

1.3.6.1 Culture

Several studies have found that the experience of pain, beliefs about pain, pain behaviour, perception of pain and emotional reaction towards pain may be influenced by an individual's cultural background (Lovering, 2006; Albertyn *et al.,* 2009; Nortjé and Albertyn, 2015; Holt and Waterfield, 2018). Indeed, a study looking at cultural attitudes and beliefs about pain found that an individual's cultural background influenced the verbalization of pain by individuals with pain, while other cultures encouraged stoicism in the face of pain (Lovering, 2006). Individuals from Asian, Filipino, Saudi, and Irish cultural backgrounds were reported to be more likely to verbalize their pain. In contrast, individuals from the Tswana and Afrikaans cultural backgrounds were likely to remain stoic in the face of pain regardless of gender (Lovering, 2006). The Tswana and Afrikaans would likely deny having pain, while the Asian, Filipino, Saudi and Irish individuals would probably disclose their pain status (Lovering, 2006).

Gender also plays a role in culturally appropriate expressions of pain. Gender differences in the report and/ or presentation of pain due to individuals' cultural background were reported by a study looking at the perception of pain in 42 Nguni and Sotho individuals from South Africa (Nortjé and Albertyn, 2015). They found that men were not encouraged to express their pain in both cultures. This is even reflected in the Sesotho culture through the idiom "a man is a sheep he should not cry" to emphasise the fact that men are not supposed to express pain as the expression of pain symbolises weakness. Men were rather expected to show stoicism in the face of pain (Nortjé and Albertyn, 2015). In contrast, women could express their pain and the intensity of pain in any way possible, as it was culturally acceptable for women to express their pain and their pain intensity (Nortjé and Albertyn, 2015).

Cultural beliefs about pain also influence how individuals respond to pain. In some African cultures, pain is considered a way that ancestors communicate with them or that ancestors punish individuals (Lovering, 2006; Nortjé and Albertyn, 2015). Some cultures believe pain is caused by supernatural causes like witchcraft or the evil eye (Lovering, 2006). These cultural beliefs about pain influenced how individuals responded to everyday pain, as pain tolerance was linked to a reward in the afterlife (Lovering, 2006). Indeed, suppose culture has an influence on the perception and expression of pain in general. In that case, it can assume that culture will likely influence the perception and expression of pain in PLWH. No studies have explored beliefs about pain in PLWH from South Africa. Therefore, there is a need for research on how culture influences pain in South African PLWH.

1.3.6.2 Demographic areas

The prevalence of pain may be influenced by where individuals reside. Culture differs between countries, and there may also be cultural differences between where individuals live within countries, for example, in rural areas vs urban areas (Tsang *et al.,* 2008; Hoffman and Meier, 2010; Docking *et al.,* 2015). Indeed, some studies from developed countries like Sweden and the USA have found that individuals from rural areas report a higher pain and pain intensity than individuals from urban areas (Andersson, 1994; Hoffman and Meier, 2010; Tripp *et al.,* 2006).

The higher prevalence of pain in rural areas, as described in studies from developed countries, was associated with how increasingly rural the area was, female sex, poor self-reported health status, lower socioeconomic status, and poor psychological health (Tripp, VanDenKerkhof and McAlister, 2006; Docking *et al.,* 2015), and these very same risk factors for pain have also been reported to be risk factors for PLWH (Rosenfeld *et al.,* 1996; Dobalian, Tsao and R Paul Duncan, 2004; Gray and Berger, 2007).

In a study looking at the prevalence of pain in South African ambulatory rural (n=125) and urban (n=369) PLWH, they found that rural PLWH reported a pain prevalence of 72%, and urban PLWH reported a pain prevalence of 56% at the time of the interview (Mphahlele *et al.,* 2012). The rural participants had lower education levels and a poorer socioeconomic status compared to the urban participants. In contrast, a study looking at the symptom experience of 607 PLWH from South Africa in Eastern Cape (rural, urban and informal settlements) found higher HIV symptom intensity was associated with urban residence, a poorer socioeconomic status and having health-care insurance (Peltzer and Phaswana-Mafuya, 2008). This suggests that the effect of the area in which PLWH reside on symptoms, including pain, may be complex and socio-demographic factors like socioeconomic status may have more influence. Further research needs to be done to determine associations between individuals' place of residence and the reporting, experience, and perception of pain in PLWH.

1.4 The impact of pain in PLWH

1.4.1 Pain and activities of daily living

Pain has been reported to cause interference with activity (activities of daily living) in people living with conditions that are commonly accompanied by chronic pain like multiple sclerosis, arthritis, and spinal cord injury (Aşkın *et al.,* 2017; Douglas *et al.,* 2009; Hassanijirdehi *et al.,* 2015). A systematic review reported on the impact of chronic pain from 68 articles and found a strong correlation between chronic pain and interference with activity (Dueñas *et al.,* 2016). Higher pain intensity, longer duration, or specific pain locations lower limbs, abdominal pain, headaches) associated with more significant interference with activity (Dueñas *et al.,* 2016).

1.4.1.1 How the activity is measured

The measurement of physical activity, which includes daily activities of living like house-chores, occupational work activity, exercise, playing sports or leisure activity, is challenging because physical activity is a multi-dimensional construct with various definitions and/or terminologies (Kelly *et al.,* 2016; Rowe, 2011; Thompson *et al.,* 2015). Physical activity can be measured using objective or subjective measurements (Prince *et al.,* 2008; Silfee *et al.,* 2018; Strath *et al.,* 2013).

The objective measurement of activity uses tools that directly measure the duration and/or intensity of the activity, time spent doing the activity and the frequency of activity (Dishman *et al.,* 2001; Prince *et al.,* 2008; Silfee *et al.,* 2018; Strath *et al.,* 2013). The tools that are commonly used to measure activity objectively are wearable monitors (e.g., accelerometers, pedometers) or directly observing individuals (Prince *et al.,* 2008; Silfee *et al.,* 2018; Strath *et al.,* 2013).

The most commonly used measurement of physical activity is subjective(Dishman *et al.,* 2001; Prince *et al.,* 2008). The subjective measurement (self-report measurement) of activity usually uses recall questionnaires, for example, the International Physical Activity Questionnaire (IPAQ), the Human Activity Profile (HAP), the Stanford Brief Activity Survey and Becke Physical activity Questionnaire (BPAQ), or activity diaries (Cleeland, 1991; Dishman *et al.,* 2001; Prince *et al.,* 2008; Strath *et al.,* 2013). Subjective measurement of activity does have its limitations in capturing activity. For example, questionnaire translations may lose their original meaning, and the questionnaires are unreliable in measuring low-intensity activity levels (floor effect), participant recall bias and desirability bias (Dishman *et al.,* 2001; Prince *et al.,* 2008; Strath *et al.,* 2013). These tools are practical, easy to use, low cost and adaptable, however, but not others (Schaller *et al.,* 2016; van Weering *et al.,* 2007; Wadley *et al.,* 2016).

1.4.2 Activity in PLWH and pain

Studies looking at activity in ambulatory PLWH from developed countries using subjective measurements of activity (questionnaires) have found that pain in PLWH causes interference with activity (Merlin *et al.,* 2012; Nair *et al.,* 2009; Newshan *et al.,* 2002). Similar results were found in a qualitative study looking at the experience and impact of neuropathic pain in 26 PLWHs from the United Kingdom (UK) (Scott *et al.,* 2019). Participants described a significant walking interference and also feared falling (Scott *et al.,* 2019). Indeed, activity in individuals living with pain and HIV in developed countries seems to follow a similar trend to activity in individuals living with other chronic pain diseases which causes interference with activity (Douglas, Wollin and Windsor, 2009; Hassanijirdehi *et al.,* 2015; Aşkın *et al.,* 2017). In contrast, some studies from African countries also using subjective measurements of activity have found that pain in PLWH caused low interference with activity (Wahab and Salami, 2011; Mphahlele, Mitchell and Kamerman, 2012; Azagew *et al.,* 2017). One study measured activity objectively for two weeks in 68 South African PLWH with and without pain using accelerometers and found no difference in duration or intensity of activity in PLWH with pain or without pain (Wadley, Mitchell, and Kamerman, 2016). This finding suggests that pain did not interfere with activity in the South African cohort of PLWH.

1.4.2.1 Factors influencing activity in PLWH and pain

Pain intensity has an impact on activity in people living with chronic pain, with high pain intensity being reported to cause greater interference with activity (Kop *et al.,* 2005; Douglas, Wollin and Windsor, 2009; Hassanijirdehi *et al.,* 2015; Steiner *et al.,* 2017). Parker and colleagues (2014) reported on nine studies investigating the effects of pain intensity on activity in PLWH. The studies from developed countries found that moderate to severe pain intensity caused a high pain-related interference with activity in PLWH and pain (Breitbart *et al.,* 1996; Merlin *et al.,* 2012; Nair *et al.,* 2009; Uebelacker *et al.,* 2015). However, some studies from African cohorts found that moderate to severe pain intensity caused only a low interference with activity in PLWH and pain (Wahab and Salami, 2011; Mphahlele, Mitchell and Kamerman, 2012). This shows that further research needs to be done to determine how pain intensity levels influence activity levels in PLWH in developed and developing countries.

A systematic review reporting on factors associated with activity in PLWH found that low levels of activity in PLWH were associated with a low $CD4^+$ T- cell count, lower levels of education, being on ART, pain, and depression (Vancampfort *et al.,* 2018). Indeed, psychological issues like depression and anxiety have been reported to be high in people living with HIV (Rosenfeld *et al.,* 1996; Uebelacker *et al.,* 2015) and depression was found to be associated with interference with activity in six cross-sectional studies looking at PLWH and pain (Scott *et al.,* 2018). The direction of the relationship between depression and activity is not clear, though. A longitudinal study in otherwise-healthy adolescent girls (11-15 years) from the USA found that depression significantly decreased activity in individuals (Jerstad *et al.,* 2010). They also found the reverse relationship that increased activity by individuals decreased the risk of developing depressive symptoms. It appears that depression and activity may have a bidirectional relationship (Roshanaei-Moghaddam *et al.,* 2009).

The bidirectional relationship between psychological factors and interference with activity has been reported by qualitative studies looking at the impact of pain on the psychological well-being of PLWH in the UK and the USA (Merlin *et al.,* 2014; Scott *et al.,* 2019). The qualitative study looking at the experience and impact of neuropathic pain in 26 PLWH from the UK reported on participants' interference with activity causing low mood and the low mood leading to worse pain and interference with activity (Scott *et al.,* 2019). Similarly, 25 PLWHs from the USA have perceptions of the psychological aspect of pain. Participants reported that low mood made them reluctant to participate in physical activity, thus causing interference with activity (Merlin *et al.,* 2014). The participants also said that interference with activity resulted in a low mood (Merlin *et al.,* 2014).

In section 1.4.2, I described a possible lack of interference by pain with activity in South African PLWH (Mphahlele, Mitchell and Kamerman, 2012; Wadley, Mitchell and Kamerman, 2016). An additional psychosocial factor that may associate with activity levels in PLWH and pain is HIV stigma. Wadley and colleagues (2016) suggested that people in their South African cohort may continue to be active despite their pain to conceal their HIV status, meaning that HIV stigma may influence activity levels in PLWH from South Africa. Nearly half of participants in this cohort had not disclosed their pain status to close friends and family members for fear of revealing their HIV status and being "gossiped about", suggesting that participants may have continued being active despite being in pain to conceal their HIV status (Wadley *et al.,* 2016). Another South African study examined the level of physical activity in people living with chronic pain but unknown HIV status and found contrasting results (Parker *et al.,* 2017). Individuals living with pain had a significant pain-related interference with activity compared to those without pain (Parker *et al.,* 2017). This may suggest that HIV status and HIV stigma may influence activity in South African PLWH because PLWH and pain continued to be active despite being in pain to conceal their HIV status, while South African people with pain but unknown HIV status stopped being active while in pain.

In their cohort of South African PLWH, (Mphahlele, Mitchell and Kamerman, 2012) attributed the continued, subjectively measured activity in the face of pain to the stoic attitude their participants had towards pain. Mphahlele and colleagues (2012) also found that individuals in this cohort had a poor socio-economic background and thus suggested participants may have considered problems related to pain to be unimportant relative to socio-economic stress. Worries about money may motivate or force individuals to stay active despite their pain (Phaladze *et al.,* 2005; Uwimana and Struthers, 2007; Wadley, Mitchell and Kamerman, 2016). Indeed, it is not clear what motivates African PLWH and pain to continue being active despite being in pain because studies reporting on the impact of pain on activity levels in PLWH have used quantitative questionnaires (Wahab and Salami, 2011; Mphahlele, Mitchell and Kamerman, 2012; Azagew *et al.,* 2017). There is a need for qualitative studies to understand the experience of pain, beliefs about pain and factors that influence activity in PLWH and pain.

1.5 HIV-related stigma, HIV-status disclosure, pain disclosure and social support

In the pain and activity study just mentioned by Wadley *et al*. (2016), they considered whether PLWH not revealing their pain status (due to HIV stigma) may affect their ability to recruit social support. In this section, I discuss the impact that HIV stigma has on the HR-QoL of PLWH and the effects of HIV stigma on HIV status disclosure, pain disclosure and social support in PLWH.

There is a high prevalence of HIV-related stigma reported in PLWH worldwide (Rao *et al.,* 2012; Rueda *et al.,* 2016; Zarei, Joulaei and Fararouei, 2016). Stigma is negative attitudes or beliefs people have about PLWH (Steward *et al.,* 2008; Chaudoir, 2015; CDC.gov, 2020). PLWH experience stigma through various mechanisms, for example, internalized stigma when PLWH experience negative feelings or harbour negative thoughts about their HIV status, making them feel guilty, ashamed, or dirty; and/or enacted stigma, which is the experience of unfair treatment, discrimination, and isolation of individuals due to their HIV-status (Steward *et al.,* 2008; Chaudoir, 2015; CDC.gov, 2020).

1.5.1 Impact of HIV-related stigma on health

Several studies show that HIV-related stigma, either internalized or enacted, has a negative impact on all components of HR-QoL in PLWH (Holzemer *et al.,* 2009; Logie and Gadalla, 2009; Rueda *et al.,* 2016; Rao *et al.,* 2012). This effect of HIV stigma on HR-QoL has been seen in various countries, as demonstrated in a study of 726 PLWH recruited from 14 sites in Africa, Puerto Rico, and the USA (Holzemer *et al.,* 2009). Specifically, HIV-related stigma has associated with greater severity of HIV-related symptoms such as pain, poor psychological health, and interference with activity resulting in poor physical health (Rueda *et al.,* 2016; Travaglini, Himelhoch and Fang, 2018).

Specifically, regarding pain, a preliminary analysis of the association between perceived HIV stigma and pain found that greater stigma was associated with worse pain intensity and depression in a cohort of 50 PLWHs from South Africa (Evangeli, Wadley and Pincus, 2019). With regards to psychological health, several studies have reported that HIV-related stigma may harm the psychological health of PLWH, with high levels of HIV-related stigma being associated with greater depressive symptoms, anxiety, emotional distress, and stress regarding disclosure of their HIV status (Rueda *et al.,* 2016; Travaglini, Himelhoch and Fang, 2018). Additionally, worse mental health is associated with greater pain intensity (Scott, 2018). These studies suggest that HIV-related stigma may have a negative impact on mental and physical health in PLWH (Rueda *et al.,* 2016; Wadley, Pincus and Evangeli, 2017; Travaglini, Himelhoch and Fang, 2018).

1.5.2 Impact of HIV stigma on HIV disclosure and obtaining social support

PLWHs who have experienced HIV-related stigma may be more reluctant to disclose their HIV status to family members, friends, and the community (French *et al.,* 2015; Rueda *et al.,* 2016). Two qualitative research studies looking at the experience and impact of pain in PLWH found that participants were reluctant to disclose their HIV status due to previously experiencing HIV-related stigma (Scott *et al.,* 2019). A qualitative research study of seven South African WLWH (four of whom had pain) found that disclosure of the women's HIV status had led to social discrimination that resulted in the loss of social support (Cameron *et al.,* 2018). Non-disclosure of HIV status by PLWH may be used as a protective mechanism to prevent discrimination, violence, and isolation (stigma) (Landau and York, 2004; Jordon *et al.,* 2008). Non-disclosure of HIV status may also cause negative personal repercussions, however. One woman from the South African qualitative research study reported often feeling guilty for not disclosing her HIV status and feeling sad (Cameron *et al.,* 2018).

HIV-status disclosure may influence the social support PLWH can recruit, but the relationship between HIV status disclosure and social support is varied (Huber, 1996; Holt *et al.,* 1998; Kalichman *et al.,* 2003; Smith, Rossetto and Peterson, 2008). While several studies report discrimination against PLWH following disclosure (French *et al.,* 2015; Rueda *et al.,* 2016), other studies have shown that disclosure of HIV status to close friends and family members may lead to increased social support (Huber, 1996; Kalichman *et al.,* 2003; Smith, Rossetto and Peterson, 2008). For example, in the qualitative study of seven WLWHs from South Africa, disclosing the women's HIV status allowed them to gain social support and self-acceptance (Cameron *et al.,* 2018).

One of the potential reasons for non-disclosure of HIV may be the impact on the disclosure targets themselves, including acute and recurrent stress for the close family and friends of PLWH (Holt *et al.,* 1998; Brashers *et al.,* 2004). Two studies concluded that potential supporters might avoid interaction with individuals needing social support because the situation may be emotionally stressful, cause them anxiety or be worrisome (Brashers *et al.,* 2004); Smith, Rossetto and Peterson, 2008). As a result, PLWH may not disclose their HIV status to protect their close friends and family from emotional stress (Brashers *et al.,* 2004).

1.5.3. Impact of HIV stigma on pain disclosure and obtaining social support

Similar reasons for not disclosing HIV status may exist for not disclosing pain status too. In a study of South African PLWH, 44% did not disclose their chronic pain status to close friends and family members (Wadley *et al.,* 2016). As mentioned above, participants feared they would be "gossiped" about (Wadley *et al.,* 2016). A lack of disclosure of pain and HIV statuses may lead to a lack of social support for PLWH (Huber, 1996; Kalichman *et al.,* 2003; Smith, Rossetto and Peterson, 2008). This is unfortunate because high levels of social support have been reported to be associated with less stigma, fewer depressive symptoms, better HR-QoL and lower HIV-related symptoms in PLWH (Ashton *et al.,* 2005; Li *et al.,* 2009; Rao *et al.,* 2012; Charkhian *et al.,* 2014). These findings suggest that social support may decrease the negative impact of HIV-related stigma on PLWH and pain (Rao *et al.,* 2012).

There is a lack of literature on the effect of disclosing pain on the subsequent experience of pain and success in obtaining social support. The lack of data on pain disclosure and social support is worldwide, including in a South African cohort of PLWH. More studies are needed focusing on the impact of cultural beliefs about pain on the disclosure of pain by PLWH and pain.

1.6 The social impact of pain in PLWH

Two recent qualitative studies have reported on the impact of pain on PLWH (Scott *et al.,* 2019; Cameron *et al.,* 2018). One key theme that emerged in these studies was the negative impact that pain has on the social aspects of lives of PLWH (Scott *et al.,* 2019; Cameron *et al.,* 2018). The qualitative study looking at the experience and impact of neuropathic pain in 26 PLWH reported that participants' pain threatened their sense of social inclusion (Scott *et al.,* 2019). These participants expressed how pain has an impact on their socially accepted gender, age, and sexual orientation roles (Scott *et al.,* 2019). The pain made them unable to achieve and/or play their socially accepted role (Scott *et al.,* 2019). For example, a female participant reported how pain affected her socially accepted gender role as a woman. She could not play her role as a home-care giver, a mother and a wife, and also enjoy life and playing her socially accepted gender roles (Scott *et al.,* 2019). In a qualitative study conducted by Scott et al. (2019), a gay man from the United Kingdom perceived that expressing pain may lead to a negative perception by his peers that he is too old (Scott *et al.,* 2019).

The study looking at the experience and impact of neuropathic pain in 26 PLWH from the United Kingdom also reported on pain affecting both close and distant relationships in PLWH pain. Participants reported that pain caused them to be "snappy", "irritable", and aggressive in response to social frustrations or stressors. This resulted in participants withdrawing from social settings (Scott *et al.,* 2019). Participants in this cohort believed that people did not understand their pain and did not believe the extent to which pain impacted their lives (Scott *et al.,* 2019). Cameron *et al.* (2018) also reported on the impact of pain on social life in the cohort of seven South African WLWH. Participants in this study indicated that pain affected every aspect of their lives, including psychological, physical, and social health and well-being, and most notably, the social aspect. However, this qualitative study did not describe how pain affected the social aspects of women's lives (Cameron *et al.,* 2018). Further qualitative research needs to be done in a South African cohort of WLWH to determine how pain affects the social aspects of women's lives, including social inclusion and obtaining social support.

