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A Qualitative Exploration of People Living with Chronic Pain in Rural South Africa

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A Qualitative Exploration of People Living with Chronic Pain in Rural South Africa



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Masters in Research Psychology

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A research project submitted in partial fulfilment of the requirements for the degree of Masters of Arts (Psychology) by Coursework and research to the Faculty of Humanities, University of the Witwatersrand, Johannesburg. 15/02/2024

Declaration

"I, Tebatso Ramoshai, declare that this research project is my own, unaided work. It is submitted for the Master of Arts (Psychology) by Coursework and research degree at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any other degree or examination at this or any other university.

Signed: 

Date: 20/01/2024

Abstract

Chronic pain is a highly prevalent global health concern. While much research has been conducted on the prevalence, treatment, and management of chronic pain, few studies have explored the experiences of people living with chronic pain, particularly in the South African context. This study aimed to explore and interpret how HIV-negative people living with chronic pain perceive their personal experiences with chronic pain and the impact it has on their lives. Part of a larger study that investigated the factors that influence the experience, daily activity, and disclosure of pain in people living with and without HIV in rural South Africa, this study conducted a qualitative exploration and interpretation of pre-collected interview data on a purposively selected sample of 16 HIV-negative individuals living with chronic pain from the Limpopo province of South Africa. Thematic analysis was used to analyse the data. Seven main themes emerged from the data: The nature of pain, participants' typical physical activity, pain interference, disclosure of chronic pain, reactions to pain disclosure, benefits of disclosing pain, and social support. The findings suggest that for HIV-negative people living with chronic pain, the impact of pain is multidimensional. All participants experienced pain interferences; however, there was little to no difference in participants' physical activity levels regardless of interferences. The findings suggest that economic stressors may be an influential factor in how pain is experienced between any two pain cohorts, determining whether there will be a change in physical activity levels or not. Furthermore, contrary to previous concerns in a South African cohort with chronic pain, pain disclosure was high in this cohort; therefore, participants were able to recruit different types of social support from close others. This research, therefore, contributes to the qualitative knowledge of the relationships between pain, physical activity, and the seeking of social support by people living with chronic pain in a South African context.

Keywords

Chronic pain; Qualitative research; HIV-negative; South Africa; Disclosure; Non-disclosure; Social support recruitment

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Chapter 1: Introduction

1.1 Introduction

Chronic pain is a highly prevalent global health concern and a significant emerging contributor to the global burden of disease and disability (T. Jackson et al., 2016; Treede et al., 2019). Chronic pain is associated with various physical and mental conditions; such as depression and anxiety (Dansie & Turk, 2013; De Ruddere & Craig, 2016; Igumbor et al., 2011b; Merlin et al., 2015; Parker et al., 2014, 2017; West et al., 2012). Additionally, chronic pain contributes significantly to healthcare costs, loss of productivity, increased disability and a possible reduction in one's quality of life (Dansie & Turk, 2013; Igumbor et al., 2011a, 2011b; Merlin et al., 2015; Parker et al., 2014, 2017; Pillay et al., 2014; West et al., 2012). Therefore, studies on chronic pain provide important information on the prevalence of, and the factors associated with the onset of chronic pain and its persistence. However, due to the subjective nature of pain experiences (Crowe et al., 2017; Pillay et al., 2014; West et al., 2012) and the influence of context (Engel, 1977; Vlaeyen et al., 2007), we cannot attribute all factors associated with chronic pain to every population. Therefore, improving the understanding of chronic pain and its impact on those living with it, in context, has the potential to inform the clinical treatment/management of chronic pain, i.e. the implementation of pain management programmes. Nevertheless, little qualitative research has been conducted with a focus on HIV-negative people living with chronic pain in a South African context. This study aims to fill that gap in the literature. Part of a larger study that investigated the factors that influence the experience, daily activity, and disclosure of pain in people living with and without HIV in rural South Africa; this study conducted a qualitative exploration and interpretation of pre-collected interview data of 16 HIV-negative individuals living with chronic pain from the Limpopo province of South Africa.

1.2 Research Aims and Objectives

This study aimed to explore and interpret how people with chronic pain perceive their personal experiences with chronic pain and the impact it has on their lives. Thus, this study had the following objectives:

Objective 1: To explore and gain an understanding of participants' perceptions about their experiences of prolonged (chronic) pain.

Objective 2: To explore participants' perceptions about the impact chronic pain has on their physical activity.

Objective 3: To explore participants' perceptions about the impact that disclosure or non-disclosure of their pain has on the social support recruited and received.

1.3 Rationale

Much research has been conducted on the prevalence, treatment, and management of chronic pain; however, few studies have explored the experiences of people living with chronic pain, particularly in the South African context. Studies that investigate the experiences of people living with chronic pain often focus either on the disruptions and limitations to physical activity (Dansie & Turk, 2013; Joelsson et al., 2017; Parker et al., 2017; Vader et al., 2021; Verbunt et al., 2005; Voscopoulos & Lema, 2010) or the concealment of pain and social stigma that is often associated with chronic pain (De Ruddere & Craig, 2016; Silva et al., 2011; Uysal & Lu, 2011). However, not much research has been conducted on the relationship between pain, physical activity, stigma, and the seeking of social support, more so in the South African context. It is important to explore this gap in the literature, through research, to gain knowledge on and an understanding of the experiences of those living with chronic pain. This is important as it has the potential to inform the clinical treatment/management of chronic pain, i.e. the creation and implementation of pain management programmes.

Furthermore, South African research on chronic pain has been predominantly quantitative and largely focused on chronic pain in people living with HIV. Very little research on chronic pain has been done qualitatively (de Villiers et al., 2015; Scott & McCracken, 2015). This study aims to contribute to this gap in knowledge.

Chapter 2: Literature Review

2.1 Introduction

The following literature review aims to locate this study in the existing literature. It will provide an overview of Western and local literature on the prevalence of chronic pain and the impact of and experiences of those living with chronic pain. It will begin by providing definitions for pain and chronic pain. Followed by a discussion on the prevalence of chronic pain, the impact it has on physical activity, the stigma associated with chronic pain and its impact on social support before providing a brief discussion on the available treatments and interventions for those living with chronic pain. It will then provide a contextualization of the available treatments and interventions for those living with chronic pain in South Africa.

2.2 Defining chronic pain

Pain is one of the first and most commonly reported symptoms across an array of illnesses and diseases (Dansie & Turk, 2013; Parker et al., 2014). Pain is subjective (Crowe et al., 2017; Pillay et al., 2014); and is defined as an "unpleasant, [uncomfortable], sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage" (Keen et al., 2021, p. 743). For pain to be categorized as chronic, it has to be experienced every day (West et al., 2012), "all the time or on and off"(Kamerman et al., 2020, p. 1629) for a period of three (3) months (Treede et al., 2019) or longer (Crowe et al., 2017; Joelsson et al., 2017; Kamerman et al., 2020; Pillay et al., 2014; Silva et al., 2011; West et al., 2012).

2.3 Prevalence of chronic pain

Chronic pain is a leading global public health concern that is considered to be large and growing (Clauw et al., 2020; T. Jackson et al., 2016; James et al., 2018; Keen et al., 2021; Parker et al., 2014; Pillay et al., 2014; Van Hecke et al., 2013). Attempts at estimating the prevalence of chronic pain in the general population vary depending on the study population and the definition of chronic pain used (de Villiers et al., 2015; Igumbor et al., 2011b). Estimates of the prevalence of chronic pain are higher in developing countries compared to developed countries (Igumbor et al., 2011b). As an example, chronic pain affects about 20–40% of the population of Western countries (Crowe et al., 2017; Dansie & Turk, 2013; Van Hecke et al., 2013; West et al., 2012) but 7-61% in Asian countries (Crowe et al., 2017), and 13-51% in African countries, specifically in Nigeria and South Africa (T. Jackson et al., 2016; Kamerman

et al., 2020; Sá et al., 2019). Possible reasons for the higher prevalence of chronic pain in developing countries include the increased prevalence of comorbidities or painful diseases such as cancer, hypertension, diabetes, HIV/AIDS, and TB (de Villiers et al., 2015; Dekker et al., 2012; K. Jackson et al., 2021; Parker et al., 2014; Wadley et al., 2016). The estimated prevalence of chronic pain among those living with HIV/AIDS in South Africa ranged from 50-87.2% (de Villiers et al., 2015; K. Jackson et al., 2021; Wadley et al., 2016). Furthermore, the higher prevalence of chronic pain in developing countries is influenced by the increased exposure to risk factors that have been associated with chronic pain such as psychological trauma, a history of abuse and interpersonal violence, low socioeconomic status, depression, stress, and anxiety (Apkarian et al., 2009; T. Jackson et al., 2016; Jeffery et al., 2011; Parker et al., 2014; Van Hecke et al., 2013; van Vreede et al., 2022).

2.4 Chronic pain and physical activity

Chronic pain can impact multiple areas of an individual's life including physical activities and exercise, one's ability to work, changes in social and familial roles, emotional and psychological well-being, and overall quality of life (Dansie & Turk, 2013; Igumbor et al., 2011a, 2011b; Merlin et al., 2015; Parker et al., 2014, 2017; Pillay et al., 2014; West et al., 2012).

Individuals living with chronic pain often struggle to perform daily physical activities, such as walking and lifting objects (Dansie & Turk, 2013). Joelsson et al. (2017) and Vader et al. (2021) have argued that physical limitations in performing daily activities often lead to reduced levels of physical activity in people living with chronic pain. However, disruptions in physical activity are not unique to people living with chronic pain and have been found in multiple pain populations (Parker et al., 2014, 2017; Verbunt et al., 2005; Voscopoulos & Lema, 2010). Moreover, some studies on South African pain populations have found little to no evidence of reduced physical activity regardless of pain intensity (Mphahlele et al., 2012; Wadley et al., 2016). It is suggested that financial stresses and fear of stigma may compel people living with chronic pain to conceal their pain and continue with daily activities, despite experiencing persistent pain (Uysal & Lu, 2011; Wadley et al., 2016; West et al., 2012). Individuals living with chronic pain may isolate themselves from social situations due to intense pain, low/reduced levels of physical activity, and/or fear of stigma (Merlin et al., 2015; Scott & McCracken, 2015; Silva et al., 2011). Nevertheless, the relationship between pain, physical activity, stigma and seeking social support has not been clarified in a South African population living with chronic pain.

Physical activity and exercise are the recommended "first-line treatment" (Vader et al., 2021, p. 1829) or self-management strategy for individuals living with chronic pain (Merlin et al., 2015) and are incorporated into pain management programmes (PMP) (Parker et al., 2019). However, the PMPs adopted globally were designed with other populations (often from Western and developed countries) in mind. The use of such programmes in the South African context has been challenging and has met with some limitations (Parker et al., 2019). Therefore, we must develop PMPs with the South African population in mind. To accomplish this, we need to have first-hand knowledge and understanding of the experiences of people living with pain, including their perceptions of the impact of pain on their physical activity, function, and overall quality of life.

2.5 Chronic Pain and stigma

Chronic pain is more than a medical condition. It is a complex and subjective experience that is "influenced by a combination of biological, psychological, and social factors" (Sendra & Farré, 2020, p. 46). In addition to physical and emotional distress (Eccleston et al., 2013; Sendra & Farré, 2020; West et al., 2012), chronic pain can cause financial strain on the individual, their family member/s, and on society (Dansie & Turk, 2013; Guzmán et al., 2001; Van Hecke et al., 2013). Due to the increased use of health care services and medications, loss of productivity and/or employment, and early retirement, people living with chronic pain may believe that they are a burden to those around them (Dansie & Turk, 2013; de Villiers et al., 2015; Igumbor et al., 2011b; Kamerman et al., 2020; West et al., 2012).

Fear of stigma is common among people living with chronic illnesses (De Ruddere & Craig, 2016; K. Jackson et al., 2021; Wadley et al., 2016); this is also true for those living with chronic pain. According to De Ruddere and Craig (2016), the complex and often misunderstood nature of chronic pain predisposes individuals to the "stigmatizing reactions of others" (2016, p. 1). These responses are often sceptical, devaluing, discrediting, and sometimes dismissing the experiences of those living with chronic pain. These stigmatizing responses are especially concerning when coming from healthcare practitioners, as people with chronic pain may present varying symptoms such as multiple/overlapping conditions such as "depression, anxiety, sleep disorder, disability, relationship distress, social role loss, isolation, and a concerning overuse of medicine" (Eccleston et al., 2013, p. 59) or present neither of the mentioned symptoms but still complain of persistent pain (Eccleston et al., 2013).

Healthcare practitioners may attribute lower pain intensity to individuals who do not present clear symptoms and are less inclined to help, trust, or empathise with individuals who do not have a clear diagnosis/medical explanation for their chronic pain (De Ruddere & Craig, 2016). These stigmatizing responses from others may further compel individuals to self-isolate and conceal their pain, which has been associated with poor physical and psychological well-being and overall quality of life (De Ruddere & Craig, 2016; Merlin et al., 2015; Scott & McCracken, 2015; Uysal & Lu, 2011). Moreover, the endurance of and continuation of activity despite persistent pain has been associated with an increased risk of chronicity and disability (Kamerman et al., 2020). Therefore, understanding the experiences of those living with chronic pain is important and necessary when designing effective pain management and treatment programmes, including prevention strategies.

2.6 Chronic Pain in South African Adults

South African pain studies have presented evidence of limited pain management resources and medicines in most rural communities (Dekker et al., 2012; Igumbor et al., 2011a). However, very few studies from South Africa have explored the pain management, treatment, and coping strategies utilised by South African people living with chronic pain. Of the available studies, South African individuals living with chronic pain were likely to use a combination of a high number of healthcare visits and medication, traditional remedies, and strong spiritual and religious beliefs (de Villiers et al., 2015; Dekker et al., 2012; Igumbor et al., 2011b). These cultural and contextual differences in pain experiences and pain management emphasise a need to understand pain experiences in context when creating and implementing pain management programmes (PMP).