1.7 Pain adds to the burden of living with HIV

Further evidence from the Cameron study of South African WLWH found that participants reported pain as an added burden in their lives (Cameron *et al.,* 2018). Indeed, living with both HIV and pain has been reported to be a double burden (Goodin *et al.,* 2018). The pain was reported to be a constant reminder of participants' HIV status in the South African WLWH (Cameron *et al.,* 2018). The continuous reminder of HIV status was reported to have an impact on the emotional health of PLWH in both South African and British qualitative studies (Scott *et al.,* 2019; Cameron *et al.,* 2018). For example, the remainder of their HIV status was reported to be accompanied by grief, frustration, and anger (Scott *et al.,* 2019). American participants reported that living with HIV was depressing and living with pain was also depressing (Merlin *et al.,* 2014). The experience of pain reduced the participant's hope in the cohort of WLWH from South Africa (Cameron *et al.,* 2018). Whilst the results from the Cameron study are a start, the sample size was only seven, and only four had pain. Furthermore, the participants were Afrikaans and English speaking, so the results cannot necessarily be generalised to the cultural experience of PLWH from African-language cultures.

Summary

The prevalence of pain in PLWH is high, with moderate to severe pain intensity affecting several anatomical sites. Pain, however, has been reported to cause a low interference with activity in some studies of African PLWH and pain. Studies on African PLWH and pain have suggested that socioeconomic factors like HIV stigma and economic stress may motivate PLWH to stay active despite chronic pain. For these studies, we hypothesize that have been suggested

> 1) PLWH may maintain high levels of activity in the face of pain to conceal their HIV status and thus avoid HIV stigma and
>
> 2) HIV stigma may result in non-disclosure of pain by PLWH, which may reduce social support

There are no qualitative studies of South African PLWH and pain, and particularly no qualitative studies exploring the relationship between pain, activity, disclosure, and social support.

Sex differences in the prevalence and intensity of pain have previously been reported. The expression and reporting of pain have also been reported to be different between the sexes. Therefore, only women were recruited for this study. Indeed, I recruited women from rural Limpopo, South Africa, who are part of an ongoing longitudinal study. This rural cohort has not been described in terms of pain before. Therefore, the first part of the study was a quantitative description of the prevalence of pain and the factors associated with pain.

The aim

This study aimed to investigate factors affecting the experience of pain, disclosure of pain and physical function in women living with HIV (WLWH) between the ages of 18 and 60 years from Groblersdal, Limpopo in South Africa.

The study had the following objectives:

1. Reported the prevalence, location and intensity of pain, and demographic associations with pain, in women participating in the Ndlovu research cohort at Groblersdal, Limpopo, South Africa
2. Used qualitative interviews to determine in WLWH with pain and without pain
    a) Beliefs about pain,
    b) Factors influencing levels of activity,
    c) Factors influencing disclosure of pain,
    d) Impact of disclosing, or not, or only partially disclosing status.

CHAPTER 2:

METHODS

The aims of this study were to investigate factors affecting the experience of pain, disclosure of pain and physical function in women living with HIV (WLWH) between the ages of 18 and 60 years from Groblersdal, Limpopo in South Africa. The project was a mixed-methods study, including quantitative and qualitative components. A hundred and twenty-five women were recruited to be part of the quantitative section of the study. For the quantitative section, the Brief Pain Inventory (BPI) was used to determine the prevalence of pain, pain intensity and activity interference. The Patient Health Questionnaire-9 (PHQ-9) was used to determine the participant's depression severity level. Univariate analyses were used to compare demographic and clinical factors associated with having pain between women with pain and women without pain. The pain severity score was calculated as the mean of the three items (worst pain, least pain and pain in the last week). Non-parametric tests were used to determine the association between demographic and clinical factors with pain intensity. For the qualitative section of the study, twenty WLWH were recruited (ten WLWH and pain and ten WLWH without pain). An interview guide developed from grounded theory was used for the in-depth interviews. In-depth interviews were audio-recorded and transcribed verbatim by experienced transcribers. Thematic analysis was used by reading through the transcripts, generating codes, and then developing themes. The themes were then used to answer the research questions.

2.1 Study design

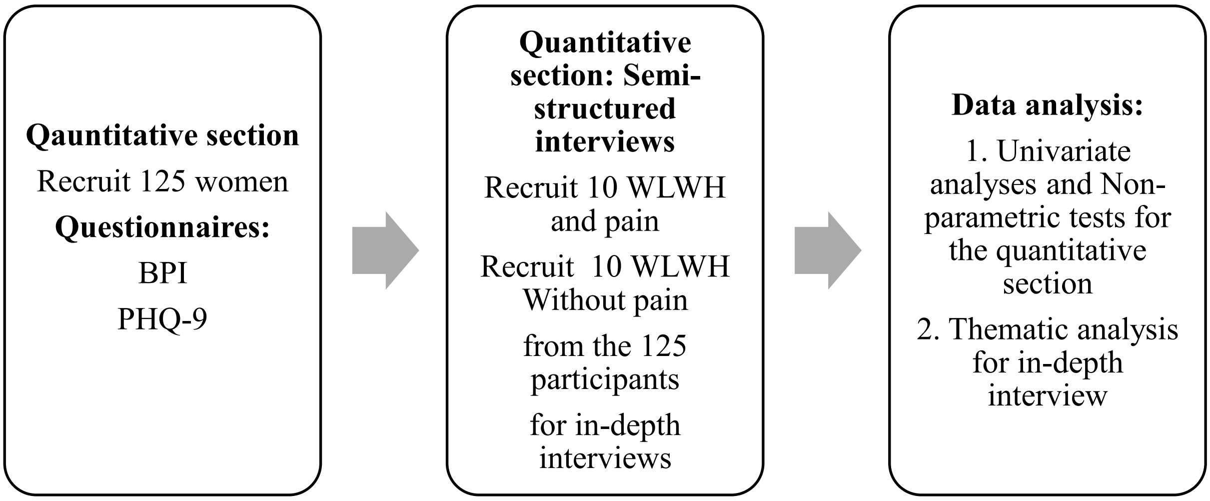

Figure 2.1: Flow diagram for methods used in this study.

2.2 Ethics approval

Ethical approval for the study protocol was obtained from the Human Research Ethics Committee (Medical) of the University of the Witwatersrand (Clearance Number: M180652) (Appendix 1) and The Limpopo Department of Health (Appendix 2).

Figure 2.2: Rural town of Elandsdoorn, Groblersdal in Limpopo South Africa

2.3 Setting

Participant recruitment took place at the Ndlovu Care Group Research Facility in the small, rural town of Elandsdoorn, Groblersdal, in Limpopo province, South Africa. The sample size calculation for this study was based on the prevalence of pain in adults being around 33% (Johannes *et al.,* 2010; Kamerman *et al.,* 2020). Therefore, assuming a 33% pain prevalence at a 95% confidence level, 125 women were required to yield a population estimate within an 8% margin of error.

Data collection took four months, from March 2019 to June 2019. The Ndlovu Care Group (NCG) is a research consortium between the Wits Reproductive Health Institute and Utrecht University in The Netherlands. The NCG has recruited a research cohort of 1928 HIV-positive and HIV-negative individuals. This cohort was recruited from the local area (Elandsdoorn) to follow up on them for ten years to explore cardiovascular risk factors of HIV. This MSc project was a sub-study of the leading research study.

Women between the ages of 18-60 years were eligible for inclusion in the study. Research shows that older people report a higher pain prevalence than younger people (Fillingim *et al.,* 2003; Holt and Waterfield, 2018; Mills *et al.,* 2019). Therefore, to avoid any confounding variables, the cut-off age for this study was 60 years old. There are other factors which may affect reporting and disclosure of pain and thus the prevalence of pain. Chapman *et al.,* 2018 reported that the gender of the experimenter may have an effect on pain reporting in both men and women. Men have been shown to report lower levels of pain in the presence of a female experimenter (Aslaksen *et al.,* 2007, Alabas *et al.,* 2012, Chapman *et al.,* 2018) because of stereotypical social and gender role factors (Robinson and Wise, 2003; Levine and De Simone, 1991). Traditionally, men are expected to be strong and possess the ability to with stand pain in the presence of women (Robinson and Wise, 2003). Thus, in this study, in order to obtain the most accurate pain reports possible, only female participants were recruited as I am a female experimenter.

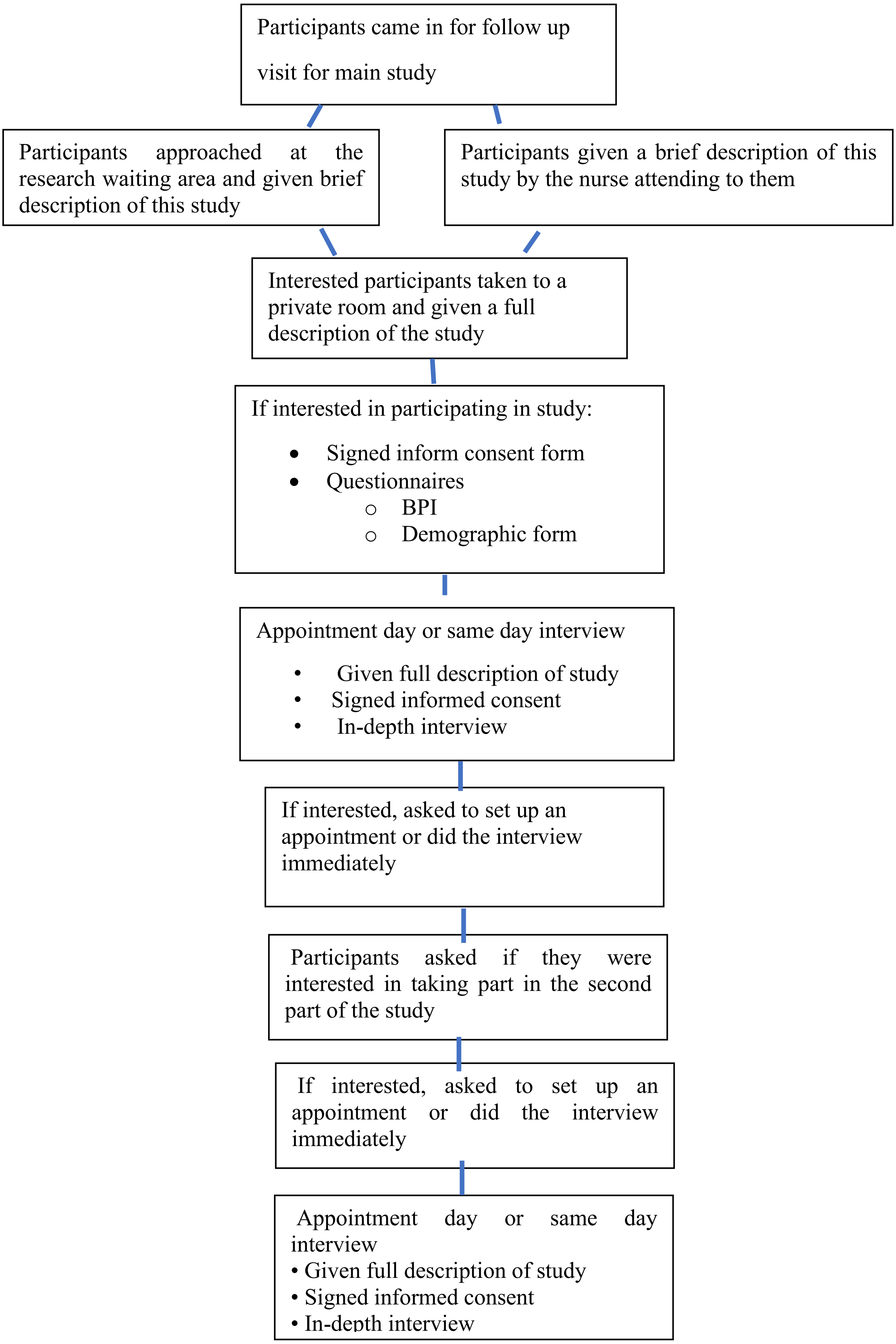

Figure 1: Recruitment process

Before participant recruitment started, the study objectives were explained to the nurses so they could assist in participant recruitment. Participants were given a brief description of the study by the nurses attending to them after their follow-up appointment for the main study. The roles of the nurses were to make the patients coming in for their follow-up visit aware of the study and assist in the recruitment of participants. Alternatively, participants coming for the main study's follow-up appointment were approached in the NCG centre waiting area by the investigator. Whilst they were waiting in the NCG centre waiting area, the investigator gave participants a brief description of the study and invited them to participate.

The participants that consented to join the study were given an in-depth description of the study verbally and were also given an information sheet. An interpreter was made available for participants who needed the study procedure and rationale to be explained in their language of choice. Participants interested in participating in the study were then asked to complete an informed consent form. The informed consent form also included a request for permission for us to access their Ndlovu medical file and their HIV status. The participants were reassured that all information retrieved from their Ndlovu medical files would be kept confidential. Participants were informed that their consent forms would be kept in a separate room from their questionnaires and that the only people with access to their information were the investigator and the research team involved in the study. Participants were also informed that we had ethical approval to conduct the study from the University of the Witwatersrand, the Limpopo Department of Health and the NCG director had permitted us to conduct the study at the consortium.

The participants were informed that the study would consist of two parts: 1) a short questionnaire section (i.e. the quantitative) and 2) a one-hour-long interview section (i.e. the qualitative) if they were interested. Each section had a separate informed consent procedure.

2.4 Questionnaires

2.4.1 Demographic forms

Demographic information was obtained from the study participants. These included their HIV status, age, sex and employment status. The demographic and clinical data will assist in determining their association with pain.

2.4.2 Brief Pain Inventory questionnaire

The Brief Pain Inventory (BPI) (Appendix 4) was used to determine the prevalence of pain as its first question asks: 'Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, toothaches). Have you had pain other than these everyday kinds of pain during the last month?'. Women who answered they had pain were asked to complete a body chart where they felt their pain and to report the worst and least pain intensity and intensity at the time of the interview. Participants in this cohort could not understand the term "average pain" on the BPI when asked to rate their average pain. "Average pain" has been found previously to not translate well in the South African context, and so average pain was not included in the analysis in this study (Mphahlele, Mitchell and Kamerman, 2008). Pain intensity was measured on an 11-point numerical rating scale from 0 = "no pain" to 10 = "the worst pain imaginable". Interference with activity was measure by how much pain intereferes with seven daily duties of living including general activity, walking, work, mood, enjoyment of life, relations with others, and sleep. Pain interference score was measured on an 11-pont numerical scale from 0 = "does not interfere to 10 = "completely interferes". BPI has been widely used in cancer patients and HIV-positive patients to assess pain prevalence, intensity, and level of functional interference. The BPI has been used in African and South African cohorts for over 18 years, consisting of both men and women (Narasimooloo, Naidoo and Gaede, 2011; Wahab and Salami, 2011; Azagew *et al.,*2017). The English version of the Wisconsin Brief Pain Questionnaire (which is identical to the BPI but asks about pain in the last week rather than the previous month) has been validated in South African second-language English speakers (Mphahlele, Mitchell and Kamerman, 2008). A translator was made available for participants needing the BPI to be explained to them in their preferred language.

The questionnaires were interviewer-administered, and data were captured electronically into REDCap hosted by The University of the Witwatersrand, Johannesburg. REDCap (Research Electronic Data Capture) is a secure, web-browser software that is used to manage and store research surveys and data (Harris *et al.,* 2009). The software was used to keep the participants' medical information confidential.

2.4.3 Patient Health Questionnaire-9 (PHQ-9)

The PHQ-9 was used to determine the participant's depression severity level. The questionnaire is a 9-item instrument that is designed to screen for depression and measure the severity of symptoms in primary care and other medical settings (Spitzer, Kroenke and Williams, 1999; Kroenke, Spitzer and Williams, 2001; Kroenke and Spitzer, 2002). The questionnaire determines whether patients were bothered by any of the depressive symptoms during the previous two weeks by scoring them, giving a depression severity score (Spitzer, Kroenke and Williams, 1999). The PHQ-9 depression severity scores are calculated by assigning scores of 0,1,2,3 to the response categories of "Not at all", "Several days", "More than half the days", and "Nearly every day", respectively (Spitzer, Kroenke and Williams, 1999; Kroenke, Spitzer and Williams, 2001; Kroenke and Spitzer, 2002). The total score ranges from 0-27 with five depression severity categories: none-minimal (0-4), mild (5-9), moderate (10-14), moderately severe (15-19) and severe (20-27) (Spitzer, Kroenke and Williams, 1999; Kroenke, Spitzer and Williams, 2001; Kroenke and Spitzer, 2002).

The validity of the PHQ-9 as a tool or instrument to diagnose depression has been established in several studies, as reported in the diagnostic meta-analysis of the PHQ-9 (Gilbody and colleagues, 2007). The meta-analysis of 14 studies which consisted of 5026 participants, validated the PHQ-9 against MDD. The meta-analysis reported a sensitivity of 0.80 and specificity of 0.92 (Gilbody *et al.,* 2007). The internal consistency of the PHQ-9 has been reported to be high, with the Cronbach alphas being reported to be 0.85 in 152 Nigerian University students and 0.81 in 926 adults attending outpatient departments in a hospital (Ethopia) Adewuya, Ola and Afolabi, 2006; Gelaye *et al.,* 2013). A trained social worker from the NRC who was fluent in English and the local languages administered the PHQ-9 to the participants prior to the beginning of the study. The social worker interpreted the questionnaire for patients who were not fluent in English. The PHQ-9 scores were captured on a web-browser software named Researchonline.org. The PHQ-9 has a good validity in South Saharan context (Bhana *et al.,* 2013; Cholera *et al.,* 2014). A study of 676 chronic care patients attending health care in South Africa showed reasonably high validity of the PHQ-9 with a sensitivity of 49% and specificity of 94% (Bhana *et al.,* 2013). At the same time, a study of 397 patients attending a South African health care facility reported a sensitivity of 78.7% and a specificity of 83.4% (Cholera *et al.,* 2014).

The participant's PHQ-9 scores were obtained from the participants' medical files, which were captured on a web browser software named Researchonline.org. Researchonline.org (UMC Utrecht 2016©) is an online electronic data collection system and data management service hosted by Utrecht University in The Netherlands. The participants' PHQ-9 scores were then captured on REDCap.

2.4.4 Assigning pin to participants

Each pin for the participants had the following format:

IDI A00, **participant's age**, **WLWH and pain status**

IDI stands for in-depth interview

The letter "A" assisted in identifying who performed the in-depth interview.

Pain status assisted in identifying if the WLWH falls under the pain group or the no pain group

Examples:

WLWH and pain: IDI A001, 38years old, WLWH and pain

WLWH without pain: IDI A002, 42 years old, WLWH no pain

2.4.5 Data analysis

The percentage of women reporting pain was calculated to determine the prevalence of pain (The number of women with pain over the sample size multiplied by 100). Data were examined for normality, and descriptive statistics were presented as mean (standard deviation) for parametric data and median (interquartile range) for non-parametric data. Univariate analyses were used to compare demographic and clinical factors associated with having pain between women with pain and women without pain: Chi-squared test (level of education, employment status), Mann-Whitney (age, current $CD4^+$ T- cell count, PHQ-9 scores) and Fisher's Exact Test (HIV status) were used. The following measures were used to determine pain intensity in this cohort: worst pain intensity in the last week, least pain intensity in the last week, and pain intensity at the time of the interview. The pain severity score was calculated as the mean of the three items (worst pain, least pain and pain in the last week) (Cleeland, 1991). Non-parametric tests were used to determine the association between demographic and clinical factors with pain intensity because the BPI pain scale is not linear (Correll, 2007): Kruskal-Wallis test (level of education, employment status), Spearman's correlation test (age, current CD4^{+} T-cell count, PHQ-9) and Mann-Whitney test (HIV status) were used to determine associations with pain intensity. Statistical significance was accepted as $p<0.05$.

2.5 Semi-structured interviews

Semi-structured interviews are widely used effective methods of collecting data for qualitative research. Semi-structured interviews enable the researcher to explore participants' experiences, beliefs, and attitudes by using open-ended questions (DeJonckheere and Vaughn, 2009; Jamshed, 2014).

After completing the first component of this study, WLWH were asked if they were interested in participating in an additional study about living with HIV and pain. The participants were informed about the one-hour-long interview section of the study verbally with the help of an information sheet. It was explained that to understand living with HIV and/or pain, both WLWH and pain and without pain, had to be interviewed.

If interested in taking part in the study, individuals were asked if they were available immediately or on a different day. An appointment day was set for individuals who wanted to interview on another day. Ten WLWH with pain and ten WLWH without pain were recruited. All potential participants were requested to sign an informed consent form, which asked for permission to have access to their Ndlovu medical file for their medical information, including their HIV status and permission to audio record the interview. The participants were reassured that all the information retrieved from their Ndlovu medical file and the recording would be kept confidential. The participants were informed that only the research staff and the transcribers would have access to their interview recordings. The transcribers' role was to only transcribe the interview recording. Therefore, the interview recordings were sent out without participants' identifiable details. The participants were also informed that their interview recordings would be kept in an online Google drive folder password-protected and immediately deleted from the recorder.

Once the informed consent form was obtained, participants were asked to be as honest and open as possible for the accuracy and validity of the study. The interviews were conducted in their preferred language. Furthermore, the participants were warned about the risks of taking part in the second part of the study, including experiencing anxiety/stress. A distress protocol was used to refer participants to a social worker at the research facility. If the participants experienced anxiety/stress due to the questions. Additionally, participants were informed that there were no direct benefits in taking part in the study, but there was a potential future benefit of informing interventions that will help people cope with living with either pain or HIV, or both HIV and pain.

The languages spoken in the area are isiZulu, Northern Sotho, Southern Ndebele and Sotho. Therefore, a translator was made available for participants who needed the interview questions to be translated to their language of choice. However, due to perceiving that the translator was influencing how the participants were answering their questions, it was decided from then on to recruit participants who were able to understand the English language. It was found that even though the participants recruited understood the English language, there were usually commonly misunderstood words (e.g., “diagnosed” and “average pain”) by the participants. Therefore, the translator was asked to translate these commonly misunderstood words e to use during the interview.

Data were collected until saturation was reached for most of the themes. Data saturation occurs when the data collected adds nothing new to the understanding of the research topic (O’Reilly and Parker, 2013). A semi-structured interview guide was developed from grounded theory (Appendix 5). Grounded theory methodology is a systematic procedure that develops a hypothesis by reviewing the literature (Draucker *et al.*, 2007). For the development of the interview guide, literature was reviewed, and questions are developed. The literature on pain, pain and activity, disclosure of pain and the impact of disclosure in people living with chronic pain and in PLWH was reviewed in order to develop the semi-structured interview guide for this study. The interview guide was developed by the supervisors and me by creating interview questions that aimed to answer the research questions or that aligned with the research objectives. A semi-structured interview was used because it allowed for easy discussion of sensitive topics and was well suited for exploring the attitudes, values and beliefs of the individual (Jamshed, 2014). The interview guide was designed to be as specific as possible in order that saturation could be reached with a relatively small sample. The questions asked helped answer the following research questions:

- How does HIV and/or 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 women living with HIV?

2.5.1 Data analysis

In-depth interviews were audio-recorded and transcribed verbatim by experienced transcribers. Interviews in local languages were transcribed into the local language and then translated into English for data analysis. Thematic analysis was used by reading through the transcripts and then generating codes, and then themes were developed. Thematic analysis was used because it allows room for flexibility in interpreting large data sets through identifying, analysing, and reporting patterns within the data set to create themes (Braun and Clarke, 2006). The themes were then used to answer the research questions. Interviewer's comments were added in some cases to give context to the participant's response, without which the response did not make sense. The first three transcripts from participants living with HIV and pain were coded independently by myself and two supervisors. Three HIV and pain transcripts were used because they were judged to be the longest interviews and therefore would generate adequate codes for the coding framework. The codes created were then used to code all the other transcripts that fall under all categories interviewed (HIV and pain and HIV without pain). New codes that were developed during further analysis of other transcripts by the investigator were shared with the analysis team. If codes were agreed on, the codes were added to the code book. A software was not used for analysis, and coding was done manually.

2.5.2 Reflexivity

Reflexivity is a way that researchers in qualitative research ensure accuracy and quality in the data collection process (The and Lek, 2018). The process is done by researchers examining their own judgements, belief systems and practices during the data collection process (Dodgson, 2019). Reflexivity allows the researcher to identify any personal beliefs that may have affected the data collection process and thus the results of the research (Berger, 2015). Socio-demographic factors like age, race, cultural backgrounds, and socioeconomic status of the researcher and the participants need to be taken into consideration while collecting data and considered that they may influence the data collection process and the analysis of the data (Berger, 2015).

During data collection I was aware that I was a young black female researcher recruiting women of a similar race and similar cultural background. I was aware that this could affect the recruitment of participants and the enrolment into the study. The women may have felt inclined to participate as they saw a young black woman collecting data. They may also have been more open to discussing their HIV and pain status with me because they identified with my race and cultural background.

During the process of data collection participants got very emotional when they were discussing their pain with me. There was great sorrow and the feeling of helplessness regarding their pain. I am aware I should have listened as a researcher. This was however hard for me. I was usually saddened by their life stories about living with HIV and additionally living with pain. This may have influenced me as a researcher in reporting their pain status and the effects that pain has on participants.

CHAPTER 3

RESULTS

Summary

A hundred and twenty-five women were recruited to be part of the quantitative section of the study. The prevalence of pain in this cohort was 50% (63/125). HIV status, age, education, employment, and current CD4+ T- cell count depressive symptoms did not associate with having pain ($p>0.05$). Education, employment, and HIV status did not associate with pain intensity. The pain was of moderate to severe intensity (5(4-6)) (median (IQR)). The most commonly reported pain sites were the chest (33%) and the lumbar spine (24%). The semi-structured interview took place at the NCR by the investigator (master's student). The interviews took an average of 45 minutes to an hour. Six themes and 11 sub-themes were identified in (Appendix 8). Results from the qualitative interviews show pain-affected activity in women but only during painful episodes. Disclosure of pain by WLWH and pain was highly motivated by the need for social support. WLWH and pain were able to recruit social support. WLWH and pain practised full disclosure of pain, selective disclosure of pain and partial disclosure of pain to prevent negative impacts of pain disclosure.

3.1 Quantitative section Sample characteristics

A total of 125 women were recruited to be part of the quantitative section of this study. Data collection took place between March and July 2019. The participants were middle-aged (40[32-50] median [IQR]), with most of them having completed secondary education (68%, 85/125) and mostly unemployed (67%, 84/125). A total of 60 participants (48%) were reported to be living with HIV, 7% (6/60) of whom had seroconverted following recruitment to the main study. The participants' HIV was well controlled (as defined by a current CD4^{+} T-cell count >500 cells/mm^{3}) (Table 5 with a median (IQR) current viral load of 2458 (199-26229) copies/ml. Seventy one percent had a viral load <20 copies/ml and 3% had a viral load <50 copies/ml. Using the PHQ-9 categories (Spitzer *et al.,* 1999), 86% (107/125) of the participants were minimally depressed. A small proportion, 12 % (15/125), reported mild depression, and 2% (2/125) reported moderate-severe depression. No one had severe depression.

3.1.1 Pain in the cohort

Half of all the women (50.4%, 63/125) reported pain for the past three months with a median (IQR) pain severity score of 5(4-6) and a pain interference score of 7(5-10). Table 4 shows the different pain intensity scores from the BPI.

Table 3: Pain sites in the 63 people with chronic pain.

Location of pain (n=63)	Frequency (n (%))
Chest pain	21 (33)
Lumbar spine	15 (24)
Abdomen	12 (19)
Thoracic spine	11 (17)
Head	10 (16)
Shoulder	10 (16)
Knees	10 (16)
Hip	9 (14)

n=63 is the number of people that reported living with pain.

The 63 women who reported pain reported a median number of 2 (range 1-3) different pain sites. The most commonly reported pain sites were the chest, lumbar spine, abdomen and thoracic spine (Table 3).

Table4: BPI pain intensity scores for the 63 women reporting pain Median (IQR)

Pain severity score	5 (4-6)
Worst pain	8 (6-10)
Least pain	4 (3-5)
Pain right now	2 (1-4)
Pain interference	7(5-10)

Pain severity score is calculated as a mean of worst pain, least pain, and right now.

Pain interference score is calculated as mean seven daily activities, including general activity, walking, work, mood, enjoyment of life, relations with others, and sleep.

3.1.2 Association between demographic and clinical factors and having pain

Univariate analyses were used to determine associations between demographic and clinical factors and having pain. None of the factors tested, including the level of education, employment status, age, current $CD4^{+}$ T-cell count, HIV status or depression status, were associated with having pain (Table 5).

Table 5: Comparison of demographic and clinical factors between participants with and without pain.

Characteristics	Entire cohort (n= 125)	Pain (n= 63)	No pain (n= 62)	p-value (pain vs. no pain)
Education (n (%))	123(98)	61(49.59)	62(50.41)	
Completed primary	25(20)	12(19.67)	13(20.97)	p = 0.69^{+}
Completed secondary	83(67)	40(65.57)	43(69.35)	
Completed tertiary	15(12)	9(14.75)	6(9.68)	
Employment (n (%))	41(33)	21(51.22)	20(48.78)	
Part-time	13(37.71)	8(38.10)	5(25)	p = 0.66^{+}
Full-time	27(65.85)	13(61.90)	15(75)	
Unemployed	84(67)	42(50)	42(50)	
Age*	40(50-32)	41(46-33)	40(51-30)	p = 0.89$^{\#}$
Current CD4 cell count (cells/mm^{3})*	580(708-431)	570(391-708)	581(687-475)	p = 0.88$^{\#}$
HIV status (n (%))				
HIV positive	63(50.4)	30(47.62)	33(52.38)	
HIV negative	62(49.6)	30(48.39)	32(51.61)	p = > 0.99$^{£}$
PHQ-9*	0(0.22-0)	0(0.28-0)	0(0-0)	p = 0.11$^{\#}$

*Data shown as median (IQR) for non-parametric data

$^{+}$ Chi squared test

$^{\#}$ Mann-Whitney two sample statistic (non-parametric data)

$^{£}$ Fishers exact test

PHQ-9 scores are presented as mean scores of the cohort

3.1.3 Association between demographic and clinical factors and pain intensity

Univariate analyses were used to determine associations between demographic and clinical factors and pain intensity. Level of education (Kruskal-Wallis test; p= 0.74), employment status (Kruskal-Wallis test; p= 0.82) and HIV status (Mann- Whitney; p= 0.69) were not associated with pain intensity. Figures 3.1.3a, 3.1.3b and 3.1.3c show that there was also no association with age, $CD4^+$ T-cell count and depression status either.

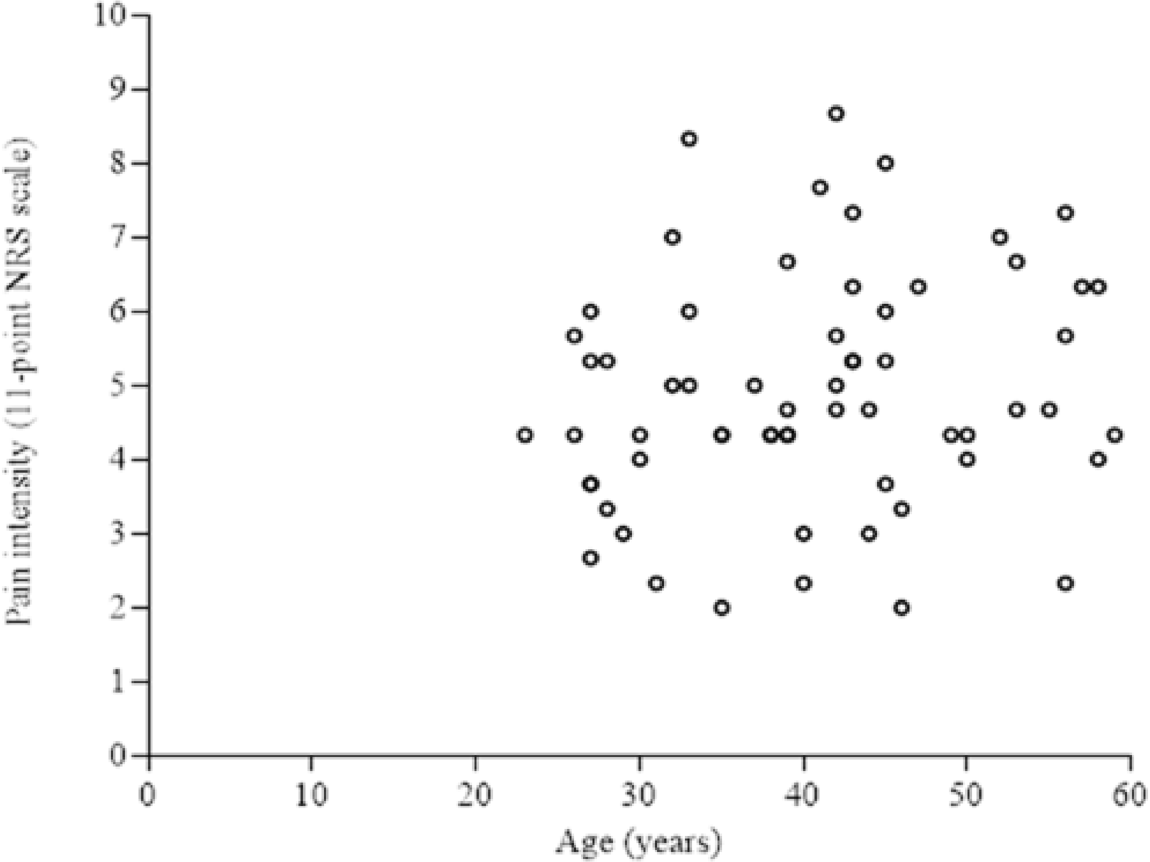

Figure 3.1.3a: No correlation between pain intensity and age (years) of 63 people living with chronic pain (Spearman's correlation: r=0.18, p=0.16)

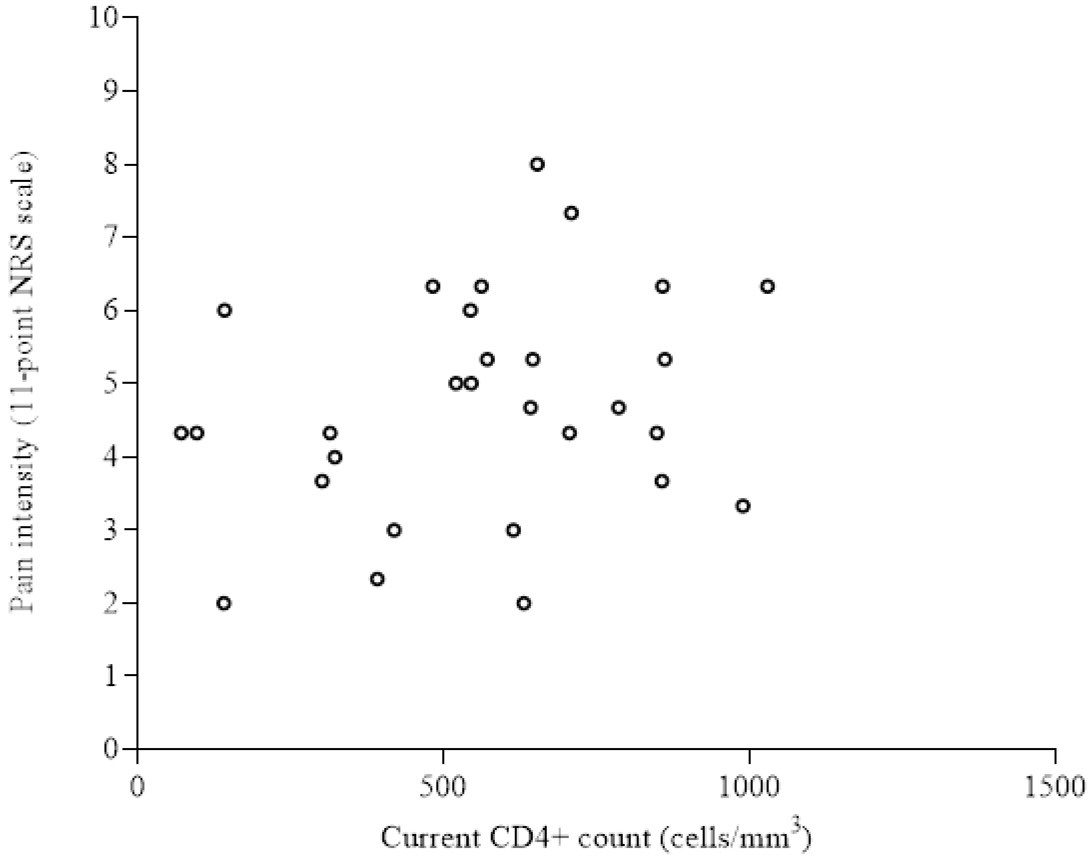

Figure 3.1.3b: No correlation between pain intensity and current $CD4^+$ T-cell count (cells/mm3) of the 63 people living with chronic pain (Spearman's correlation: r= 0.29, p=0.12)

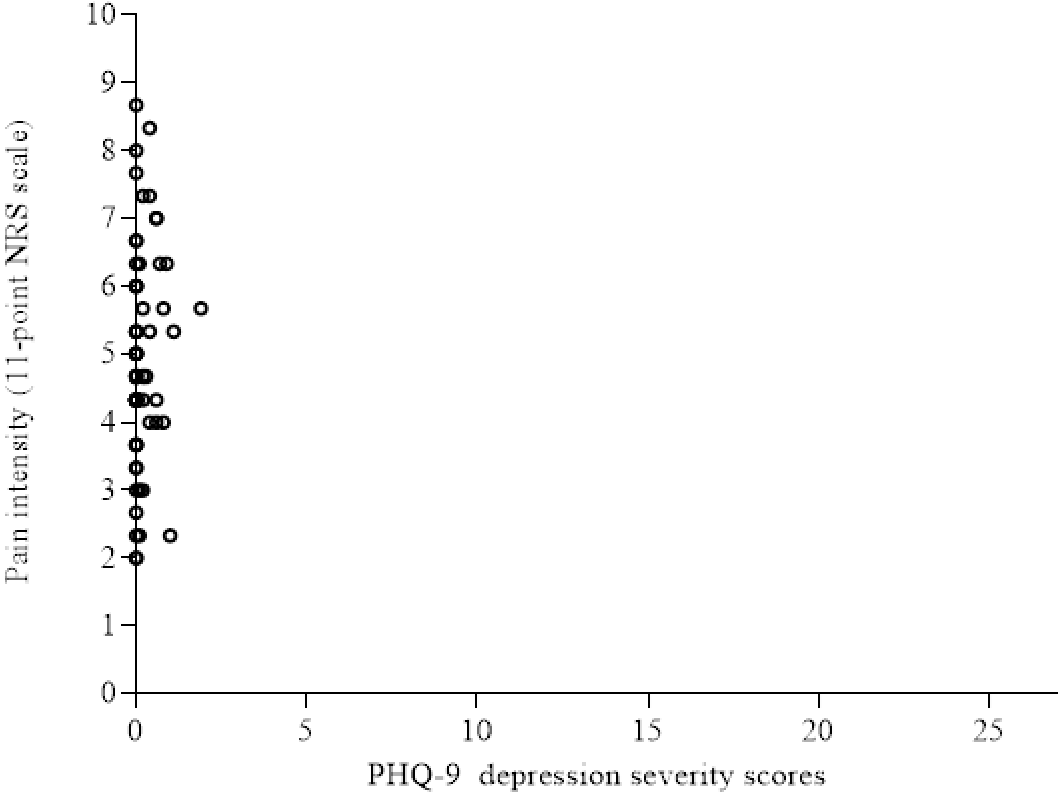

Figure 3.1.3c: No correlation between pain intensity and mean PHQ-9 depression severity scores of 63 people living with chronic pain (Spearman's correlation: r= 0.17, p= 0.19

3.2 Qualitative section

Demographic and clinical characteristics of the qualitative cohort

Ten WLWH and pain and ten WLWH without pain were recruited to take part in the qualitative component of the study. The sample of WLWH who took part in the qualitative section represented women with a median age of 38(36-44) years [all values in this paragraph are median (IQR)], with most of them having completed secondary school education (80%, 16/20) and mostly unemployed (75%, 15/20). The women had been living with HIV for 9 (4-10) years with a median current $CD4^+$ T-cell count of 618 (504-777) cells/mm^3. Their median current viral load was 13640 (9102-43443) copies/ml. Sixteen WLWH had a viral load of <20 copies/ml. One WLWH had a viral load <50 copies/ml, and three WLWH had a viral load >50 copies/ml.