2.7 Theoretical Framework

This study is located within the conceptual framework of the biopsychosocial model of illness (Appendix A). First conceptualised by George Engel (1977), the biopsychosocial model proposes a holistic perspective and approach to the understanding and treatment of illness (Engel, 1977; Turk et al., 2011; Wade & Halligan, 2017); where illness is thought to be complex, subjective, and multifactorial (Vlaeyen et al., 2007). The biopsychosocial model proposes that the experience of pain and illness is not isolated to the biological; instead, illness is the result of complex and dynamic interactions between the biological, psychological, and social aspects of one's life (Engel, 1977, 1981). The biological aspect of the model represents

the physiological facets of the illness. This refers to the changes in or damage to an individual's molecular, cellular, tissue, organ and/or nervous systems (Engel, 1977, 1981). The psychological aspect of the theory emphasises the individual's experience, specifically, emotions, thoughts, beliefs, and behaviour. And lastly, the social aspect of the theory refers to the influences of, risk factors found, and the individual's experience of illness in relation to others and the environment that they inhabit. This includes healthcare professionals, family members, community, culture, society, and the biosphere (Engel, 1977, 1981).

The biopsychosocial model is presented as a systems theory that is centred around the person; that is, the experience and behaviours exhibited when one has an illness (Engel, 1981). All systems influence and interact with each other at all times (Engel, 1981), therefore, pain and illness can be understood as stemming from the biological while the experience and behaviours of the illness are simultaneously contributed to by psychosocial factors (Vlaeyen et al., 2007; Walker, 2005). Additionally, the in-depth interview guide (Appendix B) was structured to elicit information on participants' beliefs about pain, the individual factors influencing participants' levels of physical activity, and the social factors influencing disclosure or non-disclosure of pain. This allowed the researcher to gain information on participants' psychological processing of pain, the perceived impact that pain has on their daily physical activity, thus physiology, and finally the social impact that the disclosure and non-disclosure of pain has on the participants experience of chronic pain. Therefore, the use of the biopsychosocial model as a theoretical framework, in conjunction with the interview guide, allowed for a well-rounded understanding of the experience of chronic pain and the impact it has on individuals physiologically, psychologically, and socially.

2.8 Research Questions

1. What are the experiences of pain among South African adults living with chronic pain?
2. How does pain impact the daily lives of people living with chronic pain?
3. How does the disclosure/ non-disclosure of pain impact the recruitment of social support in people living with chronic pain when experiencing a severe episode?

Chapter 3: Methodology

3.1 Research Design

This study has a qualitative and interpretative research design. A qualitative approach was deemed suitable because it is interested in understanding experiences, perceptions, and people's understanding of those experiences within their context (Willig, 2013). A commonly used paradigm in qualitative research is that of interpretivism. Within this paradigm, it is assumed that there is no definitive universal reality, nevertheless, we can still interpret or gain knowledge about reality through the use of language (Laverty, 2003). Therefore, it was deemed a suitable match for this study as it allowed the researcher to explore complex, multifaceted experiences and meanings within the specific context of South Africa (Marshall & Rossman, 2014; Willig, 2012, 2013). Furthermore, it allowed the researcher to approach the data deductively while searching for both semantic and latent themes when analysing the data. Where the use of latent themes allowed the researcher to analyse and present data that hold ideas and concepts that are coherent with the chosen theoretical framework (Clarke & Braun, 2013; Terry et al., 2017). Therefore, a qualitative interpretive design was considered most suitable for this study as it enabled the researcher to gain a rich understanding of the experiences of chronic pain.

3.2 Study Population and Setting

This study was set at the Ndlovu Care Group Research Facility in the Elandsdoorn, Groblersdal area in Limpopo South Africa. The Ndlovu Care Group is a research consortium between the Wits Reproductive Health Institute and Utrecht University in The Netherlands. The Ndlovu Care Group is running a longitudinal study called the Ndlovu Cohort Study. The study comprises nearly 1000 HIV-positive and 1000 HIV-negative participants from the Groblersdal area in the Limpopo province of South Africa, with the aim of understanding the interaction between HIV and other chronic conditions, with a particular focus on cardiovascular disease.

A sub-study exploring chronic pain was conducted by Dr Antonia Wadley et al. in 2018. This sub-study, nestled in the over-arching Ndlovu Cohort Study, involved mixed methods. Quantitative data on the prevalence and interference of chronic pain were collected on a

convenience sample of 250 individuals, and qualitative data from 54 people living with chronic pain, both with and without HIV. The data from 38 individuals living with both chronic pain and HIV have been analysed for two MSc projects elsewhere. The data presented in this dissertation are the remaining unanalysed qualitative data from 16 individuals living with chronic pain but not HIV.

The Groblersdal area in the Limpopo province, South Africa is a rural town that is predominantly inhabited by Black South Africans. Communities in Elandsdoorn predominantly speak Sepedi, Xitsonga, Tshivenda, and IsiZulu. The area is surrounded by agricultural activities, with farms that produce fruits and vegetables on large scales.

3.3 Sample and Sampling:

The sample for this study comprised sixteen (16) HIV-negative adults from the larger pain study. Due to the proposed research design and theoretical framework, sixteen participants were considered a sufficient sample size for this research as an in-depth analysis of the data produced was possible (Marshall & Rossman, 2014; Willig, 2012).

3.3.1 Inclusion and exclusion criteria.

HIV-negative, men and women, aged 18 years and older, with self-reported pain (of all kinds) for a duration of three months or longer, who had completed a qualitative interview in the larger pain study were included in the study. People with cognitive impairments were excluded from this study.

3.4 Participant Recruitment Procedure

In the larger pain study, individuals who were coming in for their annual visit to the Ndlovu Care Group Research Facility were approached and given a brief description of the study. Individuals who were willing to learn more about the study were then taken into a private consulting room and given a full description of the study. Those who were willing to participate in the study were then given and asked to fill in informed consent forms and assured that their information would be anonymised and kept confidential. This was achieved by keeping the consent forms and the completed questionnaires in separate rooms where only the investigator and the research team involved had access.

In this study, participant recruitment involved identifying individuals within the pain study who had given a qualitative interview and met the inclusion criteria of being HIV-negative and living with chronic pain. A total of sixteen (16) individuals met the specific inclusion criteria outlined for this study.

3.5 Instruments

An hour-long semi-structured interviews were conducted to determine participants' beliefs about pain, factors influencing levels of activity, disclosure of pain and the impact that disclosure or non-disclosure of pain has on the participants' pain experiences. The interview guide (Appendix B) allowed the researchers to conduct focused, in-depth interviews.

The anonymised translated transcripts of the interviews were used for this study and analysed using thematic analysis (Clarke et al., 2015; Terry et al., 2017)

3.6 Data Collection Procedure

Participants were asked if they were willing to take part in the second part of the study which consisted of an hour-long in-depth interview. Those who were interested were either asked to set up an appointment or have the interview done immediately. Participants were taken into a private room where they were given a full description of the study and asked to complete an informed consent form including consent for recording of the interview. The interview was conducted by the primary researcher with only the participant and a translator, for individuals who needed one, present. Interviews were then audio-recorded, transcribed and translated where necessary.

In this study, the researcher was given access to the anonymised translated transcripts which were downloaded and saved in electronic format onto the researcher's password-protected computer.

3.7 Data Management

Data management entailed: the secure storage of data, limited and controlled access to the data, and attention to the confidentiality of participants' information.

The audio recordings from the hour-long interviews were stored in a password-protected online Google Drive folder, to which only the primary researcher and the transcribers had access. The audio recordings were then deleted immediately from the recorder. The audio recordings were then transcribed verbatim and anonymised by experienced transcribers. Additionally, the interviews that were conducted in the local language were transcribed first into the original language and then translated into English for data analysis.

In this research, once the researcher received access to the data, it was stored on a password-protected computer. It was also not shared or disclosed to anyone. After the completion of this research project, the data will be stored and deleted after 7 years as specified in the ethics approval.

3.8 Data Analysis

Data was analysed using Thematic Analysis (TA). Conceptualised by Braun and Clarke (2006), TA is a qualitative method that aims to identify, analyse, and report themes or patterns in the data (Braun & Clarke, 2006; Terry et al., 2017) that can be used to create and develop a rich, in-depth understanding or interpretation of either the entire data set or various aspects of what is being studied. Furthermore, TA can be used across different theoretical frameworks and is not confined to a specific paradigm, or epistemology (Braun & Clarke, 2013). Thus providing a flexible and accessible approach to analysing data(Clarke et al., 2015; Terry et al., 2017). This method enabled the researcher to produce a rich and detailed interpretive analysis of participants' perceptions of their experience of chronic pain. It has enabled the researcher to discover the different aspects in which chronic pain has an impact on participants' lives, with reference to the Biopsychosocial model. TA can be applied to different types of data; both small and large "data sets and can be applied to produce data-driven or theory-driven analyses" (Braun & Clarke, 2013, p. 120). Therefore, TA was deemed a suitable approach for this study.

This research followed the six-phase process outlined by Braun and Clarke (Clarke et al., 2015; Terry et al., 2017):

Phase 1: For this phase, the researcher familiarised themselves with the interview transcripts. This was done by reading through the transcripts numerous times and taking notes in a colour-coded coding document on the patterns that were found in the data; to be used later for coding (Clarke et al., 2015; Clarke & Braun, 2013).

Phase 2: During this phase, the researcher used the notes from the colour-coded coding document to produce the initial codes that appeared to be interesting from the data (Clarke et al., 2015; Clarke & Braun, 2013). However, these codes were not considered themes as yet but were used to help create themes at a later phase. The researcher generated these codes with the biopsychosocial model in mind but kept all 102 codes - those that accounted for the model and those that did not. The codes were generated manually on a word document. Once all possible codes were created, the researcher moved on to the next phase.

Phase 3: This phase involves the use of the codes that were created in the previous phase to start searching for themes (Clarke et al., 2015; Clarke & Braun, 2013). The researcher began by sorting and analysing the codes to find potential relationships between them to create overarching themes where present. This was done using colour coding and grouping codes that had potential relationships. Thematic tables were then created by the researcher to help with the visualisation and organisation of the themes as they emerged. At this phase, no themes or data extracts were discarded in the case that they might be significant to the main themes that will be discovered in the later phases (Terry et al., 2017).

Phase 4: This phase involved the reviewing and refinement of the themes from phase three (Clarke et al., 2015; Clarke & Braun, 2013). This was done in two stages. Firstly, the researcher reviewed the themes "at the level of the coded data extracts" (Braun & Clarke, 2006, p. 91). This was done by reading through the data extracts multiple times (for each theme) and considering if they formed a clear pattern. Once they did the researcher then moved on to stage two, where they reviewed the themes "in relation to the data set" (Braun & Clarke, 2006, p. 91). The researcher then judged each theme and the thematic tables created in phase three for an accurate representation of the data set as a whole (Clarke et al., 2015; Clarke & Braun, 2013). This allowed them to ensure that any missed themes from before, or those that do not 'accurately represent' the data set, were discovered. Some overlapping themes were found and thus had to be reworked through another analysis of the codes from the data set. Once satisfactory themes, that worked together to describe the data set, had been generated; only then could the researcher move on to the next phase. At this point, the researcher moved the themes and data extracts into a different coding document.

Phase 5: During this phase, the researcher was "defining and further refining the themes" (Braun & Clarke, 2006, p. 92) that will be presented in the final analysis. This was done by looking at and analysing each theme that was generated. The researcher then wrote a

description of each theme to determine how it relates to the overall research topic and the other themes. Then determined how each theme can answer the research questions that this research is concerned with.

Phase 6: Finally, in the last phase the researcher produced and wrote up the final report on the findings from the data set used (Clarke et al., 2015; Clarke & Braun, 2013). This report has used the themes that have been generated, while providing sufficient evidence of these themes from the data set, to "tell a story" (Braun & Clarke, 2006, p. 93)) and make an argument about the data in relation to the research questions above.

3.9 Reflexivity

As this research used thematic analysis (TA), reflexivity was crucial to the successful implementation of TA (Clarke & Braun, 2013). Reflexivity allows the researcher to identify, consider and acknowledge the influence of their preconceived notions and personal beliefs that may have affected the data analysis process. For TA, reflexivity begins at the first phase of data analysis. I, as the researcher, considered and acknowledged the influence of my preconceptions about chronic pain. As someone who has previously experienced prolonged pain for more than three months, I acknowledged and took note of the presumptions I had about what experiences of chronic pain should look like and how this may have influenced the analysis (themes generated) and interpretation of the data (Marshall & Rossman, 2014; Willig, 2012). The analysis of some extracts from the data revealed and challenged a bias I held about help-seeking and gender. Although this research did not focus on gender, the extracts suggested that people living with chronic pain, regardless of gender, were able to seek help and social support from friends and family members- something that I had expected to be more prominent in female participants. Furthermore, all relationships between the themes generated during TA have been discussed followed by a demonstration of how they could be integrated with theory and existing literature (Finlay, 2006). This approach ensured the transferability of the findings of this study, highlighting their applicability beyond the immediate context. Additionally, I remained sensitive to negotiated realities, explaining any differences that arose between my interpretations and those of the participants (Finlay, 2006). And finally, to ensure the credibility of the entire research project; a final write-up that presented the material in a coherent, clear manner has been produced (Finlay, 2006). This integration of reflexivity, attention to

transferability and credibility collectively contribute to the trustworthiness of the study (Finlay, 2006).

3.10 Ethical Considerations

In every research project, it is crucial to protect human participants through the application of appropriate ethical principles (Arifin, 2018). Due to the flexible and open-ended nature of most qualitative research designs, ethical issues of confidentiality, informed consent, autonomy, and beneficence may arise (Cieurzo & Keitel, 1999; Haverkamp, 2005; Ponterotto, 2010). Therefore, these ethical concerns must be considered and applied throughout the study. This research used pre-collected data from a larger study conducted by Dr Antonia Wadley et al. in 2018; thus, ethical clearance has been attained. Permission was requested and granted from the Human Research Ethics Committee (Medical) of the University of the Witwatersrand; clearance number: M180652 (Appendix D). Ethical approval was also obtained from The Limpopo Department of Health (Appendix E). Permission was also requested and granted by the Ndlovu Care Group director to conduct the study at the research facility. Participation in this study was voluntary, hesitant participants were reminded of this throughout the research process and assured that refusal to participate would not have a negative impact on their care at the Ndlovu Care Group Centre. Participants were given full descriptions of the study during the recruitment process. They were also given informed consent forms to sign for the different parts of the study. Participants were guaranteed the confidentiality of their HIV status and medical records obtained from the Ndlovu Care Group. They were assured of both confidentiality and anonymity of their questionnaire and interview data. This was achieved through the anonymisation of the translated transcripts before data analysis. Furthermore, participants were warned about the risks of taking part in the interview part of the study where participants might experience emotional reactions to the questions asked such as anxiety or stress. Should a participant experience emotional distress during the interview, a distress protocol was followed where participants were referred to a social worker at the research facility.