3.2.1 Qualitative findings

Six themes with sub-themes were identified from the data. The themes included: participants' perceptions about their community, healthcare system, participants' experience of living with HIV; Pain management and perceived cause of pain, factors influencing disclosure of pain and the impact of disclosure for WLWH and pain. Four themes were common for WLWH and pain and WLWH without pain regarding the experience of living with HIV, the disclosure of HIV status, perception of the community, and perception of the healthcare system.

Table 6:Table of themes and sub-themes identified

Themes	**Sub-themes**
Theme 1: Participants perceptions about the community they live in	
Theme 2: Participants' perceptions about the healthcare system and healthcare providers	
Theme 3: Participants' experiences of living with HIV	**Sub-theme:** Experience of living with HIV and pain **Sub-theme:** Pain interferes with daily activities in WLWH and pain
Theme 4: Pain management and perceived cause of pain.	

Theme 5: Factors influencing disclosure of pain	**Sub-theme:** Pain disclosure to recruit social support **Sub-theme:** Partial and Selective disclosure of pain **Sub-theme:** non-disclosure of pain by WLWH and pain
Theme 6: The impact of disclosure for WLWH and pain.	**Sub-theme:** Disclosure of pain led to increased social support for WLWH and pain. **Sub-theme:** Negative impact of disclosure on WLWH and pain

Theme 1: Participants perceptions about the community they live in

To understand the context that the WLWH were living in, I first asked about their perceptions of the community that they live in. Participants described their community as underdeveloped, with some participants describing it as a rural area, a poor place, and a cheap place to live. Participants reported a lack of shops, factories, farms, or companies in their area which led to a lack of jobs within their communities. The community was also characterised by increased drug use among young people and crime.

> "It's rural, and it's very poor. There are just schools. There are no firms or shops…. there are no farms, it's like a small rural place… when you want a job you will have to go to Pretoria and then it's too far. It's rural and it's very poor. Our community doesn't have those things like shops, and there are no firms, just schools". (IDI A002, 42years old, WLWH no pain)
>
> "The small boys and small girls they are smoking dagga and the dagga leads them to smoke *Nyaope* (street drug including heroin) and in our community, there is no job so they break into the house and they steal something from other neighbours [to buy more drugs]" (IDI A056, 44years old, WLWH no pain)

For several reasons such as social HIV-related stigma and lack of support among community members, some participants did not like living in their communities. The perceived lack of social support reported resulted in some of the participants not asking for help from people in their community for fear of *"being talked about/gossip"*, which was defined as "people talking about you" or "people sharing your problem with other people". Participants feared that the people they sought social support from in the community would disclose their problems to others in the community.

> "People they like to talk too much…They talk too much about you, that's why I don't like living here. Where I am staying, we don't help each other, and each person just lives their life. I have this thing that "God must help us" (IDI A099, 44years old, WLWH no pain)
>
> "There's prejudice. Like people do not care about other people, especially when they find out you are sick. Especially when you are HIV positive, when you are sick, you get down (you feel down). They judge you, you see. I don't like to live in my area. In my area, you know, we don't help each other. I remember in 2017 at home we got a fire in our home when we were sleeping at night. But when we scream as we went out, as no one helped us" (IDI A014, 28years old, WLWH and pain)

Despite the negative community perceptions reported by other participants, there were some participants who reported being comfortable living in their community because of the lack of HIV-related stigma and the lack of crime. Consequently, participants who were comfortable living in their community reported high social support from the community, with the participants being comfortable recruiting social support from the community.

> "It's okay. They are treating me well; my neighbours know about my condition (HIV status), so I see us living well. They really support me because they address me well, they don't slag (criticize) you know. They don't go around pointing at me. You see things like that. I do get support from them". (IDI A029, 54years old, WLWH no pain)
>
> "My community has people that help each other, comfort each other and mostly go to church together. When you are hurting or when you are suffering with something, they come and sit with you and talk to you so that they can understand you. We just pray together and . . . like, what can I say? We pray together and talk too much [a lot] about your situation. I ask for help from everybody, those who are just around me. If there is anything that they can help me with, even if I am hurt, if I don't have the food, they are able to support me" (IDI A002, 42years old, WLWH no pain).

Theme 2: Participants' perceptions about the healthcare system and healthcare providers

Participants were asked about their perceptions of the healthcare system in their community and of the staff at the different healthcare facilities they visited. Participants reported receiving healthcare at different healthcare facilities, for example, in clinics, hospitals, and Ndlovu

Research Center. The healthcare facilities were described as poor and characterised by lack of doctors, and medication, especially in government-owned health facilities like clinics and hospitals.

> “At my clinic, we don’t have doctors. It’s only professional nurses. It’s the smallest clinic”. (IDI A002, 42years old, WLWH no pain)
>
> “Sometimes when you go there (local public hospital), they say that there is no treatment(medication) because my friend goes there and comes back and tells me that they say that there is no treatment” (IDI A099, 44years old, WLWH no pain).

While some participants reported poor facilities at their local clinics and hospitals, it was encouraging to learn that participants held positive perceptions about the nurses. Most participants reported that the nurses were friendly and kind to them and easy to open up to them regarding their problems. Some participants further shared that the nurses offered them counselling, encouraging adherence to their ARVs and giving them advice on living with HIV and offering food parcels.

> “The sisters are also nice and kind, and if you have a problem you can speak with them, it’s very easy there. The nurses there are happy and kind, and you can ask any question. We sit and talk, just as we are sitting and talking. Before they give you treatment, you first sit down and chat, ask you whether you are using a condom and how it is before they write down a prescription for you. You are happy, and then they tell you to have a nice day, and you become okay.” (IDI A099, 44years old, WLWH no pain)
>
> “The nurses support me. They give me support. They tell me that I will be okay. If you take your pills well, only if you take your pills well then you will be all right, they support me” (IDI A029, 54years old, WLWH no pain)

While some participants expressed a positive attitude towards the nurses, other participants in the study shared negative perceptions about the nurses. Participants reported on some nurses refusing to assist them and dragging their feet during work. Participants described nurses as lacking passion for their work, uncaring towards patients and being rude, lazy and invested in gossiping during work. One participant explains how she was mistreated during her clinic visit because she missed the scheduled appointment:

> "There's this one day when a nurse shouted at me for missing my appointment and said, 'we will not assist you now, but after we have assisted everyone else'. Sometimes, when you missed your visits, nurses will say 'we can't help you because you missed your appointment date. We'll assist you after everyone who has honoured their appointment date because you missed yours'" (IDI A037, 35years old, WLWH no pain)

Another, participants emphasised that the nurses are lazy and that they like to gossip: "They (nurses) are lazy, they are lazy, and they like other people's news/gossiping" (IDI A078, 29years old, WLWH no pain)

Theme 3: Participants' experiences of living with HIV

To better understand participants' experience with living with both HIV and chronic pain, I asked about WLWH's experience with living with HIV to compare the experience with living with HIV and pain. Most participants, both living with HIV and pain and no pain, reported a positive outlook on life, with most participants reporting treating HIV as "any other chronic disease or HIV being similar as having flu. This resulted in most women reporting their life being "normal" and being "alright or fine".

> "I am right. That is why I take it as just flu. But then I told myself that it does not matter. It's a part of life, right". (IDI A084, 45years old, WLWH with pain)

> "My life is normal now. It is not something that I am still thinking about. I just take it as a chronic illness" (IDI A096, 46years old, WLWH with pain)

This positive outlook of life resulted in most participants accepting their HIV status.

> "Now where I am at now…I have accepted everything I am fine now…there are times I even forget I am HIV positive" (IDI A078, 29years old, WLWH no pain)

> "In the first time, it was tough! I wanted to find out where I got it. Why me? That means God does not love me? It means I did not do the right things. Why mina (why me) all those things? But now I understand. And I have accepted myself that I am HIV I have to live with this disease" (IDI A056, 44years old, WLWH no pain)

Half of the participants (10/20) attributed their positive outlook on life as a result of HIV counselling, they received from the clinic or hospital where they received HIV treatment.

> "I attended counselling at the hospital and started taking my treatment there, and I become alright. My life is normal now. After starting on my medication, I noticed that when you are in therapy, they tell you that life will not change much. What you need to change is your lifestyle because you need to use a condom all the time and even though it would be difficult, you just need to try, also not to have multiple partners, and eating a balanced diet, also you need to share if something is bothering you because the more you keep quiet, the more your immune system becomes worse" (IDI A096, 44years old, WLWH with pain)

> "I went to counselling. At the clinic, when I was fetching my pills, I would request counselling. Okay then I went to counselling and then I got used to it and then I also told myself that…I will be okay" (IDI A078, 29years old, WLWH no pain)

Four participants reported that their lifestyle changed after being diagnosed with HIV. HIV was considered a life-altering experience because these women lived with the fear of being rejected by people around them. Adherence with their treatment affected their social life; some felt they were no longer in control of their lives.

> "My life has changed a lot! Because I felt bad, we used to hear about HIV from other people and we used to think that it is for people that go sleeping around, maybe too much too much boyfriend and you just wonder what people might feel, they will think you were a whore". (IDI A96, 44years old, WLWH and pain)

> "You no longer live like a normal life like before. There are changes somewhere like life controls itself, you no longer in control it". (IDI A014, 29years old, WLWH and pain)

Other participants in this study reported that their physical body had changed because of being HIV positive. Physical changes reported included losing weight due to loss of appetite and having TB.

> "My body also changed, like sometimes I get tired. Sometimes I get dizzy. Sometimes I don't want to eat food, yes, I can't eat sometimes! Sometimes I must eat too much" (IDI A014, 28years old, WLWH and pain)

> "I lost weight because I didn't discover early about the TB. It's like you are wearing something and your face does not look good and then people stare at you and some people have the courage to tell you what you can do to be okay and get to your normal self" (IDI A002, 42years old, WLWH no pain).

Living with HIV was also reported to cause an interference with daily activities, with participants reporting being dizzy or feeling drowsy while performing their daily activities like work.

> "… living with HIV like is difficult because when you take your treatment at 20H00 like you feel dizzy. When you wake up you still feel dizzy, like you have to wait until you feel right first. Sometimes when you are working you can feel that now I have to sit down" (IDI A014, 28years old, WLWH with pain)

> "So, it [HIV] used to disturb me every time and when I would be working it's…I would be drowsy" (IDI A056, 54years old, WLWH no pain)

3.1 Experience of living with HIV and pain

Ten WLWH also reported living with pain and they described their pain as being severe in intensity and constant. The pain was characterised as "very painful", "severe" or "overwhelming" and therefore unable to do anything.

> "This pain like when it hits my body it becomes very painful. It gets too painful, too much. I just like sleep. It's not nice to live with pain because this pain like when it strikes the body…it's painful. The pain is so overwhelming I can't do anything". (IDI A014, 28years old, WLWH and pain)

> "I feel this pain, man it's painful yeah. Pain is too severe I can't do anything…It's painful because it doesn't want me to move. Even at home, all family, my friend, my neighbour, and my children I tell them that this pain will kill me". (IDI A084, 45years old, WLWH and pain)

Furthermore, other WLWH and pain (3/10) expressed their experience of living with both HIV and pain as a 'constant reminder and life altering burden'.

> "When you are living with both of them, HIV and pain. You are always thinking about it. It means I have two friends, and these are friends that I am always with and I cannot take my pain or the virus and give it to you". (IDI A096, 44years old, WLWH and pain)

Half of the WLWH and pain (5/10) reported pain was more burdensome than living with HIV. Some women reported that the pain caused a negative emotional effect not only on themselves but to people around them or to their social support structure.

> "HIV is not the problem, it's this pain in my heart. It worries me. Shame, but I will make my kids unhappy, my family will also be unhappy because when it starts, even my father as old as he is worries and then not eat. Just sit there" (IDI A084, 45years old, WLWH and pain)

> "I don't have a problem with HIV. The problem that I have is this one of the pain that I am suffering from. I comply with the HIV treatment. The treatment is good on me. Yet what is not good to me is this pain. The pain does not make me to live happily. I am not even able to socialise with the community because I am not feeling good anyway because of the pain, I am not feeling good. Once I am seriously suffering from it, seriously, I don't feel good" (IDI A006, 46years old, WLWH and pain

3.2 Pain interferes with daily activities in WLWH and pain.

To explore how pain interferes with activity in WLWH with pain I compared daily activities between WLWH with pain and WLWH without pain. Participants were asked to describe a typical day for them, and what daily activities they performed. Daily activities reported by WLWH and pain and WLWH without pain included housework, child-care, self-care, and spending time resting, for example, watching television, reading books, and sleeping. Three WLWH and pain (3/10) and two WLWH without pain (2/10) were employed and their employment duties included child-care, housework, and office administration work. There were no differences in the types of daily activities performed by WLWH with pain and WLWH without pain. WLWH and pain reported that their pain interfered with their daily activities such as cleaning and other household chore and made them unable to do anything during the painful episode.

> "I can't do anything, I can't even clean or anything. When this pain hits me, it (pain) hits me to a point that I just sleep. I must sleep because the pain runs like straight to my heart. Because when it strikes like I struggle to breath. The pain is so overwhelming I can't do anything." (IDI 014, 28years old, WLWH and pain)

> "Eh there's nothing I am able to do, there's nothing I can do. When I hold something, it falls. Nothing I can do. Nothing (There is nothing I can do, I can do nothing). No, I would not do anything. I am just sitting. I just sat at the couch busy with my phone. Pain is too severe I can't do anything". (IDI A084, 45years old, WLWH and pain)

Some WLWH with pain reported the fear of continuing with daily activities or performing their daily activities while in pain. They reported the fear of collapsing while doing daily activities, making themselves tired, hurting themselves and making the pain worse. Therefore, these women usually did "minor work", rested in between daily-activities, and rested until the pain got better.

> Interviewer: Why do you do minor work?
> Participant: Because am in pain and I am afraid that I will fall
> Interviewer: so, you decrease your level of activities. Ok, why do you limit what you are doing?

> Participant: Because of the pain, I am feeling pain.
> Interviewer: if you do not limit what happens?
> Participant: the pain will be too much (IDI A096, 44 years old, WLWH and pain)

A few of the WLWH with pain also reported that while they experienced sever painful episodes, they felt compelled by their circumstances to continue with their daily activities despite the pain being severe. Compelling circumstances included work due to fear of possibly losing their job, not wanting to disclose their pain due to fear of discrimination by colleagues and lack of someone to take over the activities. Amongst the WLWH and pain who were employed, two of the women reported continuing with daily activities despite being in pain during work because of fear of losing their job and discrimination from colleagues.

> "There is a day at work I couldn't even pick up the baby. The baby was lying there crying, I was just giving the baby his bottle. I couldn't do anything to help the baby… And I was afraid to tell his mom about my pain. I thought maybe I would lose my job. Sometimes I think maybe she will go and get someone else, so I continue doing my job while in pain to keep my job. Because that money she's giving me help me with the food for the kids." (IDI A013, 43years old, WLLWH and pain).

> "I just start wondering how people at work will start treating me and viewing me, so I just continue with my work and taking my treatment". (IDI A096, 44years old, WLWH and pain).

Another participant shared her experience of living with pain and how she will continue being active or performing her daily activities despite being in pain was the lack of someone to assist with the daily activities. Especially when the children were too young or parents too old to take over the daily chores.

> "These chores must be done; no one is going to do them for me so, yah but who is going to do them? I am the one who is supposed to do them, no one is going to do them for me. I fetch water, I carry buckets full of water to the house, that is because we fetch water from outside, and so I take the water inside. Yes, who is going to fetch water for you? My kids are young, a 12-year-old will not be able to carry a 20litres bucket (IDI A060, 35 years old, WLWH and pain)

"I'm on my own my mother is 62, my father is 73 so the kids are still young I cannot say they are going to come back from school and sweep and what about the cooking? If am in too much pain that is when my mom will come and stand up and let me help you here and there, but she is old. I have just told you that I mean like I'm home alone, so the boys are like young. I am the only lady in the house. Mom is too old so how will I leave them like that I

> will not let them be there like one day or two I have to do something (IDI A089, 27 years old, WLWH and pain)

Theme 4: Pain management and perceived cause of pain.

WLWH and pain reported using various pharmacological and non-pharmacological pain relief methods. Pharmacological pain relief methods included over the counter "Painblock" tablets (which contain paracetamol and aspirin) and muscle ointment for pain (locally in South Africa called "Rub-rub"). Two participants in this study reported prescribed medication for the treatment of pain when they were seeing by the doctor.

> "The doctor told me that I have stress, it's the nerves, and my nerves are damaged. He then gave me tablets to take for the pain". (IDI A006, 46years old, WLWH and pain)

> "I have also consulted the doctor about it [pain] and the doctor prescribed some tablets to drink. When they see that the pills that they gave me are not working, they will then prescribe other tablets for me, strong ones, like the tramadol, which are strong pills for the pain" (IDI A096, 44years old, WLWH and pain)

Non-pharmacological pain relief methods including resting or relaxing and sleeping were reported as ways to treat the pain.

> "I just take pain blocks and sit down and relax a bit that's all. Sometimes it is taking long it happens to hurt me here (abdomen) and I drink [take] the pain blocks and my mom likes rub-rub and she would do that (shows massaging of muscle ointment)" (IDI A089, 27years old, WLWH and pain)

> "I always have tablets in my bag, so I take the tablets and drink. Sometimes, I normally use a rub. There is also some medicine from different companies, which helps the pain to go away for a while. I sit down and rest and start working if I feel better, but I wouldn't be as active as I was before" (IDI A096, 44years old, WLWH and pain)

Participants reported various reasons for the severe pain that they experienced such as pain caused by medical conditions (hysterectomy and a heart condition), stress or thinking too much, and a car accident. One of the participants explained that her pain was caused by her getting a hysterectomy (a surgical procedure to remove the womb (uterus)):

> "I think the pain was caused by removing the womb, I think it's that because it happened after removing the womb, before removing the womb I did not have this pain". (IDI A096, 44years old, WLWH and pain).

Another participant related her pain as a result of a heart condition affected by the lungs not functioning properly:

> "I breathe with my heart. I no longer breathe using my lungs but I breathe using my heart so that's why after some time it tires. The pain is caused by the lungs that are malfunctioned and the heart is getting weak". (IDI A084, 45years old, WLWH and pain).

Furthermore, one participant shared that her pain is because of psychological distress which she expressed as 'stress or thinking too much'

Another participant believed that her back pain was caused by an accident she had in the past.

> "The back pain? Okay it was when I got hurt by the car". (IDI A013, 43years old, WLLWH and pain).

What is very interesting to note is that none of the participants in this study who are living with HIV and pain, related their pain to their HIV status.

Theme 5: Factors influencing disclosure of pain

To determine factors influencing the disclosure of pain by WLWH and pain, I first explored factors influencing the disclosure of HIV status. I wanted to see if there were similar reasons for pain disclosure as for HIV status disclosure.

The prevalence of HIV status disclosure was high in this cohort of WLWH with and without pain. Both groups, WLWH and pain and WLWH without pain, reported disclosing their HIV status to at least one person. Among the 20 WLWH, ten had disclosed their HIV status to their parents, ten to their sisters, five to their brothers, 14 to their partner, eight to friends/neighbours, one to colleagues/boss and five to individuals from their community. The participants in both groups (WLWH and pain and WLWH without pain) reported similar reasons for HIV status disclosure to their disclosure targets. The reasons for HIV status disclosure can be reported in the following sub-themes:

HIV disclosure to avoid HIV transmission

Participants disclosed their HIV status to their disclosure targets for fear of transmitting HIV through accidents and injuries. They feared their disclosure targets would come in contact with their blood while assisting them during an accident or injury. Thus disclosing to them will ensure their safety and vigilance when they are being assisted in case of accidents involving blood or other bodily fluids.

> "I told them (family) so that when I am sick or blood is coming out from me, they know how to handle my situation. Like if I get hurt now and then maybe blood is coming, they must know because they should protect themselves right, even if you see me bleed right now, you must know that you must not just touch my blood because I am HIV positive" (IDI A096, WLWH and pain)

HIV status disclosure to seek social support

A total of eight participants (four WLWH and pain and four WLWH without pain) disclosed their HIV status to recruit for social support. Participants expressed their need for social, physical and emotional support for living with HIV.

> "So that they (family) can give me support because when you have HIV a lot of things begin to attack your body, sometimes you will become sick right?" (IDI A096, 44years old, WLWH and pain)

> "I was taking a huge load of the kids' shoulders. Now he (partner) can remind me. That now it's time to take your pills he will take the pill and give me the water". (IDI A056, 44years old, WLWH no pain)

Another participant identified the need for support during treatment. She shared that she wanted someone to assist with adherence to treatment (ART) to encourage and remind them to take the medication. Some participants wanted their sexual partners to know their HIV status and their own HIV status. These women also believed that adherence to ART would be easier if their partners knew their HIV status.

One participant in particular substantiate the need for treatment adherence support by relating her reason to disclose to her sexual partner and thus ultimately being free to take treatment openly.

> "He is my partner I have to tell him and try to influence him to go and get tested as well, so that we can take the medication together and support each other". (IDI A096, 44years old, WLWH and pain)

While other participants in this study addressed the need to disclose in order to recruit social support, other participants felt the need to live freely and without feeling suspected.

HIV status disclosure for self-liberation and to avoid suspicion from others

Participants disclosed their HIV status to be liberated from keeping their HIV status a secret. Out of 20 participants, eleven reported that they disclosed their HIV status to avoid suspicion from others. These WLWH wanted to feel free to take their ARVs without hiding them or keeping it a secret. Moreover, participants felt that keeping their HIV status a secret would affect their mental health and thus disclosed their HIV status to protect themselves from stressing over not disclosing their HIV status. Participants reported "wanting to be free", "to let it out".

> "I wanted to let it out so that I can be alright and for it not to always be on my mind because it was going to affect me". (IDI A060, 35years old, WLWH and pain)

> "I told her (sister) because most of the time we are close (together) when I have to take my pills, I have to come up with a plan of how to take it, go and drink it somewhere you see things like that". (IDI A029, 54years old, WLWH no pain)

Disclosure of HIV status maybe easy for some people and a challenge for other depending on who to disclose to and the reasons for disclosure. While most participants in this study have disclosed to at least one person, others experienced the initial hesitancy to disclose while other chose who to disclose to and who not to disclose to. The three levels of disclosure were categorised as delayed disclosure, partial and selective disclosure:

Delayed HIV status disclosure to sexual partner

Some women reported late disclosure of their HIV status to their partners because of fear of abandonment by their partners. Participants feared their partners would end their relationship if they knew their HIV status, so it took them a while before disclosing their HIV status to their partners.

> "It took a while for me to tell him (partner) until there came a time when I was forced to tell him. It wasn't easy to tell him, and I thought that he will leave me and then I told myself that if he leaves me then so be it" (IDI A037, 37years old, WLWH no pain)

While some participants were hesitant to disclose their HIV status to their partners, others decided to select who they disclose to.

Selective disclosure of HIV status

The term 'selective disclosure' in this research refer to participants disclosing their HIV status to some people and intentionally deciding not to disclose to others. While almost all participants, except for one, had disclosed their HIV status to at least one person in their lives, all had practiced selective disclosure. That is, all participants had someone that they decided not to disclose to about their HIV status for reasons such as lack of trust, that person not being important or knowing that person as a gossip monger or fear of being judged/ discriminated against and for a few others being to protect their loved ones from psychological distress.

> "Why must I tell them (community and friends)? There is no need…No! It's my business. It's none of their business. They don't need to know. My status is my status. It does not need anyone else. Like the people that I see as important I have told them and they know. It's about me. It's my business. What if they have it and they are not telling me? No! I won't tell them! No never! For what? What will they do once they know? (IDI A078, 29years old, WLWH no pain).

The lack of trust and the fear of being "gossiped about" was the driving force for selective disclosure of HIV status by most participants. Participants feared that the people they disclose to will discuss their HIV status with others in public.

> "I did not tell this other one (sister). She is someone who talks a lot. Like she is someone who talks a lot also maybe I was going to tell her, and she will go to my next-door neighbour and talk about me over a cup of tea, those types of things, I did not tell her. (A007, 45years old, WLWH and pain)

> "They will say 'do you know that sister is positive?' Then the other one says Ha I do not know.… Yes, then that one will tell that one…that one will tell that one will tell other one and that one will tell the other one. Even my brothers I did not tell them because they will tell my sisters and my mom. There are a lot of things I don't share with her (sister) anymore because she talks, and she likes to gossip". (A056, 54years old, WLWH without pain).

Furthermore, other participants chose to not disclose to others based on experience where others expressed negative perceptions and attitudes towards people living with HIV. The decision for non-disclosure is fuelled by fear of potentially expected mistreatment and discrimination for living with HIV.

> "No even my mom I have not told her. It's because when I am sitting with them, the way they talk about HIV, and you will hear them saying things like 'Ya, people with HIV are people that like men (promiscuous). I don't want anyone who is HIV positive to get close to me'. That is why I cannot tell them. I would like to tell them but the way they talk about it (HIV), that is when I decided it is not good to tell them. Even my mom, she is afraid of HIV, she takes it like in the olden days. That you should not sit next to people who are HIV positive. You must not touch a pen or drink from the same cup as them. I just don't want them to get to that level with me". (IDI A056, 54years old, WLWH no pain)

For the same reason as participant A056, participant A007 chose not to disclose her HIV status to the father of her child because of fear of discrimination. Thus she felt shame and fear that he will leave her once he knows she is living with HIV.

> "I did not disclose to the father of my son because I was shy that I have this thing. So, I realised that I have found a good person, who does not have it, so we need to use a condom so that I don't infect him with my disease". (IDI A007, 45years old, WLWH and pain)

Disclosure of HIV status in this research was determined by what made participants to decide to disclose and who did they decide to disclose or not to disclose to. Furthermore, it is also worth noting that while participants in this study had disclosed to at least some person about their HIV status, what was the level of disclosure about pain and who did participants decide to disclose their pain to. The next section focuses on disclosure of pain among WLWH and pain. Only ten women in this study were living with HIV and pain.

Pain status disclosure by WLWH and pain

Similar to disclosure of HIV status, pain disclosure by participants was high among WLWH and pain. Participants reported disclosing their pain to people close to them i.e., family (parents, siblings, and children), friends/neighbour and colleagues. Disclosure of pain severity levels was also expressed as high, characterised by participants tendency to be very vocal about their pain severity, and catastrophising their pain by using such words as "dying" the pain is "killing me":

> "The day the pain was bad too much Like, I told myself that like I'm dying. I screamed "MOM THERE'S A PAIN THAT IS ATTACKING ME HERE!". Then she came. "Where is it striking you?" I said to her "It's attacking me here, actually, I'm dying I

> can’t breathe”. She said “okay, sleep there I’m making something for you to drink” I slept. I told her “YHOOO! It’s attacking, it goes away and then comes back, strikes and goes again” (IDI A014, 28 years old, WLWH and pain)

The reasons for pain disclosure and pain severity disclosure were classified into two sub-themes: 1.) Pain status disclosure to recruit social support 2.) Partial and selective pain disclosure

5.1 Pain disclosure to recruit social support

The common reason participants reported for pain disclosure was for recruiting social support and for their disclosure targets to be aware of their pain status. Transparency about their health status was the main reason for disclosure of their pain to their disclosure targets. WLWH and pain wanted their disclosure targets to know that their pain was severe and that it interfered with their daily activities. Participants reported that they wanted their disclosure targets to understand when they are experiencing pain and when pain causes a change in their behaviour.

> I had to tell them (children) so that one day if they see me in pain they will be able to know what is happening with me. He (brother) is someone that I was born with, he is my brother, and he should know everything because he is someone I was born with, he’s my brother he must know everything about me (IDI A096, 44 years old, WLWH and pain)

> “They are supposed to know everything, everything about me. When I’m bad bad bad. They must know that, where is the pain from? From starting, and what is the cause of this pain. That is why I told them, I’m telling them that I’m living with a disease like this” (IDI A001, 38years old, WLWH and pain)

The recruitment of social support encouraged WLWH and pain to disclose their pain status to close friends and family and colleagues, so that they can be assisted during episodes of pain. Expected social support involved; disclosure targets taking over their daily activities and taking them to the doctor or hospital and in some cases financial support.

> “He is my brother he must know everything about me because when I tell him about the times when I feel pain because of my condition, then he can try and help me with whatever is going on. Or someone even when he cannot help me with anything because he is far, he is at Alexandra now but when I call him and say I am sick now, he will say I have nothing now but here is R200 or R300, make use of the money, maybe you can go to the chemist. (IDI A096, 44years old, WLWH and pain)

In one of the interviews with participants living with HIV and pain, the participant explained that she disclosed her pain status to her neighbour also so that the neighbour can assist with caring for her child during pain episodes

> "So that when I am not feeling alright, she (neighbour) must help my child, so that she can help my child. I stay next door to her" (IDI A014, 28 years old, WLWH and pain)

Similarly, another participant reported that she disclosed her pain status to her line manager and other colleagues so that when she experiences pain during work, they will understand and offer her support:

> **Interviewer:** Why did you tell your bosses?
> **Participant:** So that he can know if I am not alright at work, he must understand that the condition has started
> **Interviewer:** Why have you told the people you work with about your pain?
> **Participant:** So that they know, they must know how I am, yeah! They must not wonder once I sit down, so sometimes I change, crying, maybe…anything that would happen to me they must know what is happening to me (IDI A096, 44 years old, WLWH and pain)

Pain disclosure to health care professionals for treatment

In addition to disclosure of pain to family, friends and colleagues, half of the participants living with HIV and pain, also reported talking to healthcare providers about their pain. Disclosure of pain to healthcare providers resulted in either positive or negative outcomes for different participants. Participants who talked to the healthcare provider, in particular, the doctor, in hospital/clinic, received a thorough check-up/examination to find the cause of the pain. Participants reported a sense of compassion and attention by the doctor and taking their pain seriously and looking into ways to help treat the pain.

> "I told him 'Doctor I have a pain everywhere'. He checked and checked and checked and asked what was wrong, I told him that I have a pain everywhere. He gave me a shot of injection, and he explained that the pain is caused by the lungs that are malfunctional and the heart is getting weak" (IDI A084, 45years old, WLWH and pain)
>
> "I told the doctor about the pain. So, they took me to an x-ray… they said I have a blood clot and my chest … they told me that my lung has been eaten… I can say I'm living with one lung. The doctors helped me because most of the time the injections help me a lot" (IDI A013, 43years old, WLWH and pain).

Moreso, participants also shared that talking to the doctors about their pain led to a diagnosis of their pain and prescription for pain management.

> “The doctor told me that I have stress, it’s the nerves, and my nerves are damaged. He then gave me tablets to take for the pain”. (IDI A006, 46years old, WLWH and pain)
>
> “I have also consulted the doctor about it and the doctor prescribed some tablets to drink. When they see that the pills that they gave me are not working, they will then prescribe other tablets for me, strong ones, like the tramadol, which are strong pills for the pain” (IDI A096, 44years old, WLWH and pain)

While pain disclosure to healthcare professionals led to pain treatment and management for some participants (5/10), other participants reported negative experience from disclosing their pain to the nurses in the clinic/hospital. Participants reported a sense of disregard from the nurses they talked to about their pain. Participants felt that the severity of pain they experienced was downplayed and did not result in further examination but only treated with over-the-counter medication for moderate pain.

> “I have not told the doctor about my pain, but I told the nurses at the clinic. I once went there and told them ‘I’ve got a pain here and I don’t know what is causing it’. They gave me those pain blocks and told me ‘You will be fine it will go away’. So now and then I had since they gave me that instruction when it is there I just take the pain block the way they instructed me so when I asked them whether it will affect the breast they said it far from breast, it won’t be breast cancer or something it is far so it is just a pain maybe you didn’t sleep well or maybe you’ve been working hard or whatever and that’s where it ends” (IDI A089, 27years old, WLWH and pain)
>
> “When I tell the nurses at the clinic, they just ignore me. They say ‘Hai, maybe one day doctor can check you’ but time is going because I told the nurse in 2016 that I live with the pain. They just ignore me, they tell me that it’s an ache, its ache like it is like normal”. (IDI A014, 28years old, WLWH and pain).

5.2 Partial disclosure of pain and selective disclosure

Partial disclosure of pain

Whilst a majority of WLWH and pain reported fully disclosing their pain status to close family and friends, some participants partially disclosed their pain to some disclosure targets. ‘Partial disclosure of pain’ in this research refers to individuals disclosing their pain to others but not being vocal during a pain episode. That is while participants have made people around them aware that they are living with pain, they choose to hide their pain during an episode. For example, participant A007 explained that she reported her pain status to her partner, her son and sister, however she does not tell anyone around her when she is in pain. Further explaining that her choice to not be vocal about her pain during an episode is because of their reaction to how she deals with her pain. Her disclosure targets expressed anger regarding how she deals with her pain, usually making her feel like she does not take her pain seriously.

> “I tell her (sister) that you know yesterday, I had a particular pain, right, I will tell her after it has perhaps passed. I would say last night I was suffering from a certain pain/ailment… I could not do anything. I sometimes tell her like about my pain, but I tell her afterwards when I am feeling better. She will then ask, “So what did you do?” I then tell her that I asked my child to help me, and I sometimes drink Disprin (pain killers) like you suggested. She tells me “And now, you are just busy seated and not standing [attending to it]. Go to the doctor or clinic or hospital! You are waiting so that it can kill you! My son, he would scold at me, saying “isn’t it my aunt told you to go to hospital and you have since been not wanting to go to hospital. You want to end up dying here”. (IDI A007, 45years old, WLWH and pain)

Selective disclosure of pain

Participant A096 reported disclosing her HIV and pain status to her boss and colleagues she closely worked with but reported not disclosing her pain status to other colleagues. The fear of exposing her HIV status by disclosing her pain status was the reason she gave for the selective disclosure of her pain status to colleagues she did not work closely with. The participant also expressed she did not disclose her pain to some of her colleagues for fear of being discriminated against for having pain by her colleagues.

> “I cannot tell everyone that I am having a pain because people would be surprised that I have the pain. Does she have HIV? Asking things like that. Others do not accept this well. If I go and ask someone to take a laptop for me, they will say we know that you have a pain you see, so things like that” (IDI A096, 44years old, WLWH and pain)

Participant A013 had disclosed her pain status to her close family and friends, however she had not disclosed her pain status and/or pain severity levels to her boss for fear of losing her job.

> “…that day I couldn’t even pick up the baby… The baby was lying there crying… Just putting the bottle. I couldn’t do anything to help the baby and I was afraid to tell his mom about my pain. Maybe I will lose my job” (IDI A013, 43years old, WLWH and pain)

5.3 non-disclosure of pain by WLWH and pain

While it is found to be an isolated case in this research, one participant out of twenty did not disclose her pain status to anyone for specific reasons. Participant shared that she did not talk about her experience of living with pain with her children because they were still too young and there is nothing, they can do to help her

> **Interviewer:** Alright so have you told your kids about your pain?
> **Participant:** No, I just say I am not feeling well, I just tell them I woke up not feeling well. I have told myself that if it's something that's going to take me down it means they will know when that time comes, when I will be laying down, unable to walk, unable to do anything maybe that's when they will know that I have this problem.
> **Interviewer:** Okay if you wake up and the pain is bad, you do not tell anyone?
> **Participant:** I will just tell my kids that I am not feeling well that my body is tired and that is it
> **Interviewer:** Why haven't you told them (children)?
> **Participant:** Ahh they are still young. They are just going to look at you. They will just look at me, there is nothing they can do. (IDI A060, 35years old, WLWH and pain)

She further shares her reason for not telling her sister about her experience of living with pain because her siter lives far and there is nothing she can do to help her during episodes of pain.

> "My sister stays far from me she can't just leave wherever she is in Joburg to come and attend me and my pain. It is better when you talk to someone in person. I hate calling just to inform her that I am not well, I just woke up not feeling well. I feel like she will also get bored that I always call and tell her about my issues while she also has her own issues. So, I feel like it is better if we all deal with our issues, that's what I tell myself". (IDI A060, 35years old, WLWH and pain)

Another reason she mentioned for her decision to not tell anyone about her pain was the fact that she felt a sense of hopelessness, being alone in this pain because nobody can help her.

> **Interviewer:** Why are you scared of telling them (Family)?
> **Participant:** What will they do? There is nothing they can do.
> **Interviewer:** Oh you think there is nothing they will be able to do?
> **Participant:** No, I just take it like there's nothing they can do about it (IDI A060, 35years old, WLWH and pain)

Indeed, what would be the point of sharing about pain if there is no sense of hope of getting help to relieve or treat the pain. Most participants in this study identified their disclosure target to recruit ne necessary support required for them to deal with their pain. The main driver to disclose was the belief that whoever they talk to about their pain will be able to help. Participants in this study were asked to discuss their experience on pain disclosure and the impact of disclosing their pain.

Theme 6: The impact of disclosure of pain and HIV status

All women living with HIV were asked to share their experience of and the impact thereof disclosing their HIV status. Participants in this study reported both negative and positive experiences following disclosure of their HIV status.

Positive experience with HIV status disclosure by WLWH

Most participants (14/20) reported experiencing a positive outcome from disclosing their HIV status to their disclosure targets. Participants reported not experiencing any HIV-related stigma from their disclosure targets and that their disclosure targets did not treat them differently after knowing their HIV status. Reactions from disclosure targets included empathy, compassion and encouragement to live positively with HIV.

> "I told my mom, and she was like 'huh seriously?' yes and I told my father and they sat me down and told me 'You know what you can live with this thing but it's not the end of the world, we are going to take you the way you are, you are still our baby and you will always be, you won't change'. I was still cooking, I was still doing laundry thing, like the way I was doing it, and it wasn't like if I do cook then they will not eat my food or what, cause of how I am. No! They were fully supportive. the support that they've given me I felt like I am not sick at all, I'm still normal like the way I was, cause support that was given to me wow I felt good even now I don't feel like I am sick or anything because of the support" (IDI A089, 27years, WLWH and pain)

Participants also reported receiving encouragement from their disclosure targets to adhere to their HIV treatment (ART). More than half of the participants (11/20) reported that their disclosure targets reminded them to take their ART and talked to them about taking their HIV-treatment and how they are doing on treatment.

> "…like on my treatment my boyfriend knows that I take treatment at 8 o'clock even if we are not around, we are not on the same place, he (partner) sends an SMS 'its treatment time' one minute to 8 I know 8 o'clock I have to take treatment. He said; "you know what to be HIV positive doesn't mean that you won't live or you are dying right now, what you have to do is take care of yourself, take treatment take care of kids and see your grandchildren"". (IDI A089, 27years old, WLWH and pain)

On a personal level, the impact of disclosure was reported to be positive with participants sharing that following disclosure they experienced a sense of liberation. The sense of liberation was characterised by feeling 'relieved, free, stress free and feeling good or happy.

> "I felt free, and I wasn't even stressed of whether who says what or do what, and I didn't even think of such things. I'm sharp, I don't have stress, not even a bit". (IDI A084, 45years old, WLWH and pain)
>
> "I was relieved I was very relieved by telling him (partner) because he had to know. And he had to go and test". (IDI A013, 43years old, WLWH and pain)

Inevitably, some participants shared their negative experience of disclosing their HIV status to others. Negative experiences included breach of confidentiality, rejection and emotional effect on disclosure targets.

Negative experience with HIV status disclosure

Some women reported experiencing a negative impact after disclosure of their HIV status to their disclosure targets. Two participants reported that their disclosure targets breached confidentiality by telling other or "gossiping" about their HIV status with other people without consent. One participant shared how her friends whom she told about her HIV status went around telling other people about her HIV status:

> "My friend to tell them that I'm still with HIV [I told my friends that I am living with HIV]. So, they going to gossip with me all the place [They went around gossiping about me]. So now I decided to stay alone with my children." (IDI A001, 38years old WLWH and pain)

Another participant similarly reported being betrayed by her own siister whom she disclosed to went around talking about her HIV status and calling her promiscuous:

> "So, my sister, I told her that I am HIV positive. Where she was staying with her friend, she was talking each and every time about me. And told them that 'Uh, she's HIV, it's because she's sleeping with many men', and my mom is supporting [agree with my sister]." (IDI A013, 43years old, WLWH and pain)

Moreover, three other WLWH related their rejection by their sexual partners after disclosing their HIV status to them. Disclosure in this case resulted in break ups, participants being kicked out of their house and being scolded and called names by their sexual partners.

> "I was pregnant with my last born. So, I told the father that at the clinic they told me that I have HIV. So, he took my clothes and took it outside. Told me to go because uh, I'm just a *whore* (prostitute). Yes, he called me names. I had to go and look for a place because to tell you the truth, I didn't grow up well because of my mom. So, he told me that 'You see now you are sick. You have to take your things' and throw me out of my flat. 'Go away I don't want to see you anymore'." (IDI A013, 43years old, WLWH and pain)

> Participant: Who else did I tell? My son's father.
> Interviewer: How did he react when you told him?
> Participant: Eish, he was so angry and then that's when we had…. we broke up because he believes that I got this virus from somewhere and it's not him. He just thought I was just sleeping around. Yah, very angry. Even today he doesn't . . . we don't talk to each other. (IDI A002, 42years old, WLWH no pain)

Other participants experienced behaviour change from their families which translated into a sense of rejection or discrimination after they learned that participants had HIV. Changes in behaviour were characterised by physical isolation, participants expressing that their family members stopped visiting, did not want to utensils and space with them.