In this study, the researcher's name was added to the ethics protocol through an amendment. Additionally, an ethics clearance certificate from the Human Research Ethics Committee (Medical) was obtained (Appendix F), protocol number: M230788. The original study ensured confidentiality and anonymity to the participants, which was upheld in this research. Once the

data had been received, it was kept on a password-protected computer. It was also not shared or disclosed to anyone. After the completion of this research project, the data will be deleted to maintain confidentiality.

Chapter 4: Findings

This chapter presents the findings from the in-depth interview data. Seven main themes emerged from the data, namely: the nature of pain, participants' typical physical activity, pain interference, disclosure of chronic pain, reactions to pain disclosure, benefits of disclosing pain, and forms of social support. These themes along with their sub-themes will be presented and discussed in this chapter.

4.1 Participant characteristics:

Sixteen HIV-negative participants were included in this study. Nine of the participants were female and seven were male. Five of the nine female participants reported being unemployed, two reported working part-time, and two reported having full-time jobs. Of the seven male participants, two reported being unemployed, two reported working part-time, and three reported having full-time jobs. All participants except for one reported having obtained either a secondary or a tertiary level of education. The ages of the participants ranged from 24 to 46 years.

4.2 Table of themes and subthemes identified:

Themes:	Sub-themes:
1. The nature of pain	1.1 Nature and persistence of the pain
	1.2 Pain location
	1.3 Perceived causes of pain
	1.4 Pain management strategies
2. Participants typical physical activity	
3. Pain interference	3.1 Physical interference
	3.2 Strategies for coping with physical interference
	3.3 Social interference
	3.4 Emotional interference and consequences of pain
	3.5 Perceived pain prognosis
4. Disclosure of Chronic pain	4.1 Full disclosure of chronic pain

	4.2 Detailed disclosure of chronic pain
	4.3 Partial disclosure of chronic pain
	4.4 Reasons for disclosing chronic pain
5. Reactions to pain disclosure	
6. Benefits of disclosing pain	
7. Social support	7.1 Instrumental support

Table 4.2: Themes and sub-themes

4.3 Theme 1: The nature of pain

A large majority of the participants described their experience of pain as one that is multi-layered; something that was not only confined to the physical sensations, that come with pain, but one that had psycho-social effects and origins. This theme describes participants' perceptions about their experiences of living with chronic pain.

This includes participants' descriptions of the nature and persistence of their pain, the location of their pain, the perceived causes of their pain, as well as the strategies they use to manage that pain.

4.3.1 Nature and persistence of the pain.

Several participants experienced pain as a serious and uncomfortable sensation that would never fully disappear.

Most participants used words like *"stabbing", "burning", and "cutting"* to describe the sensations they felt when the pain would appear; thus, alluding to the intensity or nature of the pain they experience.

> *"…this one [pain] is a burning discomfort…The one that is behind [my back] burns"**(IDI-Pain-A083-Age-42- Female)***
>
> *P: stabbing.*
>
> *I: Oh, stabbing?*
>
> *P: Yes, stabbing."* ***(IDI-Pain-A098-Age-26- Female)***

Most participants experienced persistent pain. Participants described their pain as one that would *'never completely stop'*. Although the pain would slightly ease and was not felt at every hour of the day, it is something that they perceived as a constant part of their life experience; thus, alluding to the temporal nature of pain.

> *"[The] Pain. I feel like maybe it is going away, but it is not.",* ***(IDI-Pain-A033-Age-39- Female)***

> *"It gets better a bit but never completely stops but it does get better a bit because when I drink, I urinate, as I urinate, I feel that something gets better, but it never completely stops."* ***(DI-Pain-A074-Age-27- Female)***

Some participants described pain as unpredictable and would come *'out of nowhere'.* Participant IDI-Pain-A083-Age-42- Female experienced pain that would ease or subside and then return *'out of nowhere'.* Additionally, she reported feeling when the pain would be coming.

> *"It's a very serious pain that I have….It's serious, it's serious pain….Because it appears out of nowhere…Yah [Yes] I can feel it coming. Yes, it means this pain….I feel it….When it comes. I can feel that eish! Here's this pain, it's about to start again here"* ***(IDI-Pain-A083-Age-42- Female)***

4.3.2 Pain location.

A Majority of the participants experienced pain in multiple areas of their body, for some this would happen simultaneously, and for others, the pain would be felt at different times in the different body parts.

> *"I do have a problem [with] the pain and that pain it starts from under the breast, under my breast then goes back to the back, then to my rib line, then to the waist."* ***(IDI-Pain-A032-Age-42- Female)***

> *"I: Here you've indicated you have pain, on the chest and you also have pain on your lower abdomen.*
>
> *P: Yes*

I: Your hand also gives you a problem?

P: Ja. I'm like a scrap car" ***(IDI-Pain-J011-Age-36- Male)***

4.3.3 Perceived causes of pain.

Participants' perceptions about the causes of their pain can be grouped into five different categories, namely, physical injury, work-related cause, stress, a link to other illnesses or chronic conditions, and a link to inherited conditions. The chronic illnesses included arthritis and diabetes. Most participants reported believing that their pain was caused by a physical injury. As an example, some participants reported having been in an accident, while others referenced having a sports injury.

> *"Yah I was involved in an accident…That is why it caused this pain here (pointing at her chest)"* ***(IDI-Pain-A083-Age-42- Female)***

> *" My left hand, Ja [Yes]. Also gives me a problem. My left hand, it was broken you see (He shows him his hand). [be]cause of the accident, you see"* ***(IDI-Pain-J011-Age-36-Male)***

Other participants reported believing that the cause of their pain is linked to the activities they partake in at work. These activities include lifting heavy objects, standing for long periods, and other repeated actions.

> *"Oh, it's painful, like that pain yah that pain when it starts like, it starts most of the time when l am at work. So, l do feel like it is maybe because l am standing a long time for a long day every day like…I think it's this standing long period of time, like even though you use your hand, your hands."* ***(IDI-Pain-A032-Age-42- Female)***

> *"The work that I am doing, I think it is the one causing these problems. Even the wheelbarrow I push every day, we push it with pressure every day. I think maybe [it causes the pain] …"* ***(IDI-Pain-A074-Age-27- Female)***

Female participants reported believing that their pain was caused by stress or *'thinking too much'*. As an example, some participants reported having stress.

> *"I thought maybe it's [pain] stress or something."* ***(IDI-Pain-A005-Age-40- Female)***
>
> *P: Maybe it's thinking too much."* ***(IDI-Pain-A083-Age-42- Female)***

While one of the participants reported that the stress was a by-product of *'not having work'* or unemployment.

> *"I think it's [the cause of the pain is] because I don't have parent[s], I live alone, I don't work…Ya because I think about these things every morning when I wake up, thinking what am I going to eat? how am I going to make ends meet this month?... Not working, no parents, jobless and I have a child that I am raising every day."* ***(IDI-Pain-A106-Age-27- Female)***

However, other participants believed the cause of their pain to be linked to other chronic illnesses/conditions; some of which participants believed to have been inherited from their parents.

> *"I have arthritis …Well…. Actually, my mother neh [okay], my mother has arthritis, and my father. They told me it's inherited but I'm not sure."* ***(IDI-Pain-A047-Age-35-Female)***
>
> *"P: It's like my mother was bewitched and then that traditional healer helped her so that that thing [pain] won't come to us. Because when I was growing up, I didn't live with my mother, then my mother lived in Mpilong and then we lived here. So I have never lived with my mother so that she can tell me about all of this.*
>
> *I: Oh so the traditional healer healed your mother's pain but it came to you?*
>
> *P: Yes."* ***(IDI-Pain-A106-Age-27- Female)***

4.3.4 Pain management strategies.

Participants in this study reported using multiple strategies to manage their pain. The majority of the participants reported relying on pharmacological methods such as over-the-counter medication to manage their pain. Other participants reported relying on non-pharmacological methods to manage their pain as some reported feeling that the available medication made no difference in their experience of pain.

Of the participants who relied on pharmacological methods to manage their pain, some participants relied on over-the-counter medication to alleviate their pain, with some using both prescribed and over-the-counter medications.

> *"The[y] prescribed me Brufen and then also Acdo-dol and another one . So, it's the tablets that l use, l am using now."* ***(IDI-Pain-A032-Age-42- Female)***

> *"Uuuh, sometimes I put errr, some patch, pain patch. Sometimes I put errr, what do they say? …. this medication that you put on the, on the, like Voltaren cream. You see, just to rub it."* ***(IDI-Pain-J010-Age-46- Male)***

Of the participants who reported using non-pharmacological methods to manage their pain; some participants reported using methods such as drinking water with lemon while others reported using traditional medicine.

> *"There are some days it hurts a lot, but I can walk around although it hurts. When it hurts a lot I drink a lot of water, I drink a lot of water and mix it with lemon, and it gets a bit better"* ***(IDI-Pain-A074-Age-27- Female)***

> *"I went to traditional healer, but still….And then slowly they gave me something to rub whenever I feel the pain. I would rub it but then still, nothing changed."* ***(IDI-Pain-A106-Age-27- Female)***

Other methods reported by participants include: *'beating against the wall'*, the use of physical activities such as *'exercising'*, and the use of distractions to alleviate and/or manage their pain.

> *"When that pain starts in my chest, I tell my son to beat me here, at the back cause that pain … When he beats me here at least, it's like he massages He beat that pain, and*

after that, it's going to be normal…Ja. When that pain starts, I go to the wall and beat myself with my back….You see. It goes down, the pain…Yes. I can sleep but if I don't do that, ja I won't sleep" ***(IDI-Pain-J011-Age-36- Male)***

"Yoh, it hurts so bad man, like at this age, that is why I keep exercising because I keep telling myself once I lose weight, I will be better" ***(IDI-Pain-A047-Age-35- Female)***

"I: Oh alright, and then what activities do you do to relieve your pain?

P: Just going outside and getting fresh air, maybe getting something new that will relieve [the pain], or I will go out and sit with my uncle because sometimes he would drink and then make jokes, like when I am with him my brain that is always thinking about my unemployment will get distracted a bit.

I: Oh so you go and talk to them and then they distract you?

P: Ya.

I: And then they start talking and the pain gets better?

P: Ya." ***(IDI-Pain-A106-Age-27- Female)***

Furthermore, several participants reported relying on non-pharmacological methods when managing an episode of intense pain. These methods include resting/ sleeping, sitting, staying still, relaxing, or simply breathing *'through the pain'*.

"I: Oh ok, and then what do you do at work when the pain is?

P: I just sit down and just make sure that, and the problem is that if the pain is there, I can't make any movement…So I have to just listen,

I: At work?

P: Yes, until I can feel that now it's getting better. …So, I can breathe, especially when I can breathe it's going to be better just because if I breathe, I take it slowly, slowly until it's mild. It's coming back, it's coming back Then I get yah" ***(IDI-Pain-A032-Age-42- Female)***

"I: I see. Uhm! So, on these days, neh? When you are having a lot of pain and there are certain things you say, you cannot do or what happens? Like at home, would you describe how your day is like, if you have too much pain, that

day? What would you do?

P: Uh! I sleep when the pain is worse, have to sleep!

I: Most of the time, you just sleep?

P: Ja!" ***(IDI-Pain-J001-Age-34- Male)***

4.4 Theme 2: Participants' typical physical activity

A majority of the participants reported being physically active on a daily basis. Most participants reported engaging in daily household chores. The chores ranged from *"cooking, cleaning, washing, fetching water,* [to] *taking care of children etc."*. Participants reported doing these chores every day, even on the days they go to work.

"I prepare water [1]for the child[ren] because they are going to school….I iron the clothes and then they go to school. And when I [am]left at home … I clean. I go to water … fetch … I go to the tap (community tab) [to]fetch the water….I clean the house and I cook for them. So that after school they can get the food ready." ***(IDI-Pain-A008-Age-39- Female)***

*"I clean before I take a bath, I take a bath, I help with my mother and my sister's kids before they go to school and crèche….When I'm busy with my chores that's when I am walking, yah I'm walking just to keep my body busy. I'll be washing, I'm doing laundry, washing blankets just to keep my body busy….I sweep, sweep the yard outside, and inside. I clean. It's not a big house, but we have trees, and we have to sweep every day. Yah cleaning"****(IDI-Pain-A047-Age-35-Female)***

Additionally, participants reported still being able to partake in their daily activities even on the days when they would experience pain. When asked *" What can you still do when the pain*

[1] This refers to the participant boiling the water and then placing into a bath for the children.

is bad?", most participants reported small changes or no change in the activities they participated in on a daily basis.

> *"I can still sweep, I can sweep, but the only thing I won't do is when I have to clean when I'm kneeling down if I'm not using a mop."* ***(IDI-Pain-A047-Age-35-Female)***

> *"Everything. Yes, because like I am a person who can stand pain…pain can hit me, but I can do everything you see yes like except when I feel like I will collapse that's when I see that, but when it hurts, I can still continue"* ***(IDI-Pain-A074-Age-27-Female)***

Some participants also reported participating in work activities, many of which were physically demanding. These activities vary according to the different occupations of the participants. Therefore, participants engaged in work activities that ranged from walking *"up and down"*, standing, working with building materials, and heavy lifting, amongst many other activities.

> *"l am Cashier then my work is just being at the till, l also have to pack the stuff also clean the floor. We do anything you see in the store….Yah, we pack, we clean, we do fittings all of the staff, but we are Cashiers all of us, but we do things as said…We always work standing, the whole day "* ***(IDI-Pain-A032-Age-42-Female)***

> *" Maybe I'm busy with plastering, sometimes roofing….Ja. Most of the time when I'm busy….Sometimes build[ing]"* ***(IDI-Pain-J001-Age-34-Male)***

However, a pattern in the data suggests that participants in this cohort continue to work, thus taking part in these physically demanding activities, despite experiencing chronic pain. A majority of the participants reported financial motivations as the reason for continuing to work. Participants cited having a fear of being replaced at their workplace (unemployment), feeling like they do not *"have a choice"*, or feeling that they can *"maintain"* the pain.