> “She [my sister] was afraid because she’s having three kids. She didn’t want me to even touch her kids. Yes. She didn’t even want to sleep with me in a bedroom. That is why I had to move and look for a place of my own.” (IDI A013, 43years old, WLWH and pain)

> “When I told them (family) that I am sick, that I have HIV they then started not to come to see me. Then during family gatherings when we are sitting and having fun, if you open a cool drink and drink and when you leave the glass, they will say take that glass and throw it away and must not be mixed with other glasses. Then they told me that they don’t care about me and my life. At that time, they did not want me” (IDI A099, 44years old, WLWH no pain)

On the other hand, more than half of the participants (11/20) narrated a negative experience in the form of psychological distress on their disclosure target after participants disclosed their HIV status to them. Participants reported that their disclosure targets reacted with shock or and disbelief, and sadness. Sexual partners reacted with fear while children were overwhelmed with fear of death and cried.

> “They (disclosure targets) were surprised, like you could see that it’s difficult. They were scared. Even my mother is hurting you will never see that she’s hurting. My friend was also surprised ‘hau my friend you are HIV? But you don’t show’” (IDI A014, 28years old, WLWH and pain)

> “I saw her (sister) going through serious pain. She felt the pains of, she does not believe, she just does not. And she told herself that…that I was going to be weak”. (IDI A007, 45years old, WLWH and pain)

The reported impact of HIV disclosure on participants and their disclosure targets in this research was equally positive and negative. This study further explored the impact of disclosure of pain on participants living with HIV and pain and their disclosure targets.

6.1 Disclosure of pain resulting in increased social support

Disclosure of pain by WLWH and pain resulted in empathy and compassion from their disclosure targets. Participants shared that their disclosure targets advised them to decrease their daily activities and those who were working were encouraged to reduce their workload, and to take a day off from work.

> “They (children) don’t want me to do anything, even fetching water at the tap, they don’t want. They don’t want me to work, they want me to just sit.” (IDI A084, 45years old, WLWH and pain)

> “He (brother) said sometimes it might be because you are working too much, so reduce; whatever you were doing before just reduce. When you are feeling pain, sit down and take your tablet and then when the pain alleviates then you can continue. Do not force yourself to do too much work when you are in pain” (IDI A096, 44years old, WLWH and pain)

Moreover, participants saw some of their disclosure targets taking over their daily activities to reduce activities for participants. Participants shared that some of their disclosure targets took over some of their house chores, helped with taking care of their children and in some cases helped participants bath and get dressed.

> “Okay sometimes they help me at home like they know my situation then they will say ‘go back to bed and sleep for a while’ then they help to bath my daughter and prepare her school things” (IDI A014, 28years old, WLWH and pain)

> “I call my friend when I am in pain. She will take the phone and call my child or sometimes call my siblings to tell them I am not well. She will then take water to bath me, put my clothes on and do everything. After all that they (family and friend) take me to the hospital, she (friend) cleans at my house, and does my washing.” (IDI A084, 45years old, WLWH and pain)

Similarly, on a personal level, participants reported that disclosure of their pain resulted in positive psychological outcome. Participants reported feeling relieved, liberated, and cared for after they disclosed their pain status to their disclosure targets. Knowing that their disclosure targets know about their pain made participants feel positive.

> “I feel at ease since at least I coughed out this thing that I was suffering from. He (son) is now aware that my mother has this type of a disease. Yes, he (son) is now aware that oh if she is suffering from this particular thing, in order to dampen it down speedily, he has to do this and that”. (IDI A007, 45years old, WLWH and pain)

> “After I have told them (family) about my pain I feel good because they know I have this pain. My parents tell me “My child go to the doctor”. I felt good”. (IDI A006, 46years old, WLWH and pain)

Participant A096 shared a positive experience about disclosing her pain status to her colleagues. Her pain disclosure to her colleagues resulted in social support and ultimately feeling happy and cared for at work. She reported being relieved because disclosing her pain to her colleagues allowed her to recruit social support from her colleagues when she is experiencing pain at work.

> "I feel happy because I see that there are some people who care about me. They care about me, they tell me to go and they say that tomorrow I must not come to work. And they also used to call to ask 'how are you? How are you feeling today? Are you coming to work today?' I say yes, I am coming. They say 'how do you feel? I say no I am right, and they say alright come. It helped me because when the pain attack, I become relieved because they (colleagues) help me" (IDI A096, 44years old, WLWH and pain)

Although some participants shared positive experiences from disclosing their pain status, other participants in this study had negative experiences. Participants shared that disclosure of pain to their disclosure target unsuspectedly resulted in negative consequences

6.2 Negative impact of pain disclosure

At least two participants living with HIV and pain reported feeling guilty, sad and embarrassed by disclosing their pain status. One participant expressed feeling bad after telling her children about her pain and seeing her children feeling helpless with the situation during her episode of severe pain.

> "I felt bad because I could see that my kids were feeling bad, and I thought that maybe I shouldn't have told them". (IDI A096, 44years old, WLWH and pain)

Similarly, other participants reported feeling guilty for disclosing their pain status at work while another participant felt embarred after sharing her pain status with her friend. Mostly the feeling of guilt and embarrassed was driven by the assumptions that the disclosure targets will feel compelled to do something to help, either by taking over the chores, in the case of a friend, or discharging the participant from work in the case of work environment.

> "I felt ashamed for telling my boss that I am having some pain or problem actually. He could have said stop working because you are having a pain or how will I manage to continue working with the pain. So, I did feel ashamed for telling the boss how I am". (IDI A096, 44years old, WLWH and pain)

> "Disclosing my pain and/or HIV status to my friend made me feel shy (embarrassed)". (IDI A001, 38years old, WLWH and pain)

Furthermore, other participants discussed the emotional impact of pain disclosure on their disclosure target.

Negative emotional impact of pain disclosure on disclosure targets.

Similar to HIV status disclosure by WLWH, disclosure of pain resulted in an emotional impact on disclosure targets. Disclosure of pain to close family and friends by WLWH and pain was followed up by various emotional responses and concerns by their disclosure targets. Six participants reported their disclosure targets being worried, sad, scared, shocked/surprised and feeling sympathetic or bad for them.

> "They (children) get worried. You can see they are not happy and that they are uncomfortable. They want to be next to me all the time and they end up not wanting to leave. Even when I am hooked up on machines, they will keep checking up on me." (IDI A084, 45years old, WLWH and pain)

> "My mother is very scared about that pain because she says it is a serious disease because it's a pain that comes every day". (IDI A014, 28years old, WLWH and pain)

CHAPTER 4

Discussion

The aims of this study were to investigate factors affecting the experience of pain, disclosure of pain and physical function in women living with HIV (WLWH) between the ages of 18 and 60 years from Groblersdal, Limpopo in South Africa. Firstly, using the BPI the prevalence, location and intensity of pain, and demographic and clinical associations with pain, in 125 women participating in the NRC cohort was investigated. Secondly, with the use of qualitative interviews this study explored the impact of living with HIV and/ or pain in 20 WLWH, half with pain and half without pain. The prevalence of pain was high (50%). The typically moderate intensity pain affected several anatomical pain sites. None of the demographic (level of education, employment status, age) or clinical factors (current CD4$^+$ T-cell count, HIV status or depression status) were associated with having pain in women attending NRC. None of the demographic (level of education, employment status) or clinical factors (HIV status) were associated with pain intensity. To explore the relationship between activity, pain disclosure and social support, qualitative interviews were used to investigate physical function, disclosure of pain, and social support in this cohort. Pain in WLWH caused a high interference with activity with most women reporting the inability to perform their activities of daily living while experiencing chronic pain periods. Pain disclosure was high motivated by the need to recruit social support from disclosure targets, however some WLWH practised selective disclosure of pain and partial disclosure of pain. Disclosure of pain to health professionals resulted in receiving pain treatment while disclosure to close friends, family and friends led to an increase in social support.

4.1 The cohort in context

4.1.1 Quantitative description of the cohort

The prevalence of pain in the cohort of 125 women, half living with HIV and half without was 50%, which was higher than the prevalence of pain in general populations (10%-40%) (Breivik *et al.,* 2006; Jackson *et al.,* 2014; Johannes *et al.,* 2010; Langley, 2011; Mansfield *et al.,* 2016) but which is similar to the prevalence of pain reported in a cohort of South Africans attending an HIV testing centre (Wadley *et al.,* 2020). The prevalence of pain and the impact of pain in this cohort has not been described before, and therefore this study is the first to describe pain in the rural South African women attending the NRC as part of a ten-year study. The high prevalence of pain in this cohort may have been caused by psychosocial factors related to being at risk of HIV, living in a rural area or that the cohort only consisted of women. Living with HIV, low socio-economic status and being female have been reported to be risk factors of pain in PLWH and in the general population (Azagew et al., 2017; Mills, Nicolson, and Smith, 2019). Indeed, HIV itself did not associate with having pain. This is similar to recent studies that reported a prevalence of pain of 50% in a cohort of PLWH and HIV negative individuals (Sharma *et al.,* 2018 Sabin *et al.,* 2018; Wadley *et al.,* 2020).

Univariate analysis found that none of the other clinical and demographic factors in this cohort were associated with pain either. This could be due to the lack of variation in the level of education, employment status and years living with HIV between WLWH in this cohort (Wadley *et al.,* 2020). Studies show that the prevalence of pain and pain intensity is higher in people with a low socio-economic status and from underdeveloped areas compared to people with a higher socio-economic status and from developed areas (Dorner *et al.,* 2011; Macfarlane *et al.,* 2015; Miaskowski *et al.,* 2011; Mills *et al.,* 2019; Van Hecke *et al.,* 2013). Most of our WLWH and pain were unemployed, lived in an area they mostly referred to as under-developed with some participants describing it as a rural area, a poor place, and a cheap place to live, with poor health facilities that lacked in medication and doctors. The low socio-economic status and being from an under-developed area and not having access to good healthcare may have contributed to the high prevalence of pain and the high pain intensity reported in our cohort of WLWH and pain. Not only was the quantitative component only powered for the determination of pain prevalence in the population but the association between demographic and clinical variables, and pain intensity was only assessed in the smaller population of 63 women in pain. As such, the sample size may have been too small to detect an association between demographic and clinical variables and pain intensity. Future studies could investigate whether demographic and clinical variables associate with pain intensity as a primary research question and ensure a large enough sample size by conducting a power analysis.

According to the BPI, pain in this cohort caused a high interference with activities of daily living with the median pain interference score being reported to be 7(5-10). As previously reported the prevalence of pain was high in this cohort, higher than the prevalence of pain in the general population. The median pain severity score was reported to be 5(4-6) with the pain affecting several anatomical sites. The presence of pain, higher pain intensity and pain on specific anatomical sites has been reported to be associated with greater interference with activity (Dueñas *et al.,* 2016).

WLWH and pain

WLWH and pain in this cohort reported their pain to be moderate to severe in intensity and affecting several anatomical pain sites (Parker *et al.,* 2017). Participants reported a median of two anatomical pain sites similar to other HIV related studies (Breitbart *et al.*,1996; Mphahlele *et al.,* 2012; Wadley *et al.,* 2022). The most affected pain sites were the chest pain (33%), lumber spine (24%), abdomen (19%) and thoracic spine (17%). The pain sites reported in this cohort were similar to pain sites reported in other South African PLWH (Mphahlele *et al.,* 2012; Parker *et al.,* 2017; Wadley *et al.,* 2022) but different from developed countries where joint pains, muscle aches, spinal pain, upper legs, back and shoulder pain is more prevalent (Jiao *et al.,* 2016; Merlin *et al.,* 2017; Sabin *et al.,* 2020). It has been suggested that the high prevalence of chest pain and abdominal pain in South African PLWH may be somatization of depression as chest pain and abdominal pain (de Heer *et al.,* 2014; Regory *et al.,* 1999). The PHQ-9 scores showed that depressive symptoms were very low in the rural women recruited for this study and so there may be another reason for different anatomical sites of pain between countries. The WHO has estimated that globally, almost 5% of adults suffer from depressive symptoms (WHO, 2017). A meta-analysis evaluating the aggregate prevalence of depression in communities from different countries between 1994 and 2014 reported point prevalence of 12.9%, one-year prevalence of 7.2%, and lifetime prevalence of 10.8% from data of one million participants from 30 countries (Lim *et al*., 2018). The low depressive symptoms in women in this cohort may be due to the fact that these women were part of a longitudinal study with a social worker made available for them for counselling. The women in this study had also been living with HIV for about 9 years with a median current $CD4^+$ T-cell count of 618 (504-777) cells/mm3 and a suppressed viral load. The women had also accepted their HIV status. Therefore, this cohort was a relatively healthy cohort. The decrease in the burden of living with HIV may have also resulted in the low depressive symptoms in these women.

4.1.2 Qualitative description

The experience of pain in WLWH and pain

The moderate pain reported quantitatively with the use of the BPI in the women was further corroborated by the qualitative interviews. During their qualitative interviews WLWH and pain reported their pain to be severe in intensity and constant. The women described their pain as “overwhelming” and would talk to pain being “intense” or “unbearably distressing” or “excruciating” during pain episodes.

4.1.2.1 Pain patterns

A review on chronic low back pain described different patterns of pain in people with low back pain (Kongsted *et al.,* 2016). These patterns included: **persistent pain**, where individuals experience unchanging pain four or more days a week (figure 4.1.2.1a), **fluctuating pain** where pain fluctuates in intensity but is never absent (figure 4.1.2.b), **episodic pain** where individuals experience episodes of pain followed by episodes with no pain (figure 4.1.2.1 c) (Kongsted *et al.,* 2016). If these patterns are used, it would suggest that the WLWH and pain in this cohort typically experienced fluctuating pain patterns (Kongsted *et al.,* 2016). Women described periods of severe pain. For example, one of the WLWH and pain said: “This pain like when it hits my body it becomes very painful.” They also reported being active when experiencing periods of low pain intensity. They reported being able to perform duties of daily living like house-chores when experiencing low pain intensity.

Figure 4.1.2.1a: Persistent pain (Kongsted et al., 2016)

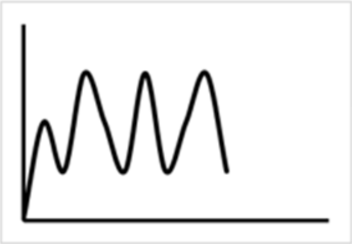

Figure 4.1.2.1b: Fluctuating pain(Kongsted et al., 2016)

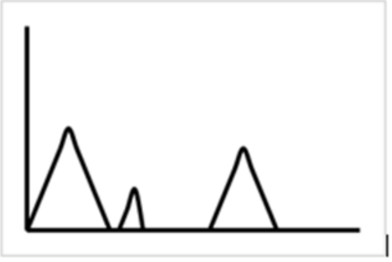

Figure 4.1.2.1c: Episodic pain (Kongsted et al., 2016)

Thinking about the patterns of pain is relevant because different patterns of pain may affect activity levels differently in people with chronic pain. For example, people experiencing fluctuating pain may report high levels of activity during less severe pain episodes and low levels of activity during severe pain episodes, compared to consistently low activity in people with persistent pain as depicted in Figure 4.1.2.1d.

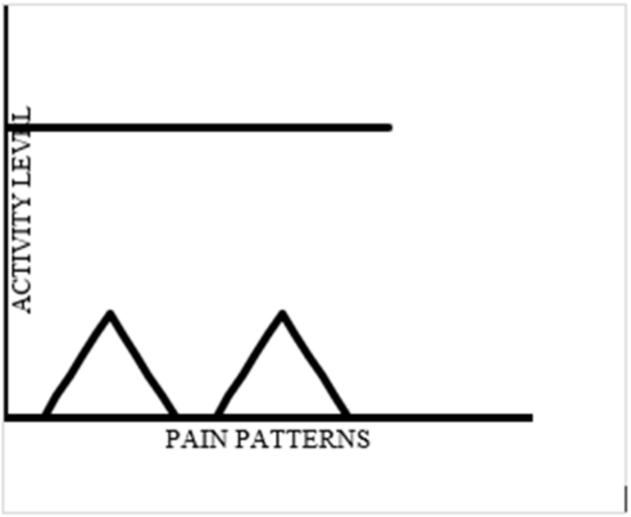

Figure 4.1.2.1d: The impact other different pain patterns on activity (Kongsted *et al.*, 2016)

4.2 Activity levels in WLWH and pain

WLWH and pain and WLWH without pain reported similar activities of daily living which included housework, child-care, self-care, and spending time resting, for example, watching television, reading books, and sleeping. Three WLWH and pain (3/10) and two WLWH without pain (2/10) were employed and their employment duties included child-care, housework, and office administration work. In the study that informed this study, there was no difference in the mean time spent being active each week or the median daily activity counts between PLWH with pain and PLWH without pain as determined using actigraphy (Wadley *et al.,* 2016). When WLWH and pain in this study were not experiencing an acutely painful episode, they reported similar activities and activity levels as WLWH without pain.

4.2.1 Factors affecting activity

Pain intensity

WLWH and pain reported that pain caused a high interference with their activities of daily living. It gets too painful, too much. I just like sleep", indicating a pain-related interference with activity for this participant. Most WLWH and pain reported being unable to perform their duties of daily living when experiencing their severe pain periods, often commenting on the inability to do anything.

Fear

The fear avoidance theory describes how individuals with pain avoid being active for fear of aggravating their chronic pain (Crombez *et al.,* 2012; Leeuw *et al.,* 2007; Vlaeyen & Linton, 2000). Individuals with pain change or decrease their activity levels as they fear activity may induce painful episodes (Crombez *et al.,* 2012; Leeuw *et al.,* 2007; Vlaeyen & Linton, 2000). The individuals get stuck in a vicious cycle of suffering by developing negative beliefs about their pain and pain catastrophizing which results in them avoiding any kind of physical activity (Crombez et al.,2012; Leeuw *et al.,* 2007; Vlaeyen & Linton, 2000).

From the results it is likely that fear avoidance may have played a role in the activity levels of WLWH and pain in this cohort when they were experiencing severe pain periods. Some WLWH and pain reported fear of continuing daily activities when experiencing their severe pain periods. These women feared falling, making themselves tired, or hurting themselves if they continued with activity and making the pain worse. One participant explained why she decreased her activity: "Because am in pain and I am afraid that I will fall".

Women who experience pain have been reported to use maladaptive cognitive styles and pain coping strategies like pain catastrophizing and fear-avoidance that negatively affect their physical function (Bartley and Fillingim, 2013; Fillingim *et al.,* 2009; Keogh and Eccleston, 2006; Sullivan, Tripp and Santor, 2000). In contrast men with pain have been reported to engage in more positive pain coping strategies that help them adapt to their pain such as behavioural distraction and problem-focus strategies (Bartley and Fillingim, 2013; El-Shormilisy *et al.,* 2015). WLWH and pain in this cohort engaged in pain catastrophizing by usually verbalizing their catastrophic thoughts with close family and friends and avoiding activity. These data seem to follow the previous sex data wherein women show fear avoidance and catastrophizing in the face of chronic pain (Sullivan *et al.,* 2006; Sullivan, Tripp and Santor, 2000). Some pain education to help WLWH and pain to better understand their pain may be helpful in decreasing fear and catastrophizing and increase resilience in the presence of pain (Jordan *et al.,* 2010; Louw *et al.,* 2011; Moseley, 2004, 2013). In a cohort of PLWH from Alabama, United States Greater pain-specific resilience was significantly correlated with lower interference with activity and less pain catastrophizing (Gonzalez *et al.,* 2019).

Encouragement from others

After disclosure of their pain status, the women's disclosure targets encouraged them to decrease their activities of daily living, like house-chores and childcare, encouraged them to reduce their workload, and encouraged those who were employed to take a day off from work when experiencing pain episodes. Overprotective family members encouraging people living with chronic pain to decrease activity has previously been reported (Gualano *et al.,* 2017). In addition to encouraging participants to decrease activity, family members also took over duties of daily living which is discussed in the social support section below (4.x). This high presence of social support for WLWH and pain may have affected their ability to be resilient in the presence of pain. The high presence of social support may have also reduced WLWH and pain's self-efficacy which resulted in woman being less active and believing they cannot be as active or perform their duties of daily living.

Other pressures

In contrast, to women reducing their activity when their pain increased, there were a few WLWH and pain who appeared to continue being active even when going through their pain periods. This persistence with activity (Ankawi *et al.,* 2017; Gonzalez *et al.,* 2019; Wright *et al.,* 2008) was motivated by two reasons: 1) a lack of assistance. Participant's close family and friends were considered as either too young or too old to assist with duties of daily living. 2) employment. Whilst the majority of the cohort were unemployed, two of the ten WLWH and pain were employed. These two women reported continued activity even when they were experiencing chronic pain episodes. These women feared they might lose their jobs if they did not attend work, being employed may motivate WLWH and pain to remain active despite experiencing pain (Phaladze *et al.,* 2005; Uwimana & Struthers, 2007; Wadley *et al.,* 2016).

4.3 Factors influencing the disclosure of pain in WLWH and pain

4.3.1 Patterns of pain status disclosure

Preliminary data on patterns of pain status disclosure suggested that South African PLWH reported the following patterns of disclosure (Wadley et al., 2016; Wadley, 2021, personal communication):

- Full disclosure of pain
- Selective disclosure of pain (defined as disclosing one's pain to some people while choosing not to disclose to other people)
- Non-disclosure of pain

Similar patterns of pain status disclosure were identified in my cohort of WLWH and pain (Table 10). WLWH and pain in this cohort reported full disclosure of pain, selective disclosure of pain, non-disclosure of pain and one WLWH and pain reported partial disclosure of pain (which I have defined as disclosing pain to others but not telling others when experiencing an acute pain episode).

Table 7 Patterns of pain status disclosure

Patterns of disclosure	Wadley *et al.* 2016 and Wadley (2021) personal communication (n=197)	WLWH and pain (n= 10)#
Full disclosure	15%*	90%
Selective disclosure	43%	20%
Partial disclosure	Not described	10%
Non- disclosure	5%	10%

*Defined as answering 'yes' to 'Have you told your family about your pain?" Friends? And colleagues (if employed). Participants answered yes or not but were not asked if they had disclosed to *all* family and *all* friends (or all colleagues) and so this number may actually reflect some self-disclosure.
Column will not equate to 100% because WLWH and pain may have selectively disclosed to some people.

4.3.2 Comparison of reasons for HIV status disclosure by WLWH vs. pain status disclosure by WLWH and pain.

Table 8 shows a comparison of the reasons for disclosure of HIV and of pain. There were no differences in reasons for HIV status disclosure between WLWH without pain and WLWH with pain. There are similarities in the patterns of pain disclosure and HIV status disclosure in WLWH, the only overlap is the reasons given for disclosure of HIV and disclosure of pain. Of all the reasons given for HIV status disclosure by WLWH in this cohort, the only common reasons with pain status disclosure were full disclosure to recruit social support, to feel liberated and selective disclosure of pain to avoid being discriminated against.

Table **8**: Reasons given for disclosure of HIV status and pain status

	HIV status disclosure by WLWH without pain (10)	HIV status disclosure by WLWH and pain (10)	Pain status disclosure by WLWH and pain
Reasons for disclosure			
HIV disclosure to avoid HIV transmission	Yes	Yes	NA
To seek social support	Yes	Yes	Yes
Self-liberation	Yes	Yes	Yes
Reasons for Non/selective disclosure			
To avoid suspicion from others	Yes	Yes	No
Fear of abandonment	Yes	Yes	No
Being "gossiped about" The fear of a breach in confidentiality	Yes	Yes	No
Fear of being discriminated or rejected	Yes	Yes	Yes
Feeling like a burden	Yes	Yes	Yes
"Shy" (ashamed)	Yes	Yes	No

Wadley and colleagues (2016) hypothesised that if PLWH and pain do not disclose their pain to close family and friends they might not recruit or receive the social support that they need. My data shows that indeed WLWH and pain disclosed their pain status to recruit social support and they received social support. This will further be elaborated in the next section.

4.4. The impact of pain status disclosure

Recruitment of social support

Full disclosure of pain to family and some friends by WLWH and pain in this cohort was motivated by the need for social support. WLWH and pain wanted their disclosure targets to know that they were living with chronic pain so that they could be assisted when experiencing severe pain episodes. WLWH and pain were very vocal regarding their pain severity level, for example, participants would describe their pain to their disclosure targets by telling them the “overwhelming” l” or “I feel bad”. Additionally, the women would verbalise their catastrophic thoughts to their disclosure targets, for example, participants would often tell their disclosure targets that they were dying when experiencing pain, and/or screaming during their pain experience.

It is highly possible that the high disclosure of pain or the expression of pain and the vocalisation of catastrophic thoughts by WLWH and pain in this cohort can be linked to the gender of the participants. In some South African Nguni and Sotho cultures it is culturally acceptable for women to express their pain and intensity of that pain in any way possible (Nortjé & Albertyn, 2015). Women being more expressive of their pain is a global phenomenon as several population studies from various countries have also been reported women to engage in pain catastrophizing more than men (Bartley & Fillingim, 2013; Keogh & Eccleston, 2006; Sullivan *et al.*, 2000). By engaging in pain behaviours and verbalizing their catastrophic thoughts women receive social support from their disclosure targets (Sullivan *et al.,* 2000, 2006).

Disclosure of pain by WLWH and pain resulted in an increase in social support similar to that experienced by women revealing their HIV status. Indeed, women have been reported to use social support networks to cope with pain in other cultures too (Racine *et al*., 2012; Van Hecke *et al*., 2013). What seems specific to this South African cohort of WLWH, was the type of support they received. Disclosure targets encouraged WLWH and pain to decrease their daily activities and then took over the participants’ daily activities. Close family and friends would come into participants’ homes and take care of house chores, childcare and even bathe the participants if their pain was too severe for them. This kind of support was also reported in the Brazilian culture, family members of people living with chronic pain also take over duties of daily living for their family member with chronic pain (da Cruz *et al*., 2004). WLWH and pain typically described feeling relieved, liberated, and also cared for with this level of support. However, one woman mentioned feeling like a baby because of the amount of support she received from her family.

Feeling like an emotional burden

Even though WLWH and pain reported experiencing a positive experience with disclosure of pain, some WLWH and pain ended up feeling like they had burdened their disclosure targets with disclosure of their pain. Six WLWH and pain reported that disclosure of pain had had a negative emotional impact on disclosure targets. Their disclosure targets would become worried, sad, and scared for them. Disclosure targets would be shocked by the news of the chronic pain status and feel sympathetic or bad for the WLWH and pain. The emotional impact of pain for both people living with pain and close family and friends who offer support and care has been extensively reported in pain literature (Dueñas *et al.*, 2016; Ojeda *et al.,* 2014).

4.5 Limitations

This study has its limitations. Firstly, the study was cross sectional, and the data were collected from a single rural site and so the data may not be generalized to all South African WLWH. Secondly, the women recruited in this study were from a longitudinal study which means these women had access to better health care and were receiving support from the study team which they would otherwise not receive if they were not part of a research study. Therefore, these women may have better health outcomes compared to women who are not part of a research study, and therefore data from this cohort must be interpreted with caution. The data here may be an under-representation of the problem of pain, therefore. During their pain episodes WLWH and pain reduced their activities of daily living or completely stopped being active because they feared continued activity would aggravate their pain. It was a limitation in this study that I did not include a measurement for kinesiophobia, the fear of pain caused by physical function (Linton & Andersson, 1990). Future studies may consider including scales that quantify the fear of painful movement like the Tampa Scale for Kinesiophobia (TSK) (Clark, 1996; French *et al.,* 2007). Furthermore, activity was measured subjectively with the use of the BPI and the interview guide. Subjective measurement of activity has its limitations in capturing activity because of participant recall bias and desirability bias (Dishman *et al.*, 2001; Prince *et al.*, 2008; Strath *et al.*, 2013). The study would have been stronger if subjective activity data could have been compared with an objective measurement.

There were limitations too around language. Language barriers between myself and the participants also played a role in data collection during interviews. Therefore, an interpreter was made available during interviews to provide suitable interpretation for the interview questions. The interpreter was a social worker within the NRC who offered HIV counselling to participants. As much as the interpreter was helpful, the interpreter would influence how participants answered by goading them to the answer she saw fit. The interpreter was also not interpreting some the questions adequately. The interpreter only assisted with two participants before it was decided to recruit only women who could fully comprehend the English language, and this may have caused sampling bias. Perhaps in future studies we may consider translating the assessment tool and/or hiring interpreters who are trained in research who understand qualitative interviews. Additionally, using the IsiZulu, Sepedi, Ndebele versions of the BPI would help (Mphahlele *et al*., 2008).

4.6 Future recommendations

Results from this study emphasized the need for the development of effective strategies for the treatment of pain and the need to educate the patient, the health care professional, and social networks on pain in PLWH (Baker *et al*., 2021; Merlin *et al*., 2021). Educational sessions like pain neuroscience education (Louw *et al*., 2011) may be used for patients (PLWH) to better understand their pain. Educational sessions about pain have been reported to result in the change in perception of pain by people with chronic pain (Jordan *et al*., 2010; Louw *et al*., 2011; Moseley, 2004, 2013) . The change in perception of pain results in the reduction in the fear avoidance of movement which improves activity, reduces catastrophizing and pain severity levels decrease considerably (Jordan *et al*., 2010; Louw *et al*., 2011; Moseley, 2004, 2013).

In order to overcome the challenges associated with adequate management of pain in PLWH, health professionals also need training in essential pain management (Sarzi-Puttini *et al.,* 2012). Improving the knowledge about pain for PLWH and the attitudes on pain of health professionals could improve the management of pain in PLWH (Baker *et al*., 2021; Merlin *et al*., 2021). For example, chronic pain management guidelines for PLWH could be developed that encourage screening for chronic pain during follow up visits to the HIV clinic and recommend counselling regarding pain. The counselling could focus on self-efficacy and resilience by fostering a positive outlook of life like the counselling given regarding living with HIV, which was so helpful to the WLWH in my study. Pain management guidelines should also make health professionals aware of cultural motivators for reducing activity in the presence of pain because reasons for reduced activity are not the same. For example, family and friends (social support structures) may motivate PLWH and pain to reduce activity.

Pain treatment for PLWH and pain has been reported to be a challenge because there are few, proven effective options (Merlin *et al*., 2021) Perhaps more funds could be used to help identify pain aetiologies in PLWH and pain and finding pharmacological and non-pharmacological treatments of pain for PLWH (Baker *et al*., 2021; Madden *et al*., 2020; Merlin *et al*., 2021). This may be helpful for countries that have a burdened health care system. The data from this study are a start towards informing culturally appropriate pain management programmes.

The pain management programmes developed in the South African context should include cultural beliefs about pain and the cultural understanding of pain. The roles that women play in their households in the South African context should also be included. Women may feel like they are not performing their socially and culturally accepted gender roles like household chores (Scott *et al.,* 2020) and therefore might continue these activities despite being in pain. Pain programmes need to take these socio-cultural factors into consideration, taking into consideration their socio-economic status. Socio-economic status of people will influence the understanding of these programmes by patients. For example, the patients' level of education will assist them understanding these programmes and using them in practice.

4.7 Conclusion

The prevalence of pain in rural WLWH and pain was 50% with the pain being reported to be severe in intensity (very painful, painful, overwhelming). Pain was not associated with HIV. Nor was pain or pain intensity associated with other clinical or demographic factors possibly because of the lack of variance in those factors. WLWH and pain experienced fluctuating pain periods of severe pain and during these pain periods the pain interfered with their duties of daily living. This study also showed that activity in WLWH and pain may be motivated by employment status but in those unemployed, activity was reduced by pain intensity, fear, and encouragement from others to reduce activity. This study identified pain status disclosure patterns in WLWH and pain which are full disclosure of pain, selective disclosure of pain, partial disclosure of pain and non-disclosure of pain. Disclosure of pain resulted in social support for WLWH and pain. Disclosure targets availed themselves immensely for WLWH and pain. This is the first time the impact of pain on rural WLWH with pain and without pain has been explored using qualitative interviews. These data are the first step in developing culturally appropriate pain assessment tools and can also inform pain management programmes.

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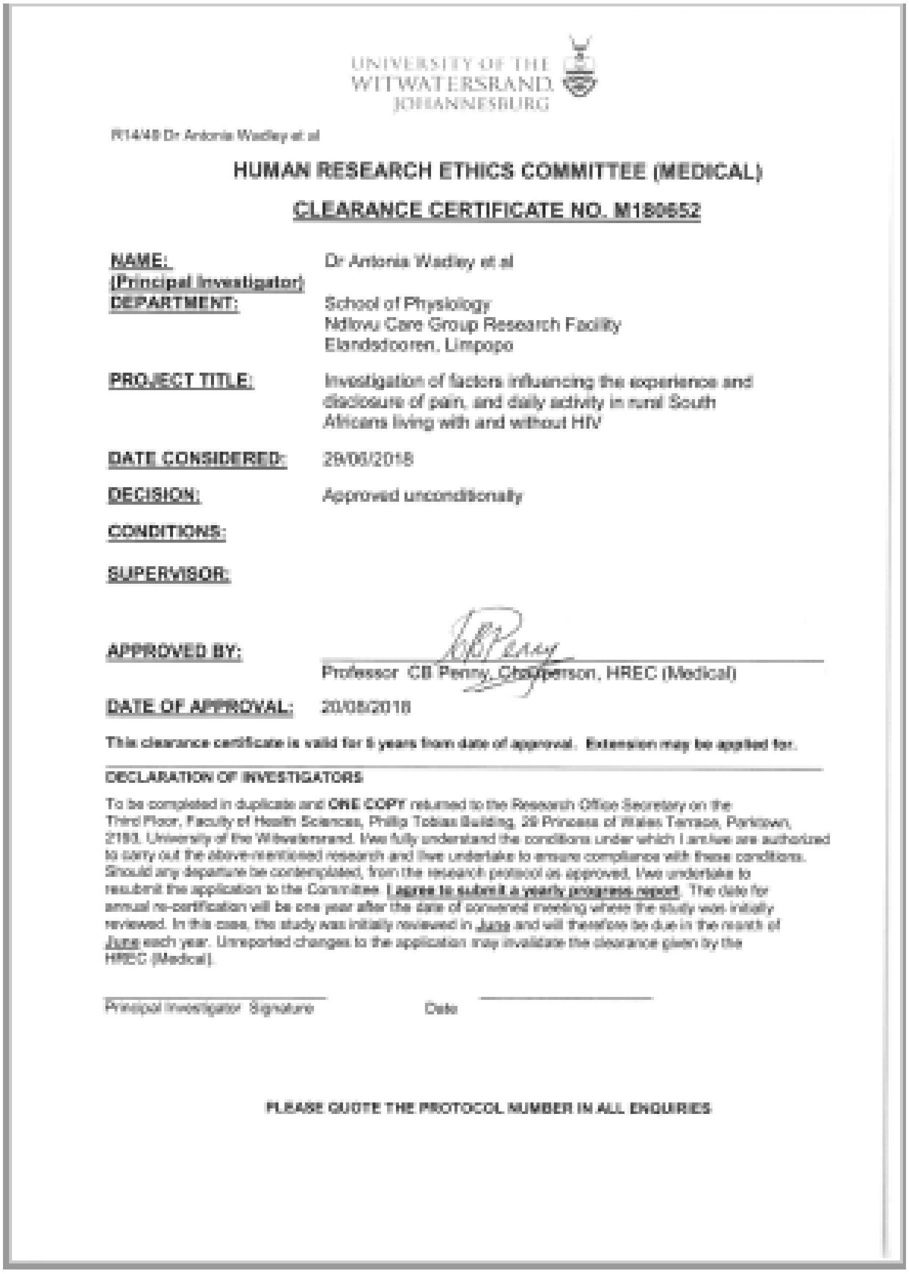
Appendix 1 Ethics clearance University of the Witwatersrand



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

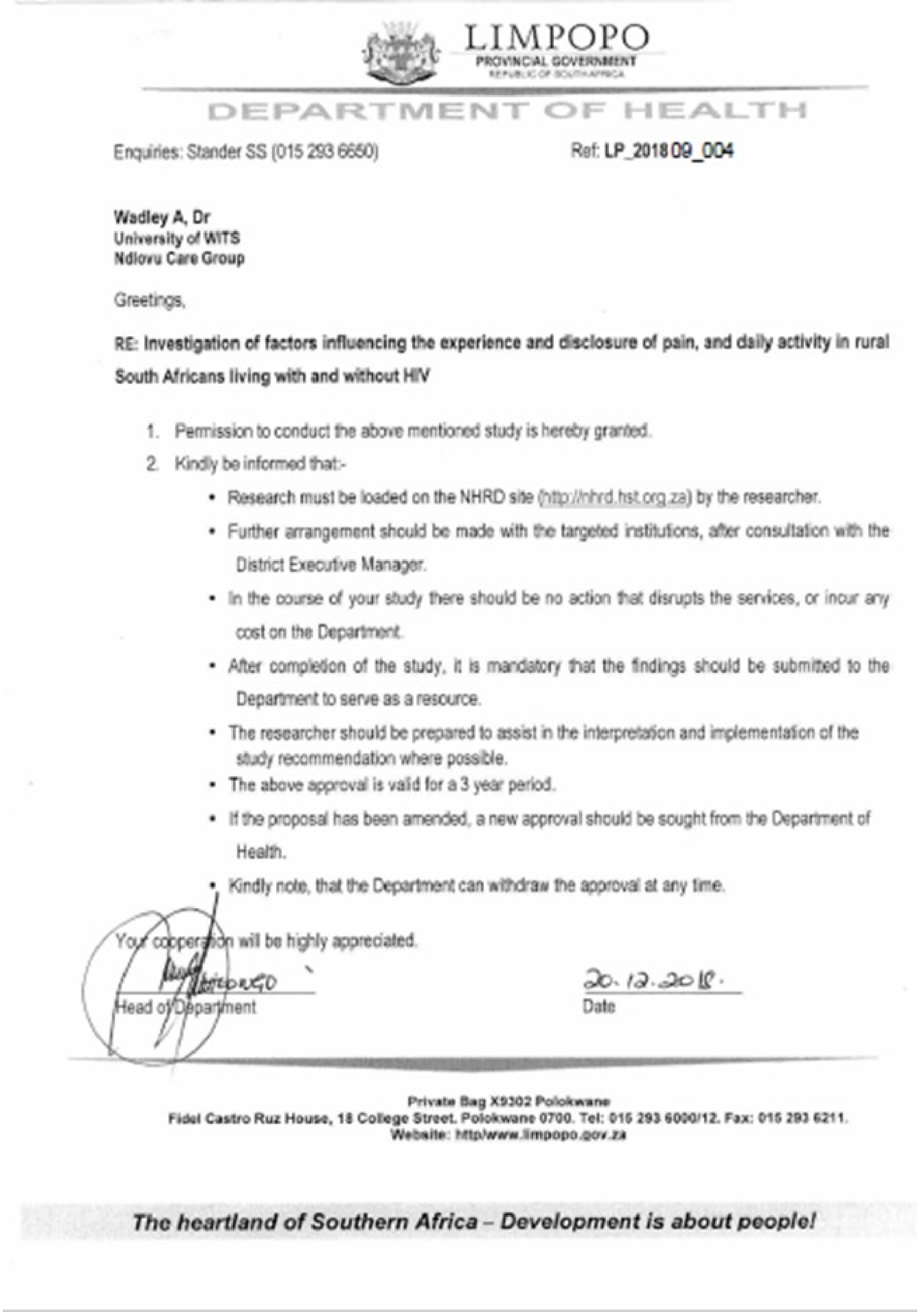
To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the Third Floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are 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

Appendix 2 Ethics clearance Limpopo Department of health



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Stander SS (015 293 6650) Ref: LP_2018 09_004

Wadley A, Dr
University of WITS
Ndlovu Care Group

Greetings,

RE: **Investigation of factors influencing the experience and disclosure of pain, and daily activity in rural South Africans living with and without HIV**

1. Permission to conduct the above mentioned study is hereby granted.
2. Kindly be informed that:-
    - Research must be loaded on the NHRD site (http://nhrd.hst.org.za) by the researcher.
    - Further arrangement should be made with the targeted institutions, after consultation with the District Executive Manager.
    - In the course of your study there should be no action that disrupts the services, or incur any cost on the Department.
    - After completion of the study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
    - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
    - The above approval is valid for a 3 year period.
    - If the proposal has been amended, a new approval should be sought from the Department of Health.
    - Kindly note, that the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated.