> *P: So, it's difficult just because I do have kids, my kids, to support, I have to take it like that then work with that pain.*
>
> *I: If you don't have a sick note,*

*P: No, they will not, they don't, they don't gonna pay you. Then they tell you that if you not…they can get another one. Another person to work, who's serious, you are not serious about your work. They say so ."****(IDI-Pain-A032-Age-42-Female)***

P: Things … where I [am]working as … I don't know [what]you guys call it … a low income.… so every second counts…So if you [are]off from those seconds, they cut your salary….So, I have to push… to be better than … to get like uh, reasonable cents….for a better living… if you don't work, you don't get paid

I: Oh, you said sometimes when you are in pain you continue?

P: Yeah, I go to work…Because I don't have a choice" ***(IDI-Pain-A098-Age-26-Female)***

"I: Ok, and why do you still do it if you are in pain?

*P: As I've said I've experienced this pain … maybe needs serious help … serious help… and I've experienced it only in the morning. And as I do seek that help, but for now, that help require money but like serious. So I decided I have to handle this pain, live with it and this pain could stop my life or stop whatever I'm doing. Yes, it's concerning … it's errr part of my health, yes, but I can maintain it, for now…. So… I can't stop working because of it."****(IDI-Pain-J007-Age-30-Male)***

4.5 Theme 3: Pain interference

Participants in this cohort reported experiencing multiple interferences in their daily lives due to their chronic pain. Therefore, this theme describes participants' perceptions about the impact that chronic pain has on their daily lives. Participants described experiencing physical, social, and emotional interferences while living with chronic pain. They also described the strategies they use when coping with the physical pain interferences.

4.5.1 Physical interference.

All participants reported experiencing physical interferences due to their pain. Participants described experiencing pain that sometimes limits or stops their physical activity. Most

participants reported feeling limited in the activities they could participate in, including not being able to bend, sit, or walk when experiencing intense pain.

> *"I can't do laundry; I can't wash blankets because I have to use my…I have to use my feet…Yah to wash the blankets. And they can't send me to the shops, yah maybe if I have to go buy bread at the shops… if they are… the pain is bad, I can't walk."* ***(IDI-Pain-A074-Age-27-Female)***

> *"P: I don't have I, I, I, I get tired as I'm sitting down like this. I don't have to spend much time sitting down on a chair. Ja, because like eh, I'm bending, I'm bending too much. Ja it's … I'm no longer normal. My, my, my back is my … this column is no longer normal."* ***(IDI-Pain-J088-Age-29-Male)***

Furthermore, a majority of the participants experienced disturbed sleep as the pain they often felt would interfere with their sleep. Most participants found that they could not sleep once they felt the pain, some would be woken up from their sleep due to the pain, while others would have to adjust how they sleep to accommodate the pain.

> *"The pain I feel on my back, sometimes when I am sleeping, it feels hot hot hot… Ja. It [the pain] interferes with my sleeping because I have listened to myself, and I feel that pain while it is going up and down. Again when I am sleeping with my stomach, it interferes with my neck. In the morning while I am supposed to do like this, it feels like my neck is too painful."* ***(IDI-Pain-A033-Age-39-Female)***

4.5.2 Strategies for coping with physical interference.

Participants in this cohort reported the use of various strategies that would allow them to continue or manage their physical activities. Participants reported delegating tasks, mostly household chores, to those around them when they have 'bad' pain episodes. Some participants reported having *"split responsibilities"* with others they live with- which can help them manage the activities they can/will do.

> *"I don't do anything because I have a boy 15 years old so he can help me there and there….Prepare for that other child….He can prepare water, iron and he, he help me"* ***(IDI-Pain-A008-Age-39-Female)***

"There are split responsibilities, I clean then another cooks." ***(IDI-Pain-A074-Age-27-Female)***

Furthermore, participants would lower the intensity of the tasks that they would have to do. Most participants reported doing *"light"* or *"easy"* jobs and/or tasks when the pain is 'bad'.

"I can clean, maybe the… like I take a mop…And then sweep the floor, I can, yeah….I dust here and there….Yeah just the easy thing that I can do." ***(IDI-Pain-A008-Age-39-Female)***

"The other hand will not be able to work… so you can do light duties, ya." ***(IDI-Pain-J007-Age-30-Male)***

Other participants reported having to modify the physical activity they are doing to accommodate the pain they might experience. These participants reported having to stand or sit in a particular way or using a different hand to continue their physical activity.

"Because it also affects my hand, like my right hand…Like I don't have any power to fold my hand, yah so I can't maybe dry the clothes from water, no I can't do that. Then maybe I can, If I am cooking yah, I can cook, like using the right hand. ***(IDI-Pain-A032-Age-42-Female)***

"I take a chair and sit down and work like this" ***(IDI-Pain-J074-Age-33-Male)***

4.5.3 Social Interference.

Some participants reported experiencing social interferences in their lives as a result of their chronic pain. One participant reported experiencing disruptions in their relations with others, due to their pain. As an example, participant IDI-Pain-A047-Age-35-Female reported avoiding having relationships with others due to having insecurities that were brought on by her chronic pain.

"P: No, I avoid, even relationships I avoid them until I feel better.

*P: It hurts because I would like to have a partner, I can share things with and even be happy with."****(IDI-Pain-A047-Age-35-Female)***

"I can't do ay. I think maybe uhm, it's my insecurity, I'm not sure. I think I'm unable to have sex because there are other positions I can't perform. I am single because of it…I am single because I think I can't perform those positions in bed, and I feel bad and lonely and small." ***(IDI-Pain-A047-Age-35-Female)***

Furthermore, other participants reported a change in their lifestyle due to the interference of pain. These participants had to change the food and drinks that they could or could not eat/drink due to it causing episodes of intense pain.

"Yoh, I remember before I knew what was happening with me, they didn't tell me what food to eat, what to eat and what not to eat….I ate beef and beef stew. The next day I couldn't wake up. Every joint, even my jaws. I couldn't speak, I couldn't wake up…Sometimes it happens and it's still happening. Last year I ate Mayo, and I couldn't wake up or speak…it was torture…every joint, my jaws were painful… The first time it happened when I had beef, they took me here to Dr Templeman. He told me arthritis is like high blood, it goes up, it goes down, it has to be normal. So he told me which food to eat and what not to eat, but because I like food, so I eat sometimes." ***(IDI-Pain-A047-Age-35-Female)***

"I: Alright so tell me what can't you do when the pain is bad? What activities can't you do when your pain is bad?

P: I can't drink beer. ***(IDI-Pain-A074-Age-27-Female)***

Additionally, some participants reported feeling that their pain limits their *"working opportunities"*. Participants expressed a fear or hesitancy to work due to their pain or fear that working may cause them more pain.

"It limits my working opportunities, but they understand I can't work. So, at home, I just work on the house, maybe paint, or do garden work. I sometimes rather do that, but when I am in pain, they know not to touch me. I just alert them, and they let me sit on the stool and rest" ***(IDI-Pain-A047-Age-35-Female)***

"I: Oh, because of it [pain] you can't really work?

P: Ja, ja. I'm, I'm afraid, I'm scared. I'm scared that eh, maybe I may damage it more. It can get worse…And then once I damage this backbone, it's over about my life. I won't… [I am]no longer going to use my feet to walk." ***(IDI-Pain-J088-Age-29-Male)***

4.5.4 Emotional interference and consequences of pain.

A majority of the participants reported experiencing emotional interference as a result of their chronic pain. Participants described a change in their mood when experiencing chronic pain. Most participants described a complete change of mood when experiencing pain, with some mentioning *"not feeling happy"*, *"not enjoying anything"*, and a need to be silent or alone once their mood changes.

"Like uh, it [the pain] changes, it changes all my mood ….So, it's like I can't, I can't do anything. I can't cook, I can't eat, like I can't even do chores, chores whatever neh, then I can't even do intercourse with my, my partner…So, it's completely interferes. " ***(IDI-Pain-A032-Age-42-Female)***

"When I have it [the pain]? It troubles me. I feel like I could just be silent…and not say anything…Yes, just listen to this pain…I don't become happy, I don't laugh, I'm not joyful when I have this pain on my chest" ***(IDI-Pain-A083-Age-42-Female)***

Furthermore, a pattern in the data suggests that multiple participants have resigned to their pain. While some participants express it as an acceptance of their pain, others seem to have given in to the belief that there is not much that they can do about their pain and so it is just something that is *'there'*.

"I end up saying it's a pain I have to live with. I just accepted in the morning I'll be living with this kind of problem when I wake up every morning. Ya…That's what I will do, but for now I take it [the pain] as if it's my problem. Ya. I have to accept it until I have a way to fix it." ***(IDI-Pain-J007-Age-30-Male)***

"I: Do you pray about your pain?

P: Not really….Not really. Pain is pain… It's not like things that they say to you or the things that are happening to you….[The] pain it's there, baba [man]….It's just there.

It strikes and you like "Yoh[2], what do I do next?"….So, it's different to that … the feeling … [It's] a deeper feeling...So it's different." ***(IDI-Pain-A098-Age-26- Female)***

4.5.5 Perceived pain prognosis.

Some participants reported feeling scared or worried about their future and experiencing emotional distress due to their chronic pain. Participants reported feeling worried about the effects that their pain would have on their lives in the future. Two participants expressed a fear of the pain worsening as they age, while others expressed a fear of partaking in certain social activities (like dating) due to their pain either worsening or later causing an interference.

"That pain is on the lung side. It can affect me in future and I'm still young. If it continues this kind of pain in the chest… eish, anything can happen." ***(IDI-Pain-J007-Age-30-Male)***

"Yoh[3] yoh! I ask myself where will [I] be at the age of 60 if I am already with arthritis…It hurts, I won't lie, it really hurts." ***(IDI-Pain-A047-Age-35-Female)***

" It hurts because I am not sure, but someone told me I can't have kids because with my joint I can't deliver properly. My ribs, my ribs can't, I can't be pregnant because of my ribs, something like that. Yah, so that's the other thing I am scared of dating because maybe I won't be able to fall pregnant, also my weight is an issue" ***(IDI-Pain-A047-Age-35-Female)***

"I: Oh, because of it [pain] you can't really work?

P: Ja, ja. I'm, I'm afraid, I'm scared. I'm scared that eh, maybe I may damage it more. It can get worse…And then once I damage this backbone, it's over about my life. I won't… [I am] no longer going to use my feet to walk." ***(IDI-Pain-J088-Age-29-Male)***

Conversely, some participants reported feeling optimistic about the future in relation to their pain. Many expressed a hope or belief that their pain would end, that they would *'get better'*, that, it would be healed and that *'things will go back to normal'*.

[2] In the context of the interview, this expression is used as an exclamation.
[3] In the context of the interview, this expression is used as an exclamation.

"Yoh, it hurts so bad man, like at this age, that is why I keep exercising because I keep telling myself once I lose weight, I will be better" ***(IDI-Pain-A047-Age-35- Female)***

"…Because I don't want it [pain] to oppress me, because I still have the belief that I will get healed and one day things will go back to normal." ***(IDI-Pain-A106-Age-27-Female)***

4.6 Theme 4: Disclosure of Chronic pain.

The prevalence of chronic pain disclosure was very high in this cohort. Participants reported disclosing their chronic pain to their families and/or to at least one other person. This theme describes the levels at which participants have disclosed their chronic pain; this includes the full disclosure of chronic pain, detailed disclosure, and partial disclosure of chronic pain. The reasons for their disclosure and non-disclosure are also described.

3.6.1 Full disclosure of chronic pain.

All participants reported disclosing their chronic pain to their families and/or to at least one other person outside of their family. Participants in this cohort reported disclosing their pain to multiple people. This includes their close family members, such as their mothers, siblings, partners/ spouses, and children, as well as others that they were close to, such as their friends and neighbours.

"Everybody knows. My mother, I have another sister, they are not staying with us. I have two sisters, we are three. So, they are not staying with us. But I told them everything about the pain. Even my neighbour. I told my neighbour." ***(IDI-Pain-A047-Age-35- Female)***

"My friends…And my girlfriend." ***(IDI-Pain-A074-Age-27- Female)***

"All of them…My mom, my brothers they know …Even my sister, even she's not staying with us…Uh. Yes, she [wife] knows. Even my son, he knows." ***(IDI-Pain-J011-Age-36-Male)***

While some participants would limit the disclosure of their chronic pain to those, they were close to, others would disclose their pain to their co-workers, extended family members, and healthcare providers.

"I: Okay. Other than your family, your friends. Who else knows about your pain?

P: At work, colleagues" ***(IDI-Pain-J012-Age-24- Male)***

"Ya, it's my uncle and my nephew…I did, they know about it because whilst I was admitted they come visit me at hospital, and even while I was recovering, they phoned me" ***(IDI-Pain-J010-Age-46- Male)***

However, there were some participants who, having already disclosed of their pain to their close family members, chose not to disclose their pain to select friends and extended family members.

"I: Okay, I see. Uhm, so your friends do they know about your pain?

P: Mmh. Uh, they don't know … they know that I have accident, but they don't know about my pains" ***(IDI-Pain-J011-Age-36- Male)***

"I: Oh, ok, I see, uhm so I want to know, uhm, does your uncle know that you have this pain

P: I didn't tell him" ***(IDI-Pain-J074-Age-33- Male)***

Furthermore, other participants who had already disclosed their pain to their close family members and friends reported not disclosing their pain to any healthcare providers such as a doctor or nurse.

"I: Oh, alright. (0.4)Did you told the doctor or a nurse about your pain?

P: No, I haven't told them" ***(IDI-Pain-A008-Age-39- Female)***

"I: Ok. Cool, other than your family and your friends, is there anyone else that you have told about your pain you have?

P: No, no!

I: Even doctors or nurses? So, you haven't told … spoken to anyone in the Health Care System? Ok. Why?

P: I don't know (chuckles) because when I'm having, going to [the] clinic or where just here. I didn't go anywhere, maybe clinic or hospital." ***(IDI-Pain-J001-Age-34- Male)***

4.6.2 Detailed disclosure of chronic pain.

Some participants reported providing detailed explanations of their chronic pain, including the intensity or severity of their pain, to those they would disclose their pain to. This form of disclosure included participants letting others know of their chronic pain and the intensity of that pain.

"I: Did you tell her how much pain you have? I want to get clarity on that.