Head of Department

20.12.2018.
Date

Private Bag X9302 Polokwane
Fidel Castro Ruz House, 18 College Street. Polokwane 0700. Tel: 015 293 6000/12. Fax: 015 293 6211.
Website: http/www.limpopo.gov.za

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Appendix 3 HIV Disease stage classifications

A. CDC HIV disease stage classification by AIDS-defining illnesses

CDC HIV disease stage	AIDS-defining illnesses
Clinical stage A	Asymptomatic
Clinical stage B	• Bacillary angiomatosis • cervical dysplasia • candidiasis, oropharyngeal • Shingles etc • tuberculosis
Clinical stage C	• Wasting syndrome • Lymphoma • Encephalopathy • Cytococcosis

B. CDC HIV disease stage classification by $CD4^+$ cell count

CDC HIV disease stage	$CD4^+$ cell count (cells/mm^3)
Category 1	≥500 cells/mm^3
Category 2	200-499 cells/mm^3
Category 3	>200 cells/mm^3

C. CDC HIV classification

$CD4^+$ cell count (cells/mm^3) category	Clinical stage A, Asymptomatic	Clinical stage B, symptomatic	Clinical stage C, AIDS-defining illnesses
≥500 cells/mm^3	A1	B1	C1
200-499 cells/mm^3	A2	B2	C2
>200 cells/mm^3	A3	B3	C3

Appendix 3 HIV Disease stage classifications

D. WHO HIV disease stage classification using clinical and immunological classification.

WHO HIV clinical HIV disease stage	clinical classification	$CD4^+$ cell count (cells/mm^3)
Stage I	Asymptomatic	≥500 cells/mm^3
Stage II	• <10% body weight loss • Recurrent respiratory tract infection • Herpers zoster • Recurrent oral ulcers	350-499 cells/mm^3
Stage III	• Pulmonary TB • Oral candidiasis • Bacterial pneumonia	349-200 cells/mm^3
Stage IV	• Severe wasting • Extrapulmonary TB • HIV encephalopathy • Candida of trachea, bronchi or lungs	<200 cells/mm^3

Appendix 4: Brief Pain Inventory

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?

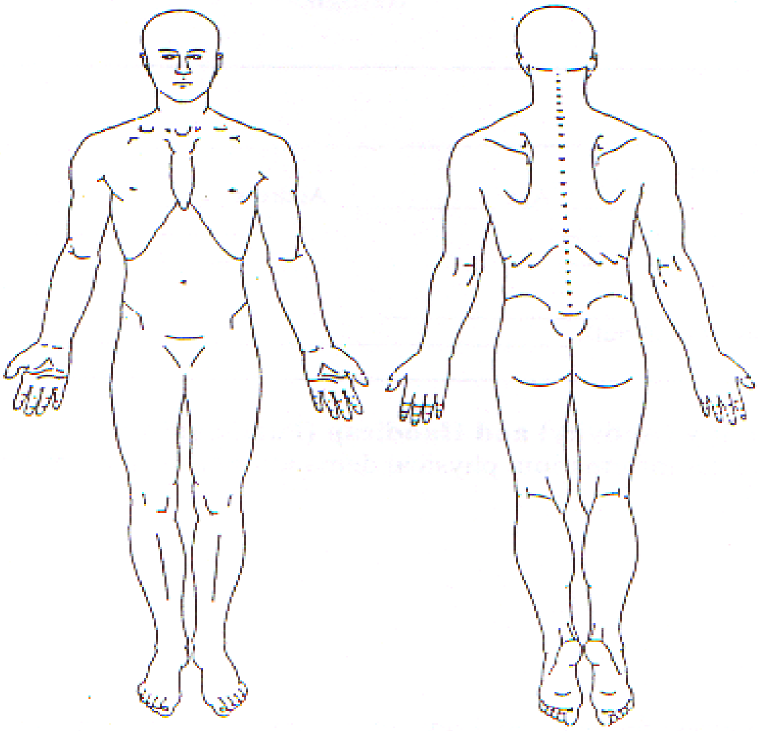
Yes ☐ No ☐

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 ***lea*** 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

C. ***Walking Ability***

0	1	2	3	4	5	6	7	8	9	10
Does not interfere										Completely interferes

D. ***Normal 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

F. ***Sleep***

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 5 Interview guide

In-depth Interview guide for Reactive with No Pain

The following interview guide, drawn from grounded theory, will guide the interview:

Different sections will be asked according to the HIV and pain statuses of the participant.

B1. For all participants:

1. How long have you been living in your community?
2. What is it like to live in your community?
   a. How easy or difficult is it to find a job there?
   b. Tell me about your friends? What do you talk about with your friends?
   c. How do people help when things get difficult?
3. Tell me what you think about the health care system here.
   a. what do you think about the service you receive at the clinic/hospital?
   b. What do you think about the nurses, doctors and other service providers?
4. Could you describe a typical day for you?
   a. What would you do on a normal day? How busy is it?

B2. For those living with HIV

1. Would you tell me about living with HIV?
   a. When were you diagnosed with HIV?
   b. How has life been since then?
   c. How does living with HIV affect you?
      (E.g. emotionally, physically, work, study, socially, sexually/in relationships)
2. Who in your family did you tell about having HIV?
   a. how did they react?
   b. why did you tell them?
   c. If you did not tell anyone in your family, can you tell me why you didn't tell them?

3. Who else did you tell about having HIV? (probe for spouse/partner, friends, priest)
    a. how did they react?
    b. why did you tell them?
    c. If you did not tell anyone, can you tell me why you didn't tell them?
4. Who can you ask for help if you need it, either at work, in the community or from friends or family? Is there support available?
    a. What kind of help/support?

In-depth Interview guide for Reactive with Pain

The following interview guide, drawn from grounded theory, will guide the interview:
Different sections will be asked according to the HIV and pain statuses of the participant.

B1. For all participants:

5. How long have you been living in your community?
6. What is it like to live in your community?
    a. How easy or difficult is it to find a job there?
    b. Tell me about your friends? What do you talk about with your friends?
    c. How do people help when things get difficult?
7. Tell me what you think about the health care system here.
    a. what do you think about the service you receive at the clinic/hospital?
    b. What do you think about the nurses, doctors and other service providers?
8. Could you describe a typical day for you?
    a. What would you do on a normal day? How busy is it?

B2. For those living with HIV

5. Would you tell me about living with HIV?
    a. When were you diagnosed with HIV?
    b. How has life been since then?

    c. How does living with HIV affect you?

    (E.g. emotionally, physically, work, study, socially, sexually/in relationships)

6. Who in your family did you tell about having HIV?
    a. how did they react?
    b. why did you tell them?
    c. If you did not tell anyone in your family, can you tell me why you didn't tell them?
7. Who else did you tell about having HIV? (probe for spouse/partner, friends, priest)
    a. how did they react?
    b. why did you tell them?
    c. If you did not tell anyone, can you tell me why you didn't tell them?
8. Who can you ask for help if you need it, either at work, in the community or from friends or family? Is there support available?
    a. What kind of help/support?

B3. 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. How often do you feel the pain?
2. What do you think is the cause of your pain?
3. What do you do to relieve the pain? e.g. medications, activities/rest.
4. Tell me about the things you are still able to do even when the pain is bad.
5. Tell me about a day you were unable to do any activities when the pain was bad.
6. Tell me about a time you were able to ask for help when the pain was bad.

7. Who in your family have you told about your pain?
    a. For those people you told, did you tell them just that you had pain, or how much pain you have?
    b. What were your reasons for telling them about your pain?
    c. How did they react when you told them about your pain?
    d. How did it feel to tell them?
8. Who else have you told about your pain? (probe about spouse/partner, friends, priest
    a. For those people you told, did you tell them just that you had pain, or how much pain you have?
    b. What were your reasons for telling them about your pain?
    c. How did they react when you told them about your pain?
    d. How did it feel to tell them?
9. If you have not told anyone, can you tell me why you didn't tell them how much pain you were in?
        i. How did it make you feel not being able to tell them the full extent of your pain?
10. Have you told a doctor or nurse about your pain?
    a. Please tell me how that went?
    b. Were you able to tell them how much pain you had or just that you had pain?
        i. How do you think they were they able to help?
    c. If you couldn't tell a doctor or nurse, please tell me:
        i. Why you didn't tell them?
        ii. Why you didn't tell them how much pain you were in?

B4. For those living with HIV *and* pain:

1. What is it like to live with both HIV and pain?

2. What kind of support do you think is available, at work, in the community or from friends or family? Tell me about a time you were able to ask for help.
    a. Please tell me about people you know who live with both HIV and pain.
        i How did you find out about them?

Appendix 6: Information sheet and informed consent forms

INFORMATION LEAFLET AND INFORMED CONSENT FORM FOR PARTICIPANTS 18 YEARS AND OLDER FOR QUESTIONNAIRES

PROTOCOL

Investigation of factors influencing the experience and disclosure of pain, and daily activity in rural South Africans living with and without HIV

Part 1: Prevalence and characteristics of pain in the Ndlovu cohort

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VERSION: English Information Leaflet and Consent Form for Participants 18 Years and Older for pain prevalence questionnaire, Version 1.0, dated 07 Jun 2018

PRINCIPAL INVESTIGATOR: Antonia Wadley

ADDRESS: Brain Function Research Group
School of Physiology
Faculty of Health Sciences
7 York Road
Parktown
Johannesburg 2196

TELEPHONE NUMBER: 011 717 2163

INTRODUCTION

Good day, my name is Antonia Wadley. I am a lecturer and researcher in the School of Physiology at the University of the Witwatersrand in Johannesburg. I would like to invite you to consider participating in a research study ‘Factors affecting the experience of pain, pain disclosure, and physical function in a rural South African cohort’.

Before agreeing to participate, it is important that you read and understand the following explanation of the purpose of the study, the study procedures, benefits, risks, discomforts, precautions and your right to withdraw from the study at any time. This information leaflet is to help you to decide if you would like to participate. You need to understand what is involved before you agree to take part in this study and ask the investigator or other research staff any questions you may have.

Once you understand the study, if you decide to take part, we will ask for your written consent to participate. You will receive a copy of this consent form for your records. This process is called informed consent.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to learn how many people experience pain in the Ndlovu research cohort. We would also like to understand which factors might make people’s pain better or worse, including whether living with HIV makes you more likely to experience pain.

WHY AM I BEING ASKED TO TAKE PART?

You are being asked to consider taking part because you are part of the Ndlovu research cohort.

WHERE WILL THE STUDY BE DONE?

If you agree to be part of the study, we will complete the 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 THE STUDY?

This is a 5-year research project. You will be one of 250 people taking part. There is only one visit required to complete the questionnaires but we will also ask if you are interested in one more visit, to take part in an In-Depth interview on another day. The total amount of time required for your participation in this part of the study is approximately 15 minutes.

WHAT DO I HAVE TO DO IF I AM IN THIS STUDY?

- If you agree to take part, you will be asked to complete a short questionnaire.
- We will ask if you live with pain, and if so where the pain is, and how bad it is.
- We will also ask if you are living with HIV. (This information will be kept absolutely confidential).
    - Participant initials ________
- We also ask that we may collect some information that is already in your Ndlovu file including your age, your employment status, and your CD4 count if you are living with HIV.
    - Participant initials ________

WHAT ARE THE BENEFITS OF BEING IN THE STUDY?

There are no benefits to you for participating in this study. But if you join the study you will help us understand how common pain is in the community and which factors may make pain worse or better.

WHAT ARE THE RISKS OF BEING IN THE STUDY?

There are no direct risks for taking part in this study.

WHAT ALTERNATIVES DO I HAVE?

You can choose not to participate in this study.

WHAT ARE MY RIGHTS?

Your participation in this study is voluntary and you can decline to participate or stop at any time without stating any reason. Your withdrawal will not affect your belonging to the larger Ndlovu research study if you wish to continue participating in that.

WITHDRAWAL FROM THE STUDY

As, stated above, you can leave this study at any time. If you decide to leave the study, please tell the study staff that you wish to leave. You do not have to give a reason why you want to leave the study, but any information you provide to study staff will be helpful. Leaving the study will not affect your relationship with the other Ndlovu research staff.

WHAT ABOUT CONFIDENTIALITY?

All your information will be kept secret and will only be available to me (the investigator) and the study staff assisting me. The information will not be available to your doctors and nurses, or the other Ndlovu research staff.

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 research study will be stored in locked filing cabinets and kept in secure computer files. No individual identities will be used in any reports or publications that may result from this study. The study documents will be kept for 2 years if research results are published, or 6 years if there is no publication and thereafter destroyed.

INCENTIVE FOR PARTICIPATION

There is no cost for you to be in this study. Refreshments will be provided.

WHAT DO I DO IF I HAVE QUESTIONS OR PROBLEMS?

If you have questions about this study or any problems that you think may be related to this study, contact a member of the research staff, or principal investigator, Antonia Wadley on 011 717 2163 or 078 802 8182.

ETHICAL APPROVAL

This study protocol has been submitted to the University of the Witwatersrand, Human Research Ethics Committee (Wits HREC – Medical) and written approval has been granted by that Committee. The Committee is a group of staff at the University who look after patients' rights have checked my study to make sure it is fair and treats patients well. If you want to know more about your rights when you are taking part in research you can contact Professor P Cleaton-Jones on 011 717 2301, peter.cleaton-jones1@wits.ac.za

Or the administrative officers:

Ms Z Ndlovu - zanele.ndlovu@wits.ac.za

Mr Rhulani Mkansi - rhulani.mkansi@wits.ac.za

Mr Lebo Moeng lebo.moeng@wits.ac.za

SIGNATURE PAGE

STATEMENT OF CONSENT

Before you sign this consent form, make sure of the following:

- You have read this informed consent form, or someone has read it to you.
- This study has been explained to you and had your questions answered.
- You understand you can ask more questions at any time.
- You have understood everything that has been explained to you and you consent to participate in this research study.
- You understand that you can without prejudice withdraw your consent at any time.

Participant's Name and Surname (Print)	**Participant's Signature**	**Date**	**Time**
Study Staff conducting consent discussion Name and Surname (Print)	**Study Staff Signature**	**Date (dd/mmm/yyyy)**	**Time**

Retain original Informed Consent Form on file. Offer participant a copy.

INFORMATION LEAFLET AND INFORMED CONSENT FORM FOR PARTICIPANTS 18 YEARS AND OLDER

FOR IN-DEPTH INTERVIEWS

PROTOCOL

Investigation of factors influencing the experience and disclosure of pain, and daily activity in rural South Africans living with and without HIV

Part 2: In-depth interviews

VERSION: English Information Leaflet and Consent Form for Participants 18 Years and Older for In-depth Interviews, Version 2.0, dated 02 August 2018

PRINCIPAL INVESTIGATOR: Antonia Wadley

ADDRESS:
Brain Function Research Group
School of Physiology
Faculty of Health Sciences
7 York Road
Parktown
Johannesburg 2196

TELEPHONE NUMBER: **011 717 2163**

INTRODUCTION

Good day, my name is Antonia Wadley. I am a lecturer and researcher in the School of Physiology at the University of the Witwatersrand in Johannesburg. I would like to invite you to consider participating in a research study ‘Factors affecting the experience of pain, pain disclosure, and physical function in a rural South African cohort’.

Before agreeing to participate, it is important that you read and understand the following explanation of the purpose of the study, the study procedures, benefits, risks, discomforts, precautions and your right to withdraw from the study at any time. This information leaflet is to help you to decide if you would like to participate. You need to understand what is involved before you agree to take part in this study and ask the investigator or other research staff any questions you may have.

Once you understand the study, if you decide to take part, we will ask for your written consent to participate. With your written consent, we will also record the In-depth Interview. You will receive a copy of this consent form for your records. This process is called informed consent.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to learn what things make people’s pain better or worse. We want to understand how active people are even when they’re in pain and what motivates them to be active. We also want to know what motivates people to tell others about their pain and if telling others is helpful.

WHY BEING AM I ASKED TO TAKE PART?

So, we can understand the things that affect people living with HIV, and also people living with pain, we also want to interview people who *aren’t* living with HIV or pain. We are asking you to consider taking part because you’re either living with or without HIV, and with or without pain.

WHERE WILL THE STUDY BE DONE?

If you agree to be part of the study, the interview will take place 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 THE STUDY?

This is a 5-year research project. You will be one of 80 people taking part. There will only be one study visit where the in-depth interview takes place. There will be no more visits after this. The total amount of time required for your participation in this study is approximately one hour for the informed consent and in-depth interview.

WHAT DO I HAVE TO DO IF I AM IN THIS STUDY?

- If you agree to take part, you will be asked to complete a short demographic questionnaire asking you some basic information about yourself.
- You will then take part in an in-depth interview.

- Each In-depth Interview will be in a private room and will last for about 60 minutes. You can decide not to answer any questions or leave the interview at any time.
- During the in-depth Interview we will talk about what it's like to live in this community, how active you are, and how you go about getting help when things are difficult.
- Depending on whether you are living with HIV and/or pain, we will ask you how you manage, and how active you are able to be. We will ask if you have disclosed to anyone about your living with HIV and/or pain, and if that was helpful for you.
- Only you and the investigator, and an interpreter if you need, will be present during the in-depth Interview.
- In-depth interviews will be audio recorded with your permission and then transcribed by trained research staff.

Participant initials_________

- We will ask that you use a fake name to make sure that the information you provide will be private.

WHAT ARE THE BENEFITS OF BEING IN THE STUDY?
There are no benefits to you for participating in this study. But if you join the study you will help us understand what things at home and in the community help people when they're in pain. Your answers will also help us understand how people cope and what might help them cope better. We'd like to develop interventions to help people cope with living with pain and with HIV. Your answers will help us to start developing such interventions.

WHAT ARE THE RISKS OF BEING IN THE STUDY?
There are no direct risks for taking part in this study. However, some of the questions may make you feel anxious. You may stop the discussion at any time if you are upset and do not wish to continue. In addition, if you become very upset and distressed as a result of participating in our study, we will provide counselling and/or refer you appropriately.

WHAT ALTERNATIVES DO I HAVE?
You can choose not to participate in this study.

WHAT ARE MY RIGHTS?
Your participation in this study is voluntary and you can decline to participate or stop at any time without stating any reason. Your withdrawal will not affect your belonging to the larger Ndlovu research study if you wish to continue participating in that.

WITHDRAWAL FROM THE STUDY
As, stated above, you can leave this study at any time. If you decide to leave the study, please tell the study staff that you wish to leave. You do not have to give a reason why you want to leave the study, but any information you provide to study staff will be helpful. Leaving the study will not affect your relationship with the other Ndlovu research staff.

The investigator may also withdraw you from the study if it is considered to be in your best interest. The investigator has the right to withdraw you from the study, should:

- Your safety be compromised such as experiencing anxiety/stress during study participation

- You be judged to possibly interfere with the validity of the study results, such as being under the influence of drugs or alcohol during the process of data collection, or
- You be non-compliant with study requirements such as disrespecting other participants or study staff

WHAT ABOUT CONFIDENTIALITY?

All your information will be kept secret and will only be available to me (the investigator) and the study staff assisting me. The information will not be available to your doctors and nurses, or the other Ndlovu research staff.

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 research study will be stored in locked filing cabinets and kept in secure computer files protected by passwords. All in-depth Interviews will occur in a private room and will be transcribed immediately afterwards. Real names will not be included during the in-depth interview or in the transcripts. No individual identities will be used in any reports or publications that may result from this study. The study documents, and transcripts, including audio files, will be kept for 2 years if research results are published, or 6 years if there is no publication and thereafter destroyed.

INCENTIVE FOR PARTICIPATION

There is no cost for you to be in this study. You will receive reimbursement of R200.00 for your participation in this study to cover travel. Refreshments will be provided.

WHAT DO I DO IF I HAVE QUESTIONS OR PROBLEMS?

If you have questions about this study or any problems that you think may be related to this study, contact a member of the research staff, or principal investigator, **Antonia Wadley** on **011 717 2163** or **078 802 8182.**

ETHICAL APPROVAL

This study protocol has been submitted to the University of the Witwatersrand, Human Research Ethics Committee (Wits HREC – Medical) and written approval has been granted by that Committee. The Committee is a group of staff at the University who look after patients' rights have checked my study to make sure it is fair and treats patients well. If you want to know more about your rights when you are taking part in research you can contact Professor P Cleaton-Jones on 011 717 2301, peter.cleaton-jones1@wits.ac.za

Or the administrative officers:

Ms Z Ndlovu - zanele.ndlovu@wits.ac.za

Mr Rhulani Mkansi - rhulani.mkansi@wits.ac.za

Mr Lebo Moeng lebo.moeng@wits.ac.za

SIGNATURE PAGE

STATEMENT OF CONSENT

Before you sign this consent form, make sure of the following:

- You have read this informed consent form, or someone has read it to you.
- This study has been explained to you and had your questions answered.
- You understand you can ask more questions at any time.
- You have understood everything that has been explained to you and you consent to participate in this research study.
- You understand that you can without prejudice withdraw your consent at any time.

Participant’s Name and Surname (Print)	**Participant’s Signature**	**Date**	**Time**
Study Staff conducting consent discussion Name and Surname (Print)	**Study Staff Signature**	**Date (dd/mmm/yyyy)**	**Time**

Retain original Informed Consent Form on file. Offer participant a copy.