*P: How much pain I have, yah. I do explain. Like my mom, I think it's as my friend also, because I share everything with my mom and if I am not well, I have to explain, mom I have this kind of a pain and it start in here, it goes to this side, back to this one, so, so that she can understand,"****(IDI-Pain-A032-Age-42- Female****)*

"I: Ja. Ok. Uhm (0.4) ok I guess this, but, when you tell all the people about the pain? Did you like tell them how bad the pain is, or you just told them that you just have pain?

P: I told them how bad it is! ***IDI-Pain-J001-Age-34- Male)***

Interestingly, of those who would fully disclose the intensity of their pain to those around them, it is important to note that only two of the seven male participants shared the intensity of the pain they experienced while six of the nine female participants reported sharing this with those, they disclosed their chronic pain to.

4.6.3 Partial disclosure of chronic pain.

While some participants would provide details on the severity or intensity of their chronic pain to those, they would disclose their pain to, other participants reported being partial and selective about the details of their chronic pain. This form of disclosure includes participants not disclosing the intensity of their pain and giving vague descriptions of their pain to those who would ask about their pain.

"I: And you told him how much pain?

P: No I didn't, I just told him I am in pain a lot so I decided to go to sleep but he must get me a grandpa and water." ***(IDI-Pain-A005-Age-40- Female)***

"I: Mmm, oh ok. Alright your neighbour as well, did you tell them, did you just tell them that you've got pain, or did you tell them how much pain you have?

P: No, I just tell them that I do have a pain, it's just I didn't describe to them, but like I'm not feeling well, like there's a pain that's been coming every day like continuously, yah." ***(IDI-Pain-A032-Age-42- Female)***

When asked why they would not fully disclose the details of their chronic pain, participants cited multiple reasons. Some participants reported not wanting to *"stress"* and worry those they were disclosing to, while others *"did not see the need"* or find it necessary to share this information with others.

"Like I didn't want to stress her a lot, so I told her that, like, there is pain. So like I think that it'll go away. So it hurts but I didn't tell her it hurts how much because she saw me continue with my life well… I told just told her that just I have pain here because I didn't want to stress her. She would've said go to the clinic by force, so I told her it hurts only." ***(IDI-Pain-A074-Age-27- Female)***

"No, I don't tell him because I don't think it's necessary, mm…Uh, they believed me when I told them I have a pain. So I don't see the reason to tell them the pain is very much" ***(IDI-Pain-A008-Age-39- Female)***

However, one participant who also chose not to fully disclose their pain to their family members reported experiencing emotional distress as a result of the non-disclosure. Participant IDI-Pain-A098-Age-26- Female chose not to disclose her pain to her family members due to a fear that this news would cause them to become *"heartbroken"*. However, her family members not knowing about this part of her life causes her a lot of emotional distress.

"It doesn't feel okay at all cause there'll be a time when I'm gonna relapse. And they have to know about it, so, I'm just scared that what's going to happen to them?... Yeah, cause uhm, the only person that I can say I'm attached to is my grandmother. I don't have parents, so, I'm left with only my sisters, but they live very far. But letting my

grandmother know about this, she's gonna be very heartbroken and she's very sensitive. She's old mind you, she's over a hundred and imagine telling her such a thing. Her heart is very fragile. I'm sad, I'm very disappointed that they don't know about what's happening about my life and there's nothing I can do. It's either I save her, or I kill her. I'm afraid to tell her cause if I tell her, it's gonna kill her. So, it's good that she doesn't know but when I see her my heart, it's really sore." ***(IDI-Pain-A098-Age-26- Female)***

4.6.4 Reasons for disclosing chronic pain.

Participants in this cohort reported multiple reasons for disclosing their chronic pain. These reasons varied from participant to participant. Some participants reported disclosing their pain to those around them as a precautionary measure. These participants reported disclosing their pain so that those around them would know what to do *"if there's an emergency"* or if *"something would happen"*.

"Unless maybe something can happen, they know that I told them about the pain…They will know what to do maybe they can call er the ambulance or they can take me to the Doctor or something or hospital" ***(IDI-Pain-A005-Age-40- Female)***

*"So if there's an emergency, they tell them that no, your child it's been admitted to, send to the hospital or to doctor what's the problem, like it must [be] simpler recognize [remember]oh ok she told me about this pain. No matter she didn't, she doesn't know what's the cause, what, she's not a doctor…But she's alert. That ok my daughter today she's having problem with this. So if the emergency came and then they say your child is in hospital, or she's been admitted in hospital. she is more alert than not knowing anything."****(IDI-Pain-A032-Age-42- Female)***

Additionally, participant IDI-Pain-A083-Age-42- Female further explained that the reason for their disclosure is so that those close to them would know *"the cause of death"* if they were to die from their chronic pain.

"I do it because whatever happens…They should know that I was suffering from pain. I want her to know….My mom, my mother, she must know everything about me….I should not hide anything from her…I can't, why should I hide? If I'm sick? But she's supposed to know…. (Laughs) how can…maybe I die…Should I die, what will she say the cause of death was?" ***(IDI-Pain-A083-Age-42- Female)***

Furthermore, some participants reported the reason for disclosing their pain being due to "*needing help"*. Therefore, these participants would disclose their pain in hopes of getting help from those around them. Interestingly, these participants were mostly male.

"Uuuh, the reason I tell them I was needing help. Like "eish, errr, as you know, I've been injured years back, I do have this kind of pain," ya. So errr, I can say I was needing help from them… that I need help to go to private hospital and then help me to…to do an operation and check what is it inside this hand because I do feel pain always since I've done the operation at the public hospital. So maybe they can help me. Private hospital is the one that can help because they are much concerned… if there is something like this, then they would help and make sure that you become well … But as I told them, nobody was concerned about that. They all said you must be on your own bruh... [no one] seems to care about that because there was not any response since then " ***(IDI-Pain-J007-Age-30- Male)***

"Because I feel the pain, It's the pain, because I'm bothered by this knee wherever I go, she buys me the pills and sends someone, someone must come in there at home, give the pills and give another pills" ***(IDI-Pain-J074-Age-33- Male)***

Other participants reported the reason why they had disclosed their pain to those around them, mainly their families, being due to them not wanting to be perceived as *"lazy"*.

"I wanted them to understand what I was going through, that way they don't get angry at me and assume that I am lazy, and I don't want to work. They have to understand that there are some things I can't do when I'm sick." ***(IDI-Pain-A047-Age-35- Female)***

"Ja. I told them because they started to see … doing lazy like, I was like to them I was, I was reflecting as I was lazy but worse, I was not lazy because I was … had this

problem because of this problem. So I, I didn't manage to do other … some of the other jobs they are sending [me] to, to do. Ja. So, they started to ask; "why … what is the problem with you. Why don't you do this and this, this because we are asking you to do them?" Then I told them about the problem I'm facing right now that, no this is the problem I'm facing. I have scoliosis problem" ***(IDI-Pain-J088-Age-29- Male)***

Another participant, IDI-Pain-A098-Age-26- Female, reported disclosing their pain to their boss at work so that they would understand if they have a pain experience while at work or if they might need to get days off from work.

"I: why did you tell your boss about your pain?

*P: Uh … cause I felt it's chronic sometimes. I felt it is chronic….Cause it happens, in most days, either I'm off, in or working. Sometimes I go back to work whilst in a pain…So, I had to tell her that; "You know what … I think I'm experiencing this kind of a thing…and please bear with me". And I ask for a few minutes….and let me sit for a bit and chill and to know that I … I'm good at what I'm doing…So, obviously, they had… they had to give it to me."****(IDI-Pain-A098-Age-26- Female)***

4.7 Theme 5: Reactions to pain disclosure

This theme describes the reactions participants received from those they disclosed their pain. Participants in this study reported receiving varying reactions from those they chose to disclose their pain. While some participants reported receiving positive reactions, other participants received negative reactions which led to them feeling hurt.

Most of the participants reported receiving positive reactions from their family members when they disclosed their chronic pain. Where the family members and/or the person they disclosed their pain to would comfort them, ask them further questions about their pain or ask them how they are managing the pain, and/or offer them advice and help.

"She asked me that you took some tablets ?" ***(IDI-Pain-A005-Age-40- Female)***

"Uhm, very comforting. Very comforting about it…Talking, that they can see that I'm not well, that I'm not fine. It will be fine; I should get the medication. I should consult, things like that" ***(IDI-Pain-J010-Age-46- Male)***

Conversely, some participants reported receiving negative reactions from their family members when they disclosed their chronic pain. Where the family members and/or the person they disclosed their pain to would express feeling *"scared"* about the participant's condition. Family members or individuals to whom participants disclosed their pain often cried, possibly due to concern for the participant.

"Oh, she was scared" ***(IDI-Pain-J074-Age-33- Male)***

"P: Because they are too young, they are not sharp like that; but the older one was too afraid when I told her that when I have a problem like this and that … and she said why mama, are you sick serious. I said to her I am not sick serious; I am just talking because nowadays life is not good. You can hear people saying that person who was crying about a headache two minutes she is gone.

I: And the eldest you said she was scared?

P: Yes, she was scared when I explained to her about that. She was scared because with us black people we believe in witchcraft. I think maybe she was afraid of that. I told her there is no one who is witchcrafting me" ***(IDI-Pain-A033-Age-39- Female)***

Participant IDI-Pain-A032-Age-42- Female, reported that seeing her family members cry left her feeling *"like [her family members were already] mourning [her death]".*

"I: How did your kids react?

P: Oh, they were crying…There were tears all over their face,

I: How did that make you feel?

P: Painful, so I did feel like you know, I'm dying now. Why all these people are crying with me like these

I: Oh, you felt like they were mourning you?

*P: Yes. They were mourning me. They were saying oh our sister is going down…They were saying that …I thought that like they were saying ooh our sister is going down now. Yah going down now, it is going to the grave now," **(IDI-Pain-A032-Age-42-Female)***

Furthermore, participant IDI-Pain-J007-Age-30- Male, reported receiving a negative reaction from his family members when he disclosed his chronic pain. This participant reported feeling as though none of the family members he disclosed his pain to were *"concerned about [his condition]"* as none of them offered him help. This reaction left the participant feeling hurt and possibly alone.

*"But as I told them, nobody was concerned about that. They all said you must be on your own brother. …[no one] seems to care about that because there was not any response since then…You know I was just telling them to know what I'm experiencing, and then I need help, coz (because) there are so many things … but if I come across things in life and I can't come to them… "I do have this problem, then I need help", but they seem to be concerned about their families, coz (because) my sisters already have families. Unfortunately, I don't have a big brother, I'm a big brother myself, but I do have sisters. And they're wealthy, they have everything, but talking about …It's just … there's nothing they do after that. Ya." **(IDI-Pain-J007-Age-30- Male)***

Other participants reported that their family members and/or the person they disclosed their chronic pain to were *"shocked"* or *"surprised"* when they found out about the pain.

*"She was surprised, maybe shocked at this age, this pain is for older people. Yah she was shocked and sad" **(IDI-Pain-A047-Age-35- Female)***

*"Oh, they were like shocked, they were like shocked, wow. Okay, really? Yes, but they took it easy like easy, not that much serious." **(IDI-Pain-J088-Age-29- Male)***

4.8 Theme 6: Benefits of disclosing pain

This theme describes the benefits of disclosing pain. Participants reported how disclosing their pain to those close to them has benefited them.

A majority of the participants reported feeling relieved after disclosing their chronic pain to their close ones. Most participants reported feeling *"better"*, *"good"*, *"free"*, and *"relieved"* after disclosing their pain.

> *"When I tell him, I was free…I feel free, and I feel good."* ***(IDI-Pain-A008-Age-39-Female)***
>
> *"Oh, also hurting but I also, it's a hurting side neh but also relieved that they know something about me and I'm their mother, they have to know. Yah, there's no one who can know me better than them."* ***(IDI-Pain-A032-Age-42- Female)***
>
> *"I feel at least better when I told them because they know. It's not like when I keep quiet!"* ***(IDI-Pain-J001-Age-34- Male)***

4.9 Theme 7: Social support

The final theme describes the different forms of social support employed both by the participants and their support system (which consists of their family members, friends, and neighbours). The main form of social support identified by participants in this cohort is instrumental support.

4.9.1 Instrumental support.

The majority of the participants reported receiving instrumental support from their support system. This form of support consists of participants receiving physical assistance from their friends, family members, or other close ones.

Some participants reported receiving physical assistance from their family members when they experienced severe or intense pain episodes. As an example, participant IDI-Pain-A083-Age-42- Female, describes her mother coming to cook for her and helping her take her medication. Furthermore, participant IDI-Pain-A047-Age-35- Female describes her family members feeding her, lifting her, and helping her when she could not walk.

"My mother comes to help me out. She cooks…She helps me take my medication…To see if I eat…Take my medication and then take care of the child" ***(IDI-Pain-A083-Age-42- Female)***

"I: Mm oh ok. Uhm, can you tell me more about that day when you couldn't do any activities neh, what kind of help did you get from your family? I know you said they were feeding you,

P: They were helping me…They took me to the toilet to uhm relieve myself. They lift me up so that I can watch TV, yah, slept on the sofa." ***(IDI-Pain-A047-Age-35- Female)***

Furthermore, two other participants reported receiving physical assistance during a pain experience as well as assistance in managing the pain. Participant IDI-Pain-A032-Age-42-Female describes receiving physical assistance from her co-worker when she had a severe pain episode while she was at work. Participant IDI-Pain-J012-Age-24- Male describes receiving assistance from his brother whenever his shoulder gets dislocated. His brother would help him *"put it back"*.

"So she came there and then she asked me like what's wrong, I was not in the mood like the way the pains hit me, I was like I'm losing breath, like I can't be able to talk, like I was shaking, like feeling dizzy…Then the colleague takes me to the canteen, where we eat like…Then they put me there, he gave me some water, then to like to drink cause, just because I wasn't able to talk like she was thinking like maybe I get the water then maybe I will be more better than like I can tell what's happen. So like she gave me those water, then I drink the water then I ask her to give me my tablets in the bag," ***(IDI-Pain-A032-Age-42- Female)***

"P: My little brother knows that. Okay. Whenever I have a dislocation, he knows where to start. Like stretching ... so whenever he is not there. I do it by myself

I: Okay. So there was a time when it was bad and he helped you?

P: Yes

I: Tell me about that time, then.

P: Okay. I was sleeping, he was in his room. And whenever ... okay I slept, whenever I slept, I stretched my hand like this (Shows him). Yeah, this shoulder dislocated inside. ...So I called him, and he came up. Actually, there is no ceiling, like we have two rooms there are no ceiling. So he actually ... cause I couldn't go even to the door and open the door. He jumped to my room…And then he came in, then he tried to help me. Asked what to do and then I was like; it's out again since after the hospital. And then he says, what must I do? Then I said, doctors did this and this and then he normally did that." ***(IDI-Pain-J012-Age-24- Male)***

Additionally, these participants were able to recruit these four forms of social support because they were willing to ask for help from those in their social circles. However, some participants were not willing to ask for help. These participants cited finding it hard to ask for help, not wanting to bother others, and feeling less than for asking/receiving help from others as the reasons for not asking for help.

"And me [if] I have a problem. I don't want to have a person …[I have a] Hard time to ask a person something ." ***(IDI-Pain-A033-Age-39- Female)***

"It's been a long time now since I asked [for help]. Lately, at home, I don't tell them, I just leave it, the only person I bother is my sister, actually when I want my own things, but I just don't bother them." ***(IDI-Pain-A083-Age-42- Female)***

Chapter 5: Discussion

This chapter presents the discussion of the results presented in the previous chapter. This study aimed to explore and interpret how HIV-negative people living with chronic pain perceive their personal experiences with chronic pain and the impact it has on their lives. Within this overarching aim, the study also aimed to explore and gain an understanding of participants' perceptions about their experiences of prolonged pain, explore participants' perceptions about the impact chronic pain has on their physical activity and explore participants' perceptions about the impact that disclosure or non-disclosure of their pain has on the social support recruited and received. This was achieved through a thematic analysis of in-depth interview data where seven themes were identified: pain as a multifaceted experience, participants' typical physical activity, pain interference, disclosure of chronic pain, reactions to pain disclosure, benefits of disclosing pain, and forms of social support. Together these themes illustrate the subjective and multifaceted nature of chronic pain experiences; which includes physical, psychological, and social elements (Crowe et al., 2017; de Villiers et al., 2015; Engel, 1977; Pillay et al., 2014; West et al., 2012).

5.1 The nature of pain

Participants in this study used descriptions that alluded to the quality and persistence of the pain they felt, the location of the pain, the varying causes of their pain, and the strategies they used to manage their pain as a way of describing their experiences of chronic pain.

Characteristics of pain.

Several participants described their experience of pain as one that has unpleasant and uncomfortable sensations; words such as *"stabbing", "burning", and "cutting"* were used to describe the sensations they felt when the pain appeared. These descriptions align with the findings from Yam et al.'s (2018) systematic review, which suggests that sensations of pain are linked to actual or potential tissue damage- with each sensation acting to notify the brain of potential and/or further damage through the activation of receptors in the brain/body. Therefore, the perception of certain sensations is often associated with specific types of pain. This study's findings align with these results, as the types of sensations reported by the participants in this cohort correlate with the specific types of pain described by Yam et al. As an example, neuropathic pain, which is commonly described as an injury or impairment to the

nerves, is often associated with the sensation of 'burning' (Finnerup et al., 2016; Yam et al., 2018). 'Stabbing', on the other hand, is frequently associated with nociceptive pain which is pain that is activated upon the stimulation of receptors in response to actual or potentially harmful stimuli- also indicating potential local damage (Yam et al., 2018)However, this research cannot comment on the types of pain experienced by the participants in this cohort as the researcher did not have access to the medical records detailing the medical causes of their pain. Nevertheless, it can be said that the sensations described by the participants contribute to their nuanced experience of pain.

Temporality of pain.

This theme alludes to the idea that chronic pain extends beyond a singular moment; it unfolds and persists throughout an extended duration of time. Furthermore, it highlights the unpredictable nature of chronic pain. According to Fillingim et al (2016), the temporal features of chronic pain suggest that pain is episodic as it often comes and goes and often varies in intensity and duration. These findings were also evident in this study's cohort. Therefore, the findings from this study align with the multiple descriptions and definitions found in the existing literature on chronic pain (Crowe et al., 2017; Joelsson et al., 2017; Kamerman et al., 2020; Pillay et al., 2014; Silva et al., 2011; West et al., 2012).

Multiple pain sites.

Furthermore, similar to what has been reported in several other studies, several participants in this cohort reported experiencing pain in multiple areas of their body. For some participants, the pain would be experienced at multiple sites simultaneously, and for others, the pain would be felt at different times in the different body parts. Most participants reported experiencing pain in at least two separate sites on their bodies. According to a systematic review by Parker et al (2014), several studies that investigated pain in people living with HIV reported that pain presented at multiple pain sites at varying intensities. This finding suggests the possibility of multiple differing pathological processes contributing to the pain at the same time (Engel, 1981; Parker et al., 2014). Furthermore, with multiple pain sites, the possibility of the presence of nociplastic pain is even higher; where nociplastic pain refers to a type of pain that occurs when the central nervous system becomes hypersensitive, causing pain even in the absence of obvious injury of tissue damage (Kosek et al., 2021). These observations are crucial as they highlight the complex and multifaceted nature of chronic pain. The prevalence of pain at multiple sites emphasises the need for a comprehensive approach to pain assessment and

management. However, as mentioned above, this study cannot comment on the types of pain experienced by the participants in this cohort as the researcher did not have access to the medical records detailing the medical causes of their pain.

Perceived causes of pain.

Participants in this study identified five different categories of pain causes they believed were the causes of their chronic pain. These categories were: physical injury, work-related cause, stress, linked to other illnesses or chronic conditions, and linked to inherited conditions. The interpretation of these results suggests that individuals' perceptions of pain causation are multifaceted and influenced by a variety of factors, both physical and psychological. Physical injury was the most common cause identified by a majority of the participants. Other participants reported believing that the cause of their pain was linked to the activities they took part in at work. These activities include lifting heavy objects, standing for long periods, and other repeated actions. Additionally, other studies had identified similar beliefs of 'work being injurious' among European and Australian populations, however, these studies also found this belief and the fear of re-injury at work to be predictors of failure to return to work (Bunzli et al., 2017; Van Hecke et al., 2013). No evidence of a similar relationship was found in this cohort. This divergence could indicate cultural or systematic differences in how chronic pain is managed and perceived in the workplace for this cohort.

Participants identified stress to be the cause of their pain. For some participants, this stress was often linked to their 'work' where participants cited *"thinking too much"* as the cause of their pain. This idiom or phrase, which is used worldwide but often in non-European and non-American contexts, is used to refer to one's "ruminative, intrusive, and anxious thoughts" (Kaiser et al., 2015, p. 170). Individuals often use this idiom to "reflect aspects of experience, distress, and social positioning" (Kaiser et al., 2015, p. 170), including economic vulnerability. Furthermore, other participants cited unemployment or "*not having work"* as the cause of their pain. These reports suggest that participants in this cohort experience environmental, psychological and economic stress (Clauw et al., 2020; Mickle et al., 2020), which, according to Roditi & Robinson (2011) and Chou et al (2016), may exacerbate and help maintain chronic pain. These findings highlight the complex interplay between mental stress and physical pain, emphasising the need for a holistic approach to pain management and treatment that addresses both the psychological and socioeconomic factors contributing to chronic pain.

Pain management strategies.

The findings in this theme were similar to what was found in other South African cohorts of people living with both chronic pain and HIV (de Villiers et al., 2015; Mohale, 2021; Ratshinanga, 2022). More similarities can be found between the findings from the South African pain and HIV studies and those of a pain and HIV study conducted in America. According to Uebelacker et al (2022), fair use of both pharmacological and non-pharmacological methods was used by participants to treat/manage their pain. It is interesting to see that people from different pain populations utilise more or less the same strategies for pain management regardless of HIV status. This is especially interesting when you take into context the limited pain management resources and medicines in most rural communities in South Africa (Dekker et al., 2012; Igumbor et al., 2011a) where healthcare facilities often run out of medication and patients were often given non-opioid analgesics when they were available- which is vastly different for patients in a country such as the United States of America (Dekker et al., 2012; Yang et al., 2020). Therefore, this difference in availability of resources and medicines in most rural communities may explain why participants in this cohort favoured the use of the mentioned non-pharmacological methods, especially, when managing an episode of severe/ intense pain over the use of pharmacological methods. Additionally, the use of non-pharmacological methods and self-treatment are highly prevalent in rural areas (Eaton et al., 2018), which may also explain this cohort's preference for non-pharmacological methods when treating pain.

However, it is worth noting that a majority of the participants in this cohort reported not disclosing their pain to healthcare providers and of those that did disclose their pain, those participants reported receiving adequate treatment and care. And so it can be argued that disclosure or non-disclosure of pain affects the perception one may have about the pain management resources and help available to them.

5.2 The impact of chronic pain on physical activity

A quantitative study by Wadley et al. (2016) on chronic pain and physical activity in a South African HIV-positive population found objective data revealing that individuals living with chronic pain engage in physical activity at the same level as those without pain. Through a qualitative exploration, this study had similar findings. Participants in this study reported being physically active on a daily basis. Most participants reported engaging in daily household

chores. Participants reported doing these chores every day, even on the days they go to work. Furthermore, participants reported still being able to partake in their daily activities even on the days when they would experience pain. However, on the days when the participants would feel more pain or 'bad' pain; participants reported small changes or no change in the activities they participated in on a daily basis. Thus suggesting that there may be little to no difference in physical activity between people living with chronic pain and those living without pain (Parker et al., 2017; Wadley et al., 2016). Furthermore, the findings from this study also support similar findings from studies such as Mohale (2021) and Ratshinanga (2022) who also both found qualitatively little to no difference in physical activity between HIV-positive people living with pain and HIV-positive people living without pain. This is interesting as it suggests that South African chronic pain populations deviate from the current understanding in the literature that suggests that people living with chronic pain tend to be less active (Joelsson et al., 2017; Vader et al., 2021).

A potential reason for this continued activity despite pain emerged from the data on work. Participants in this cohort reported continuing to work, including participants who reported working in environments that required them to partake in physically demanding activities, despite experiencing chronic pain. A majority of the participants reported financial motivations as the reason for continuing to work. Participants cited having a fear of being replaced at their workplace (unemployment), feeling like they do not *"have a choice"*, or feeling that they can *"maintain"* the pain. These findings support the idea that financial stresses in African pain populations may compel people living with chronic pain to conceal their pain and continue with daily activities, despite experiencing persistent pain (Chou et al., 2016; Reardon et al., 2023; Uysal & Lu, 2011; Wadley et al., 2016). Thus suggesting that a relationship between chronic pain, physical activity, and economic stress exists (Mickle et al., 2020; Niederstrasser & Attridge, 2022) in both HIV-positive and HIV-negative South African pain populations.

Pain interference.

Even with most participants reporting little to no difference in physical activity regardless of their pain, participants still reported experiencing physical, social, and emotional interferences while living with chronic pain. With regard to physical interference, some participants described experiencing intense pain episodes that occasionally limited or paused their physical activity. These participants reported feeling limited in the activities they can participate in including not being able to bend, sit for prolonged periods, or walk when experiencing intense

pain. This finding is significant as it corroborates existing literature that suggests people living with chronic pain often experience physical limitations when performing daily activities (Dansie & Turk, 2013; Joelsson et al., 2017; Vader et al., 2021), emphasising the pervasive impact of chronic pain on physical function. According to Vlaeyen et al (2016), pain is interruptive by nature. When pain is intense it is likely to interrupt not only the physical performance but the cognitive performance of an individual as well. Participants in this cohort reported experiencing similar interruptions, highlighting the need for comprehensive pain management strategies that address the full spectrum of chronic pain's disruptive effects on individuals' lives.

5.3 Disclosure of chronic pain and social support

Wadley et al.'s (2016) study on chronic pain and physical activity in a South African HIV-positive population found that a proportion of their participants weren't disclosing their pain to people close to them. Contrary to those findings, this study found chronic pain disclosure to be very prevalent in this cohort. Participants reported disclosing their chronic pain to their families and/or to at least one other close person. However, some participants were selective about the details of their pain when disclosing it to their close ones. Similar to the findings of Uysal & Lu's (2011) study on chronic pain and self-concealment-conducted on American undergraduate students with diagnosed and undiagnosed chronic pain, the participants in this study often chose to disclose their pain but would conceal the details about the intensity or severity of their pain from those they have disclosed their pain to. These participants cited multiple reasons for this self-concealment, including not wanting to *"stress"* and worry those they were disclosing to, not *"see[ing] the need"* or finding it necessary to share this information with others. Additionally, some participants reported experiencing emotional distress as a result of concealing the details of their pain from their close family members. According to Uysal & Lu (2011), self-concealment of chronic pain was "associated with higher levels of self-reported pain and lower psychological well-being, independent of disclosure of feelings regarding pain" (p. 606). Therefore the findings from this study allude to a possible similarity of how self-concealment of pain may result in lower psychological well-being (Franqueiro et al., 2023; Uysal & Lu, 2011). Unfortunately, this study cannot make definitive conclusions on whether this is true for this cohort as the researcher did not have access to any psychological well-being assessments, such as depression and anxiety, for this cohort.

Reasons for disclosing chronic pain and the benefits of pain disclosure

Participants in this cohort reported multiple reasons for disclosing their chronic pain. While these reasons varied for every participant, common reasonings for participants' disclosure of their chronic pain included disclosing pain as a precautionary measure, disclosing to ask for and receive help from others, and disclosing pain to gain understanding from others. These findings are similar to what has been reported by Mohale (2021) and Ratshinanga (2022) for pain disclosure among the HIV-pain South African population. This similarity in findings suggests that there may be cultural or societal norms influencing the decision to disclose pain. After disclosure, most participants reported feeling relieved. Participants described feeling *"better"*, *"good"*, *"free"*, and *"relieved"* after disclosing their pain. Interestingly, both participants who completely disclosed their pain to those they are close to and those who chose to conceal certain details about their pain to close others reported experiencing the same feeling of relief. The common feeling of relief reported by participants suggests that disclosing pain can be a significant emotional and psychological release. Indicating that carrying the burden of chronic pain in silence may have a profound impact on an individual's mental health. However, it can be also argued that these feelings of relief are linked to the reactions that participants receive from close others when disclosing their chronic pain.

Reactions to pain disclosure.

Participants in this study reported receiving varying reactions from those they chose to disclose their pain. While some participants reported receiving positive reactions, other participants received negative reactions which led to them feeling hurt. According to Uysal & Lu (2011), the reactions of close others to an individual's disclosure are far more critical than those of any other people. These reactions may influence the level at which individuals may conceal or disclose the details of their chronic pain to others (Franqueiro et al., 2023; Uysal & Lu, 2011). Nevertheless, most participants in this study reported receiving positive reactions from their family members when they disclosed their chronic pain. Where the family members and/or the person they disclosed their pain to would comfort them, ask them further questions about their pain or ask them how they are managing the pain, and/or offer them advice and help. According to De Ruddere & Craig (2016), friends and family members of individuals living with pain are likely to exhibit less stigmatizing behaviours towards them; this often results in them

expressing empathy towards those living with pain. Instead, it is often observers and people outside of one's in-group that are likely to exhibit stigmatizing behaviour, including negative reactions to an individual's disclosure of pain. Conversely, some participants in this cohort reported receiving negative reactions from their family members when they disclosed their chronic pain. Where the family members and/or the person they disclosed their pain to would express feeling *"scared"* about the participant's condition. For most of these participants, the family members and/or the person they disclosed their pain to would cry, perhaps out of worry for the participant. These reactions may then lead to participants experiencing emotional distress and/or worry for those they disclosed their pain to (Franqueiro et al., 2023); it may also lead to them choosing to conceal certain details about their pain from those they already disclosed their pain to. Furthermore, these findings were similar to the findings of Wakefield et al's (2021) study on chronic pain and concealment among adolescents in the United States of America with diagnosed chronic pain. Where Wakefield et al (2021) found that to avoid similar reactions from close others, adolescents would conceal their pain symptoms to avoid feeling like a social burden to their friends and family members.

Social support.

It can be argued that, for participants in this cohort, full disclosure of chronic pain was motivated by the need for social support. As discussed above, participants' reasons behind their disclosure included disclosing to ask for and receiving help from others and disclosing pain to gain understanding from others. Therefore, participants in this study were able to recruit different forms of social support from their support system (which consists of their family members, friends, and neighbours). The main form of social support identified in this cohort was instrumental support. Participants reported being able to ask for help and receiving support from those close to them. The recruitment of social support was reported to have important beneficial effects on the physical and mental health of those living with chronic pain (Franqueiro et al., 2023; Vlaeyen et al., 2016). However, since the prevalence of chronic pain disclosure was very high in this cohort, with all participants reporting disclosing their chronic pain to their families and/or to at least one other person outside of their family, it is difficult to determine the impact that non-disclosure of chronic pain may have on the social recruitment of support in this cohort. Nevertheless, it is important to note that regardless of the level at which participants disclosed their pain, every participant reported having at least one person who was

their pain, and every participant reported having at least one person aware of their pain, making it possible for them to seek support from that person when necessary.

Chapter 6: Limitations, Implications and Recommendations

6.1 Limitations

This study has some limitations. The study's use of pre-collected/secondary data limited the researcher's control over the data collection process and thus the data that was analysed. This led to some challenges where the researcher had insufficient information to address some questions throughout the research process. Additionally, the lack of access to medical records to confirm the types of pain experienced by participants restricted the ability to draw definitive conclusions about the causes and nature of their pain. Furthermore, this study's limitation to account for the depression and anxiety levels of the sample limited the conclusions that the study could make about the psychological well-being of the participants. Although the sample size was adequate for a qualitative study, the data were collected from one site (the Ndlovu research centre) in rural Limpopo; this hinders the generalisability of the study's findings and limits them to the context in which the data was collected; due to a possible under-representation of sub-groups in the larger population of South Africa. It also does not account for gender discrepancies in any detail. Furthermore, the use of Thematic analysis allowed for a rich descriptive interpretation of the data, however, due to its flexibility, another researcher could have different findings to that of this study.

6.2 Implications

The findings of this research may have significant implications for policymakers, healthcare providers, and the design of pain management interventions. Policymakers can incorporate these findings into the development of workplace health policies; taking into consideration the complex nature of chronic pain. This may result in the establishment of workplace regulations, such as flexible working arrangements and economic support systems, that foster a healthier work environment and support for those living with chronic pain. Furthermore, the findings suggest the necessity for multidisciplinary, holistic, pain management programs that take into consideration the cultural and socio-economic differences that may exist in the different populations they will be implemented in. Lastly, the findings highlight a need for empathetic, patient-centric care that encourages communication between the healthcare provider and the patient.

6.3 Recommendations

Based on the findings and limitations of this study, future research should consider measuring depression and anxiety as the intertwined relationship between chronic pain and depression and anxiety is already known. Additionally, future research should aim to include a larger and more diverse sample size, possibly collecting data from various areas in South Africa, to enhance the generalisability of the findings. Finally, future research should consider investigating chronic pain with gender at the forefront of the research questions. By doing so, researchers can uncover the nuanced ways in which chronic pain manifests and is experienced differently across gender lines.

Conclusion

This study demonstrated the multidimensional nature and impact of chronic pain. For HIV-negative men and women living with chronic pain in rural South Africa, chronic pain was understood and identified by the intensity or severity felt, the frequency and length of time it would be felt, and the location on one's body it would be felt. This pain was not associated with age or gender but was linked by participants to varying causes, including physical injuries and psychological and financial stress. In accordance with some existing data, HIV-negative people living with chronic pain reported similar physical activity levels to those without pain. This may be attributed to the economic and financial stressors that motivate people living with chronic pain to continue with their physical activities despite their chronic pain. Furthermore, the prevalence of chronic pain disclosure was very high in this cohort. Therefore, participants reported being able to recruit different types of social support from close ones they have disclosed their pain. Overall, there are some similarities in the experience and impact of chronic pain for people living with pain and HIV and HIV-negative people living with chronic pain. However, this study's findings suggest that economic stressors may be the biggest influential factor in how pain is experienced between any two pain cohorts; determining whether one can afford to limit their physical activity long enough to recover or not.

This research therefore contributes to the qualitative knowledge on the relationships between pain, physical activity, and the seeking of social support by HIV-negative people living with chronic pain in a South African context.

References

Apkarian, A. V., Baliki, M. N., & Geha, P. Y. (2009). Towards a theory of chronic pain. *Progress in Neurobiology*, *87*(2), 81–97. https://doi.org/10.1016/j.pneurobio.2008.09.018.

Arifin, S. R. M. (2018). Ethical considerations in qualitative study. *International Journal of Care Scholars*, *1*(2), 30–33. https://doi.org/10.31436/ijcs.v1i2.82.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa.

Bunzli, S., Singh, N., Mazza, D., Collie, A., Kosny, A., Ruseckaite, R., & Brijnath, B. (2017). Fear of (re) injury and return to work following compensable injury: Qualitative insights from key stakeholders in Victoria, Australia. *BMC Public Health*, *17*, 1–9. https://doi.org/10.1186/s12889-017-4226-7.

Chou, E. Y., Parmar, B. L., & Galinsky, A. D. (2016). Economic insecurity increases physical pain. *Psychological Science*, *27*(4), 443–454. https://doi.org/10.1177/0956797615625640.

Cieurzo, C., & Keitel, M. A. (1999). *Ethics in qualitative research.* https://doi.org/*10.4135/9781452225487.n6*.

Clarke, V., & Braun, V. (2013). Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *The Psychologist*, *26*(2).

Clarke, V., Braun, V., & Hayfield, N. (2015). Thematic analysis. *Qualitative Psychology: A Practical Guide to Research Methods*, *3*, 222–248. https://doi.org/10.1007/978-981-10-5251-4_103.

Clauw, D. J., Häuser, W., Cohen, S. P., & Fitzcharles, M.-A. (2020). Considering the potential for an increase in chronic pain after the COVID-19 pandemic. *Pain*, *161*(8), 1694.

Crowe, M., Whitehead, L., Seaton, P., Jordan, J., Mccall, C., Maskill, V., & Trip, H. (2017). Qualitative meta-synthesis: The experience of chronic pain across conditions. *Journal of Advanced Nursing*, *73*(5), 1004–1016. https://doi.org/10.1111/jan.13174

Dansie, E., & Turk, D. C. (2013). Assessment of patients with chronic pain. *British Journal of Anaesthesia*, *111*(1), 19–25. https://doi.org/10.1093/bja/aet124.

De Ruddere, L., & Craig, K. D. (2016). Understanding stigma and chronic pain: A-state-of-the-art review. *Pain*, *157*(8), 1607–1610. https://doi.org/10.1097/j.pain.0000000000000512.

de Villiers, M., Maree, J. E., & van Belkum, C. (2015). The influence of chronic pain on the daily lives of underprivileged South Africans. *Pain Management Nursing*, *16*(2), 96–104.

Dekker, A. M., Amon, J. J., le Roux, K. W., & Gaunt, C. B. (2012). "What is killing me most": Chronic pain and the need for palliative care in the Eastern Cape, South Africa. *Journal of Pain & Palliative Care Pharmacotherapy*, *26*(4), 334–340.

Eaton, L. H., Langford, D. J., Meins, A. R., Rue, T., Tauben, D. J., & Doorenbos, A. Z. (2018). Use of self-management interventions for chronic pain management: A comparison between rural and nonrural residents. *Pain Management Nursing*, *19*(1), 8–13.

Eccleston, C., Morley, S., & Williams, A. de C. (2013). Psychological approaches to chronic pain management: Evidence and challenges. *British Journal of Anaesthesia*, *111*(1), 59–63. https://doi.org/10.1093/bja/aet207.

Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science*, *196*(4286), 129–136. https://doi.org/10.1126/science.847460.

Engel, G. L. (1981). *The clinical application of the biopsychosocial model*. *6*(2), 101–124. https://doi.org/10.1093/jmp/6.2.101.

Fillingim, R. B., Loeser, J. D., Baron, R., & Edwards, R. R. (2016). Assessment of chronic pain: Domains, methods, and mechanisms. *The Journal of Pain*, *17*(9), T10–T20.

Finlay, L. (2006). 'Rigour','ethical integrity'or 'artistry'? Reflexively reviewing criteria for evaluating qualitative research. *British Journal of Occupational Therapy*, *69*(7), 319–326.

Finnerup, N. B., Haroutounian, S., Kamerman, P., Baron, R., Bennett, D. L., Bouhassira, D., Cruccu, G., Freeman, R., Hansson, P., & Nurmikko, T. (2016). Neuropathic pain: An updated grading system for research and clinical practice. *Pain*, *157*(8), 1599. https://doi.org/10.1097/j.pain.0000000000000492.

Franqueiro, A. R., Yoon, J., Crago, M. A., Curiel, M., & Wilson, J. M. (2023). The Interconnection Between Social Support and Emotional Distress Among Individuals with Chronic Pain: A Narrative Review. *Psychology Research and Behavior Management*, 4389–4399. https://doi.org/10.2147/PRBM.S410606.

Guzmán, J., Esmail, R., Karjalainen, K., Malmivaara, A., Irvin, E., & Bombardier, C. (2001). Multidisciplinary rehabilitation for chronic low back pain: Systematic review. *Bmj*, *322*(7301), 1511–1516. https://doi.org/10.1136/bmj.322.7301.1511.

Haverkamp, B. E. (2005). Ethical perspectives on qualitative research in applied psychology. *Journal of Counseling Psychology*, *52*(2), 146. https://doi.org/10.1037/0022-0167.52.2.146.

Igumbor, E. U., Puoane, T., Gansky, S. A., & Plesh, O. (2011a). *Prevalence and risk indicators of chronic pain in a rural community in South Africa*.

Igumbor, E. U., Puoane, T. R., Gansky, S. A., & Plesh, O. (2011b). Chronic pain in the community: A survey in a township in Mthatha, Eastern Cape, South Africa. *Southern African Journal of Anaesthesia and Analgesia*, *17*(5), 329–337. https://doi.org/10.1080/22201173.2011.10872801.

Jackson, K., Wadley, A. L., & Parker, R. (2021). Managing pain in HIV/AIDS: a therapeutic relationship is as effective as an exercise and education intervention for rural amaXhosa women in South Africa. *BMC Public Health*, *21*, 1–14.

Jackson, T., Thomas, S., Stabile, V., Shotwell, M., Han, X., & McQueen, K. (2016). A systematic review and meta-analysis of the global burden of chronic pain without clear etiology in low-and middle-income countries: Trends in heterogeneous data and a proposal for new assessment methods. *Anesthesia & Analgesia*, *123*(3), 739–748. https://doi.org/10.1213/ANE.0000000000001389.

James, S. L., Abate, D., Abate, K. H., Abay, S. M., Abbafati, C., Abbasi, N., Abbastabar, H., Abd-Allah, F., Abdela, J., & Abdelalim, A. (2018). Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990–2017: A systematic analysis for the Global Burden of Disease Study 2017. *The Lancet*, *392*(10159), 1789–1858. https://doi.org/10.1016/S0140-6736(18)32279-7.

Jeffery, A. E., Wylde, V., Blom, A. W., & Horwood, J. P. (2011). "It's there and I'm stuck with it": Patients' experiences of chronic pain following total knee replacement surgery. *Arthritis Care & Research*, *63*(2), 286–292. https://doi.org/10.1080/02813432.2017.1288815.

Joelsson, M., Bernhardsson, S., & Larsson, M. E. (2017). Patients with chronic pain may need extra support when prescribed physical activity in primary care: A qualitative study. *Scandinavian Journal of Primary Health Care*, *35*(1), 64–74. https://doi.org/10.1080/02813432.2017.1288815.

Kaiser, B. N., Haroz, E. E., Kohrt, B. A., Bolton, P. A., Bass, J. K., & Hinton, D. E. (2015). "Thinking too much": A systematic review of a common idiom of distress. *Social Science & Medicine*, *147*, 170–183. https://doi.org/10.1016/j.socscimed.2015.10.044.

Kamerman, P. R., Bradshaw, D., Laubscher, R., Pillay-van Wyk, V., Gray, G. E., Mitchell, D., & Chetty, S. (2020). Almost 1 in 5 South African adults have chronic pain: A prevalence study conducted in a large nationally representative sample. *Pain*, *161*(7), 1629–1635. https://doi.org/10.1097/j.pain.0000000000001844.

Keen, S., Lomeli-Rodriguez, M., & Williams, A. C. de C. (2021). Exploring how people with chronic pain understand their pain: A qualitative study. *Scandinavian Journal of Pain*, *21*(4), 743–753. https://doi.org/10.1515/sjpain-2021-0060.

Kosek, E., Clauw, D., Nijs, J., Baron, R., Gilron, I., Harris, R. E., Mico, J.-A., Rice, A. S., & Sterling, M. (2021). Chronic nociplastic pain affecting the musculoskeletal system: Clinical criteria and grading system. *Pain*, *162*(11), 2629–2634. https://doi.org/10.1097/j.pain.0000000000002324.

Laverty, S. M. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative Methods*, *2*(3), 21–35.

Marshall, C., & Rossman, G. B. (2014). *Designing qualitative research*. Sage publications. https://doi.org/10.5070/L412004995.

Merlin, J. S., Walcott, M., Kerns, R., Bair, M. J., Burgio, K. L., & Turan, J. M. (2015). Pain self-management in HIV-infected individuals with chronic pain: A qualitative study. *Pain Medicine*, *16*(4), 706–714. https://doi.org/10.1111/pme.12701.

Mickle, A. M., Garvan, C., Service, C., Pop, R., Marks, J., Wu, S., Edberg, J. C., Staud, R., Fillingim, R. B., & Bartley, E. J. (2020). Relationships between pain, life stress, sociodemographics, and cortisol: Contributions of pain intensity and financial satisfaction. *Chronic Stress*, *4*, 2470547020975758.

Mohale, J. (2021). *Factors affecting the experience of pain, and physical function in South African males living with HIV*. https://hdl.handle.net/10539/33670

Mphahlele, N. R., Mitchell, D., & Kamerman, P. R. (2012). Pain in ambulatory HIV-positive South Africans. *European Journal of Pain*, *16*(3), 447–458. https://doi.org/10.1002/j.1532-2149.2011.00031.x.

Niederstrasser, N. G., & Attridge, N. (2022). Associations between pain and physical activity among older adults. *PloS One*, *17*(1), e0263356. https://doi.org/10.1371/journal.pone.0263356.

Parker, R., Bergman, E., Mntambo, A., Stubbs, S., & Wills, M. (2017). Levels of physical activity in people with chronic pain. *South African Journal of Physiotherapy*, *73*(1), 1–7. https://doi.org/10.4102/sajp.v73i1.323.

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

Parker, R., Stein, D. J., & Jelsma, J. (2014). Pain in people living with HIV/AIDS: a systematic review. *Journal of the International AIDS Society*, *17*(1), 18719. https://doi.org/10.7448/IAS.17.1.18719.

Pillay, T., van Zyl, H. A., & Blackbeard, D. (2014). Chronic pain perception and cultural experience. *Procedia-Social and Behavioral Sciences*, *113*, 151–160.

Ponterotto, J. G. (2010). Qualitative research in multicultural psychology: Philosophical underpinnings, popular approaches, and ethical considerations. *Cultural Diversity and Ethnic Minority Psychology*, *16*(4), 581. https://doi.org/10.1037/a0012051.

Ratshinanga, A. (2022). *Factors influencing pain and activity in rural South African women living with HIV*. https://hdl.handle.net/10539/35528

Reardon, C., Wadley, A., & Parker, R. (2023). Context counts: Investigating pain management interventions in HIV-positive men living in a rural area. *African Journal of Primary Health Care & Family Medicine*, *15*(1), 1–11.

Roditi, D., & Robinson, M. E. (2011). The role of psychological interventions in the management of patients with chronic pain. *Psychology Research and Behavior Management*, 41–49. https://doi.org/10.2147/PRBM.S15375.

Sá, K. N., Moreira, L., Baptista, A. F., Yeng, L. T., Teixeira, M. J., Galhardoni, R., & de Andrade, D. C. (2019). Prevalence of chronic pain in developing countries: Systematic review and meta-analysis. *Pain Reports*, *4*(6), e779. https://doi.org/10.1097/PR9.0000000000000779.

Scott, W., & McCracken, L. M. (2015). Psychological flexibility, acceptance and commitment therapy, and chronic pain. *Current Opinion in Psychology*, *2*, 91–96. https://doi.org/10.1007/s10879-016-9328-5.

Sendra, A., & Farré, J. (2020). Communicating the experience of chronic pain through social media: Patients' narrative practices on Instagram. *Journal of Communication in Healthcare*, *13*(1), 46–54. https://doi.org/10.1080/17538068.2020.1752982

Silva, F. C. M., Sampaio, R. F., Mancini, M. C., Luz, M. T., & Alcântara, M. A. (2011). A qualitative study of workers with chronic pain in Brazil and its social consequences. *Occupational Therapy International*, *18*(2), 85–95. https://doi.org/10.1002/oti.302.

Terry, G., Hayfield, N., Clarke, V., & Braun, V. (2017). Thematic analysis. *The SAGE Handbook of Qualitative Research in Psychology*, *2*, 17–37. https://doi.org/10.1007/978-981-10-5251-4_103.

Treede, R.-D., Rief, W., Barke, A., Aziz, Q., Bennett, M. I., Benoliel, R., Cohen, M., Evers, S., Finnerup, N. B., & First, M. B. (2019). Chronic pain as a symptom or a disease: The IASP Classification of Chronic Pain for the International Classification of Diseases (ICD-11). *Pain*, *160*(1), 19–27. https://doi.org/10.1097/j.pain.0000000000001384.

Turk, D. C., Wilson, H., Swanson, K. S., Ebert, M., & Kerns, R. (2011). The biopsychosocial model of pain and pain management. *Behavioral and Psychopharmacologic Pain Management*, 16–43. https://doi.org/10.1017/CBO9780511781445.003.

Uebelacker, L. A., Cherenack, E. M., Busch, A., Baker, J. V., Pinkston, M., Gleason, N., Madden, S., Caviness, C. M., & Stein, M. D. (2022). Pharmacologic and non-pharmacologic treatments for chronic pain used by patients with pain, HIV, and depression. *AIDS and Behavior*, *26*(3), 864–873. https://doi.org/10.1080/09540121.2022.2136349.

Uysal, A., & Lu, Q. (2011). Is self-concealment associated with acute and chronic pain? *Health Psychology*, *30*(5), 606. https://doi.org/10.1037/a0024287.

Vader, K., Doulas, T., Patel, R., & Miller, J. (2021). Experiences, barriers, and facilitators to participating in physical activity and exercise in adults living with chronic pain: A qualitative study. *Disability and Rehabilitation*, *43*(13), 1829–1837. https://doi.org/10.1080/09638288.2019.1676834.

Van Hecke, O., Torrance, N., & Smith, B. (2013). Chronic pain epidemiology and its clinical relevance. *British Journal of Anaesthesia*, *111*(1), 13–18. https://doi.org/10.1016/j.pain.2013.11.013.

van Vreede, J. J., Parker, R., & van Nugteren, J. (2022). A history of depression in patients attending a chronic pain management clinic in South Africa: A retrospective chart review. *South African Journal of Psychiatry*, *28*, 1673.

Verbunt, J. A., Sieben, J. M., Seelen, H. A., Vlaeyen, J. W., Bousema, E. J., van der Heijden, G. J., & Knottnerus, J. A. (2005). Decline in physical activity, disability and pain-

related fear in sub-acute low back pain. *European Journal of Pain*, *9*(4), 417–425. https://doi.org/10.1016/j.ejpain.2004.09.011.

Vlaeyen, J. W., Crombez, G., & Goubert, L. (2007). The psychology of chronic pain and its management. *Physical Therapy Reviews*, *12*(3), 179–188.

Vlaeyen, J. W., Morley, S., & Crombez, G. (2016). The experimental analysis of the interruptive, interfering, and identity-distorting effects of chronic pain. *Behaviour Research and Therapy*, *86*, 23–34. https://doi.org/10.1016/j.brat.2016.08.016.

Voscopoulos, C., & Lema, M. (2010). When does acute pain become chronic? *British Journal of Anaesthesia*, *105*(suppl_1), i69–i85. https://doi.org/10.1093/bja/aeq323.

Wade, D. T., & Halligan, P. W. (2017). The biopsychosocial model of illness: A model whose time has come. *Clinical Rehabilitation*, *31*(8), 995–1004. https://europepmc.org/article/med/28730890

Wadley, A. L., Mitchell, D., & Kamerman, P. R. (2016). Resilience does not explain the dissociation between chronic pain and physical activity in South Africans living with HIV. *PeerJ*, *4*, e2464.

Wakefield, E. O., Puhl, R. M., Litt, M. D., & Zempsky, W. T. (2021). "If it ever really hurts, I try not to let them know:" the use of concealment as a coping strategy among adolescents with chronic pain. *Frontiers in Psychology*, *12*, 666275.

Walker, S. (2005). Psychological aspects of chronic pain: A literature review. *Southern African Journal of Anaesthesia and Analgesia*, *11*(4), 139–145.

West, C., Usher, K., Foster, K., & Stewart, L. (2012). Chronic pain and the family: The experience of the partners of people living with chronic pain. *Journal of Clinical Nursing*, *21*(23–24), 3352–3360. https://doi.org/10.1111/j.1365-2702.2011.04005.x

Willig, C. (2012). *Qualitative interpretation and analysis in psychology*. McGraw-Hill Education (UK).

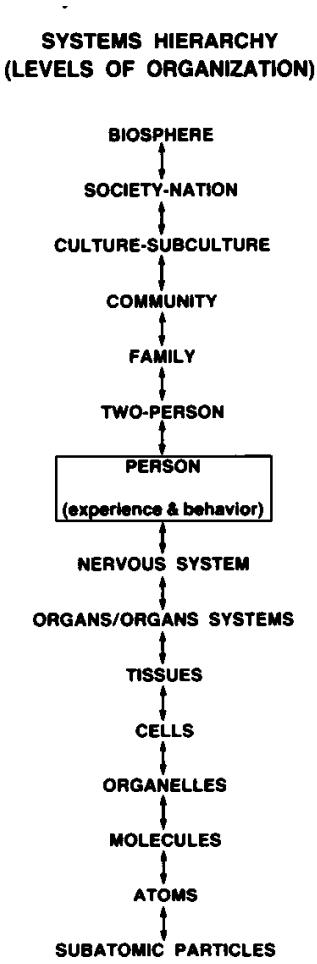
Willig, C. (2013). *Introducing qualitative research in psychology*. McGraw-hill education (UK).

Yam, M. F., Loh, Y. C., Tan, C. S., Khadijah Adam, S., Abdul Manan, N., & Basir, R. (2018). General pathways of pain sensation and the major neurotransmitters involved in pain regulation. *International Journal of Molecular Sciences*, *19*(8), 2164. https://doi.org/10.1037/13619-002

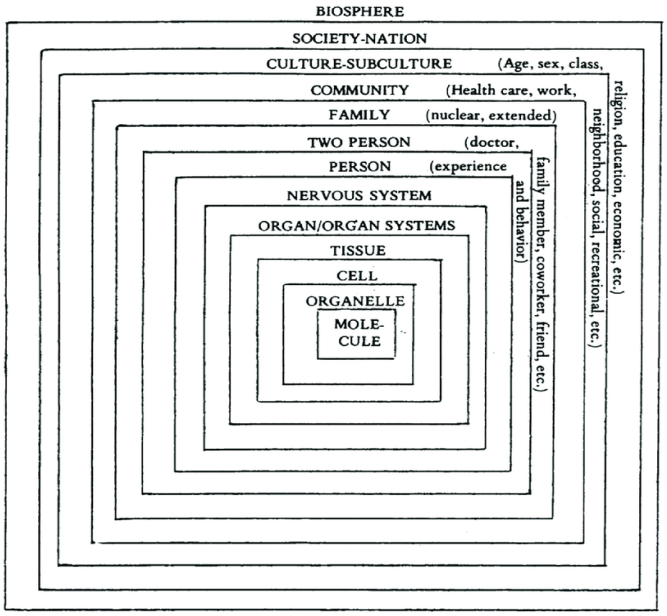
Yang, J., Bauer, B. A., Wahner-Roedler, D. L., Chon, T. Y., & Xiao, L. (2020). The modified WHO analgesic ladder: Is it appropriate for chronic non-cancer pain? *Journal of Pain Research*, 411–417.

Appendices

Appendix A: Theoretical Framework



(Fig 1): Engel, G. L. (1981). *The clinical application of the biopsychosocial model*. *6*(2), 104



(Fig 2): Engel, G. L. (1981). *The clinical application of the biopsychosocial model*. *6*(2), 105

Appendix B: Interview guide (In-depth interview and BPI talk-aloud)

In-depth Interview guide for Non-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:

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?

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?

11. Talk aloud of the Brief Pain Inventory interference scale

I'm going to ask some questions about how much your pain interferes with everyday activities, your mood and so on. There is a scale from '0, the pain does not interfere with this activity at all' to '10, pain completely interferes with this activity'. I'm then going to ask you to tell me a little bit more about what that means for you and why you gave the question that particular score.

Appendix C: Ethics clearance form- Human Research Ethics Committee (Medical) of the University of the Witwatersrand (original study)

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

R 14/49 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:	

Professor CB Penny, Chairperson, HREC (Medical)

APPROVED BY:

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

Appendix D: Ethics clearance form- The Limpopo Department of Health

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Stander SS (015 293 6650) Ref: LP_201809_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 E: Ethics clearance form- Human Research Ethics Committee (Medical) of the University of the Witwatersrand (Current study)

UNIVERSITY OF THE
WITWATERSRAND
JOHANNESBURG

R49 Ms TNM Ramoshai

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M230788

NAME: (Principal Investigator)	Ms TNM Ramoshai
DEPARTMENT:	School of Human and Community Development Department of Psychology University
PROJECT TITLE:	*Understanding pain experiences: a qualitative exploration of pain in people living with chronic pain in South Africa*
DATE CONSIDERED:	Ad hoc
DECISION:	Approved unconditionally
CONDITIONS:	Sub-study under M18/06/52
NOTE:	If contact information regarding student study participants is required, please contact the Registrar's office - <Nicoleen.Potgieter@wits.ac.za>
SUPERVISOR:	Dr M Mulaudzi and Professor A Wadley
APPROVED BY:	Professor P Ruff, Chairperson, HREC (Medical)
DATE OF APPROVAL:	2023/08/23 **EXPIRY DATE:** 2028/08/22

This Clearance Certificate is valid for 5 years from the date of approval. An extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office secretariat on the 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

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 submit details to the Committee. I agree to submit a yearly progress report. When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in July and therefore reports and re-certification will be due in the month of July each year. Unreported changes to the study may invalidate the clearance given by the HREC (Medical).

Signature of Principal Investigator

Date